OCCUPATIONAL PERFORMANCE OF CHILDREN WITH AUTISTIC SPECTRUM DISORDER IN MALAYSIA: REVIEW OF PRACTICE, PARENTS' PERSPECTIVE AND GOALS

A thesis submitted in fulfilment of the requirements

for the Degree of

Doctor of Philosophy (Occupational Therapy)

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STATEMENT

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education. Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given. Copyright permission for third-party contents included within the thesis has also been obtained (See Appendix 1).

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ABSTRACT

The ability of children with Autistic Spectrum Disorder (ASD) to achieve independence in their daily living activities may be affected by the characteristics of their underlying condition. The main characteristics of children diagnosed with ASD include impairments in communication, socialisation and behaviour. These impairments are likely to hinder children's ability to learn and experience life like their typically developing peers. Often, enabling their participation in daily life requires extra support and guidance for successful integration into school and family routines, as well as being active participants in community life. The issues and impairments that children with ASD have are life long, and, consequently, children with ASD and their family members need support throughout their whole life. Occupational therapy is one of the healthcare professions involved in providing services to these children and their family members.

Services for children with ASD in Malaysia are developing, but are much less advanced than in Western countries. This thesis (a) explored how occupational therapy services were provided in Malaysia, (b) compared these to services in Victoria (Australia) given the considerable differences in socioeconomic, cultural, educational and healthcare systems in both regions, and (c) evaluated whether services that children received in Malaysia met the identified needs and goals of parents of children with ASD.

Points (a) and (b) were addressed in phase one of the research, through a descriptive survey design study. Point (c) was addressed in a cross-sectional mixed methods study, using standardised assessments and qualitative interviews of the parents of children with ASD. In the first phase of the study, occupational therapy participants from Malaysia and Victoria (Australia) were recruited through their respective professional organisation and were send a questionnaire regarding the services they provided for children with ASD. The questionnaire was developed to gain information regarding the

frames of reference, models of practice, assessments and interventions provided, trainings and professional development needed in the occupational therapy services for children with ASD. In phase two of the study, parents of children with ASD were asked about their child's abilities in managing daily living activities through a mix-methods survey.

It was found that occupational therapy services in both regions were similar in terms of the focus given in the aspects of assessments and interventions used and professional development needed. The services provided and continuing professional development that the practitioners felt they needed tended to focus on managing sensory issues in children with ASD and less on the functional aspects of daily occupation.

In summary, this research provided preliminary information regarding the occupational therapy services provided for children with ASD in Malaysia. The occupational therapy services for children with ASD in Malaysia was found to be closely similar to the services offered by the occupational therapists in Victoria (Australia). In the second phase of the research, it was found that there were disparities between the occupational therapy services provided and the parents' priorities for their children with ASD. In order for occupational therapy services to be relevant, they should be tailored to meet the needs of the clients and culturally valid for the population receiving the service.

The utilization of the gold standard standardized assessment of the Vineland-II was able to identify the areas that needed attention in the studied domains of communication, socialisation and daily living skills. This gold standard assessment paired with the client- and occupational-centred assessment tool, the COPM, facilitated the creation of a more accurate and detailed problem list to guide the occupational therapy goals and intervention planning according to the specific and unique needs of the children with ASD and their families.

LIST OF ABBREVATIONS

AAC	Alternative and Augmentative Communication
AAMR	American Association of Mental Retardation
ABA	Applied Behavioural Analysis
ABAS-II	Adaptive Behavior Assessment System-Second Edition
ADEC	Autism Detection in Early Childhood
ADI-R	The Autism Diagnostic Interview-Revised
ADL	Activities of Daily Living
ADOS	Autism Diagnostic Observation Schedule
AMPS	Assessment of Motor and Process Skills
AOTA	American Occupational Therapy Association
APA	American Psychiatric Association
ASD	Autistic Spectrum Disorder
Bayley-III	Bayley Scales of Infant and Toddler Development, Third Edition
BEERY VMI	Beery-Buktenica Developmental Test of Visual-Motor Integration
BOT	Bruininks-Oseretsky Test of Motor Proficiency
BOT-2	Bruininks-Oseretsky Test of Motor Proficiency- Second Edition
CARS	Childhood Autism Rating Scale
CBR	Community-based rehabilitation
CDC	Centers for Disease Control and Prevention
ChIPPA	Child Initiated Pretend Play Assessment
CMOP-E	Canadian Model of Occupational Performance and Engagement
CO-OP	Cognitive Orientation to daily Occupational Performance
COPM	Canadian Occupational Performance Measure
DCD	Developmental Coordination Disorder

continued

DIR®	Developmental-Individual Differences-Relationship-based approach
DSM-V	Diagnostic and Statistical Manual of Mental Disorders- Fifth Edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders- Fourth Edition-Text Revision
EPU	Economic Planning Unit
ETCH	Evaluation Tool of Children's Handwriting
FaHCSIA	The Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
FAI	Functional Assessment Interview
FAO	Functional Assessment Direct Observation
FEAS	Functional Emotional Assessment Scales
FOR	Frame of Reference
GAS	Goal Attainment Scaling
HDI	Human Development Index
HELP	Hawaii Early Learning Profile
IQ	Intelligence Quotient
M-CHAT	The Modified Checklist for Autism in Toddlers
M-FUN	Miller Function and Participation Scales
MOHO	Model of Human Occupation
MOP	Model of practice
MOTA	The Malaysian Occupational Therapists Association
MOVEMENT ABC	Movement Assessment Battery for Children
MUHREC	The Monash Human Research Ethical Committee
NASOM	The National Autism Society of Malaysia
NGO	Non-government organisation
OPM-A	Occupational Performance Model-Australia
OT	Occupational therapy

continued

OTAL, Vic	Occupational Therapy Australia Limited, Victoria Division
OT-SI	Occupational Therapy using a Sensory Integrative approach
PASW	Predictive Analytics Software
PECS	Picture Exchange Communication System
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified
PDMS	Peabody Developmental Motor Scales
PDMS-2	Peabody Developmental Motor Scales-Second Edition
PEDI	Pediatric Evaluation of Disability Inventory
PEO	Person-Environment-Occupation model
PEP-3	Psychoeducational Profile-Third Edition
QNST-II	Quick Neurological Screening Test-2nd Edition
RCT	Randomised control trial
SCERTS	Social Communication, Emotional Regulation and Transactional Support model
SCHOOL AMPS	School Version of the Assessment of Motor and Process Skills
SD	Standard Deviation
SFA	School Function Assessment
SI	Sensory Integration
SIB-R	Scales of Independent Behaviour-Revised
SIPDC	Symbolic and Imaginative Play Developmental Checklist
SIPT	Sensory Integration and Praxis Test
SPD	Sensory Processing Disorder
SPM	Sensory Processing Measure
SPSS	The Statistical Package for the Social Sciences

continued

TEACCH	Treatment and Education of Autistic and Related Communication- Handicapped Children programme
THS	Test of Handwriting Skill
TLP	The Listening Programme
ToP	Test of Playfulness
UK	United Kingdom
UKM	Universiti Kebangsaan Malaysia
UKMMC	Universiti Kebangsaan Malaysia Medical Centre
US	United States of America
VABS	Vineland Adaptive Behaviour Scales
Vineland-II	Vineland Adaptive Behaviour Scales-Second Edition
Wee FIM	Functional Independence Measure for Children

LIST OF SEMINARS AND CONFERENCES ATTENDED

1 **2 One Day Seminars – Autism Spectrum Disorders**
Royal Children's Hospital, Melbourne, 31st July 2009.
- *Participant.*

2 **Cultural-Historical Approaches to Video Observations and Analysis**
International Society for Cultural Activity Research (Regional Group) and Monash University Research Group – Furthering Early Childhood Research and Learning, 19th October 2009.
- *Participant.*

3 **OT AUSTRALIA Victoria 2010 State Conference**
MCG, Melbourne, 12th November 2010.
- *Participant.*

4 **Peninsula and Berwick PhD and Masters Student Presentation morning, Monash University**
MPARC, The Peninsula Campus, Monash University, 10th July 2012.
- *Oral presentation – Occupational Performance of Children with Autistic Spectrum Disorder: Review of Practice, Parents' Perspective and Goals.*

5 **Malaysian Occupational Therapy Annual Scientific Meeting 2013 in Conjunction with MOTA AGM 2013 - Towards Better Living".**
Dynasty Hotel, Kuala Lumpur, Malaysia, 13th – 15th June 2013.
- *Oral presentation – Visual Supports Approach in Occupational Therapy for Children with Special Needs.*

6 **International Seminar on Autism 2014 – "Autism is Not A Tragedy, Ignorance Is".**
Putrajaya International Convention Centre (PICC), Putrajaya, Malaysia, 22nd – 23th April 2014.
- *Participant.*
- *Chairperson for the workshop session – Soft skills in services provision, by Dr. Andy Shih (Vice President of Scientific Affairs, Autism Speaks).*

7 **Malaysian Occupational Therapy Association Annual General Meeting and Workshop.**
Allied Health Sciences College, Ministry of Health, Malaysia, 23rd – 24th May 2014.

- *Poster presentation – 1) Challenges in managing personal care activities in children with ASD: parents' perspectives.*
  2) Identifying the magnitude of behavioural composition of temper tantrum in young children with autism.

- *Oral presentation – Advancing your profession: Taping local postgraduate opportunity.*

CHAPTER I

INTRODUCTION

An increasing prevalence of children diagnosed with Autistic Spectrum Disorder (ASD) has been widely reported (Baird et al., 2006; Baron-Cohen et al., 2009; DiGennaro Reed, Hirst, & Hyman, 2012). In Australia, the prevalence of ASD is estimated at 1 in 160 children aged between 6 -12 years old (MacDermott, Williams, Ridley, Glasson, & Wray, 2006). ASD is reported to affect more males than females at a ratio of 4:1 and is reported to occur in all racial, ethnic, and socioeconomic groups [Centers for Disease Control and Prevention (CDC), 2014]. The prevalence of autism in Malaysia is reported at 1.6 per 1,000 (Mohd Kassim, Othman, Lai, & Mat Yusoff, 2009). The increasing prevalence creates difficulties in ensuring that appropriate services are available, maintained and pertinent issues addressed (Zachor & Curatolo, 2013).

Children diagnosed with ASD often have severe challenges in managing daily activities such as social skills, personal care, school and play activities throughout their life (Bailey, Hatton, Mesibov, Ament, & Skinner, 2000; Douglas & Taylor, 2004; Duncan & Bishop, 2013) and require a wide range of supports and services throughout the person's entire life (Baird et al., 2006; Boulet, Boyle, & Schieve, 2009; Burrell & Borrego, 2012).

In order to receive a diagnosis of ASD, a number of criteria need to be met, including impairments in social communication and interaction, as well as restricted, repetitive patterns of behaviour, interest, or activities. These impairments must present in early childhood and impair the child's everyday functioning (American Psychiatric Association, 2013a). The diagnosis of ASD does not predict the person's functional capability. Therefore, identifying the needs and priorities of children with ASD can be considered important for planning interventions for those children (Gupta & Singhal, 2009). Children with ASD may exhibit different characteristics despite having the same

diagnosis (Lollar & Simeonsson, 2005; Spreckley & Boyd, 2009). The disorder affects each child differently in terms of characteristics and severity and each child needs to be treated as an individual to improve his or her *occupational performance* - the ability to perform tasks in daily activities appropriate to his or her role, developmental age, culture and environment (Law et al., 2005).

Background Information about the Criteria of Autistic Spectrum Disorder

ASD is a complex developmental disability and further research is needed in this field. ASD is of increasing concern to health care practitioners as (a) there are no identified causes to date, (b) its prevalence is increasing, and (c) the negative effects of the condition impact on the ability for people with the disorder to perform and participate in the activities that they want and need to do (Carothers & Taylor, 2004; Duncan & Bishop, 2013). These issues mean that a diagnosis of ASD can impact significantly on the quality of life of these children and also their family members (DeGrace, 2004; Herlihy, Knoch, Vibert, & Fein, 2013).

ASD was first identified by Dr. Leo Kanner (1943) who described 11 children with "fascinating peculiarities" (p. 217). Since then, extensive research has been done to attempt to understand ASD. Much has been theorised on its clinical criteria and classifications that help in early identification of the condition. Currently, one of the diagnostic tools used to identify ASD is the recently published *Diagnostic and Statistical Manual of Mental Disorders – 5th Edition* (DSM-V) (American Psychiatric Association, 2013a) which specified two major characteristics of impairment consisting of:

1. Deficits in social interaction and social communication, and
2. Restricted, repetitive patterns of behaviour, interests, or activities.

The DSM-V recognises that the four previously separate disorders under the *Diagnostic and Statistical Manual of Mental Disorders-IV-text revision* (DSM-IV-TR)

classification (American Psychiatric Association, 2000), that is (a) autistic disorder, (b) Asperger's disorder, (c) childhood disintegrative disorder and (d) pervasive developmental disorder not otherwise specified, are actually a single condition with different levels of symptom severity in the two core deficits mentioned earlier. These symptoms and the levels of severity rating as stated in DSM-V are presented in Table 1.1 and Table 1.2, respectively.

The two core deficits puts ASD on a continuum of severity level ranging from "requiring support" (Level 1), "requiring substantial support" (Level 2) to "requiring very substantial support" (Level 3) (American Psychiatric Association, 2013a, p. 52). According to the DSM-V, symptoms in those two core deficits must be present from early childhood, even if those symptoms are not fully demonstrated until later, when increased social demands impact on the child's ability to function effectively in his or her everyday activities. The revised definition and classification of ASD in the DSM-V encourages earlier diagnosis of children compared with the DSM-IV-TR, which was geared towards identifying school-aged children presenting with symptoms of ASD. However, according to the DSM-V Work Group, those diagnosed with one of the four separate disorders listed in the DSM-IV-TR, will still meet the criteria for ASD diagnoses under the DSM-V. It was anticipated that the newly published criteria would not affect the number of children being diagnosed as ASD (Huerta, Bishop, Duncan, Hus, & Lord, 2012), although this is yet to be determined.

The ASD criteria as stated under the DSM-IV-TR (American Psychiatric Association, 2000) was used as a basis for this current research as the DSM-V (American Psychiatric Association, 2013a) was published in 2013 after the data collection was completed. Under the DSM-IV-TR, a total of at least six criteria from three core impairments are needed for the diagnosis to be made. These criteria are listed in Table 1.3.

Table 1.1

DSM-V Autism Spectrum Disorder Diagnostic Criteria, 299.00 (F84.0), p. 50-51

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):
    1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
    2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
    3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

    Specify current severity:

    Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
    1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
    2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
    3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to preoccupation with unusual objects, excessively circumscribed or perseverative interests).

    Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Table 1.1

DSM-V Autism Spectrum Disorder Diagnostic Criteria, 299.00 (F84.0), p. 50-51 (continued)

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behaviour (see Table 2).

A. Symptoms must be present in the early development period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

B. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

C. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor (Coding note: Use additional code[s] to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behaviour disorder (Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (**Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

[1]

[1] *Note*: Reprinted with permission from the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, (Copyright© 2013). American Psychiatric Association.

Table 1.2

DSM-V Severity Level for Autism Spectrum Disorder, p. 52

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behaviour, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behaviour causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

[2]

[2] *Note:* Reprinted with permission from the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, (Copyright© 2013). American Psychiatric Association.

Table 1.3

DSM-IV-TR Diagnostic Criteria for 299.00 Autistic Disorder, p. 75

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
    1. qualitative impairment in social interaction, as manifested by at least two of the following:
        a. marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
        b. failure to develop peer relationships appropriate to developmental level a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
        c. lack of social or emotional reciprocity
    2. qualitative impairments in communication as manifested by at least one of the following:
        a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
        b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
        c. stereotyped and repetitive use of language or idiosyncratic language
        d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
    3. restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
        a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
        b. apparently inflexible adherence to specific, nonfunctional routines or rituals
        c. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements).
        d. persistent preoccupation with parts of objects.

Table 1.3

DSM-IV-TR Diagnostic Criteria for 299.00 Autistic Disorder, p. 75 (continued)

B.	Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
C.	The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

[3]

The onset of these characteristics is prior to the age of three years old (Kleinman et al., 2008) and a confirmed diagnosis can only be made after the age of three years (DeGiacomo & Fombonne, 1998; Kleinman et al., 2008), even though the symptoms of ASD may be obvious during the first year of life.

The Impact Autistic Spectrum Disorder has on a Child's Occupational Performance

For children diagnosed with ASD, successful occupational performance is likely to be affected by the presence of the core characteristics of ASD, consisting of communication, social and behavioural impairments (American Psychiatric Association, 2000, 2013a). In order to discuss this, the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko, Townsend & Craik, 2007) is the theoretical framework used to guide this research (Figure 1.1).

The CMOP-E is a model that emphasises client-centred practice in occupational therapy. In client-centred practice, occupational therapists aim to provide and achieve assessment and intervention considered relevant and meaningful to clients themselves (Sumsion, 1999). The CMOP-E is composed of three main elements: (a) the person, consisting of cognitive, physical, affective and spirituality factors, (b) their occupations, constituted by activities of self-care, productivity and leisure, and (c) the environment,

[3] *Note.* Reprinted with permission from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision,* (Copyright©2000). American Psychiatric Association.

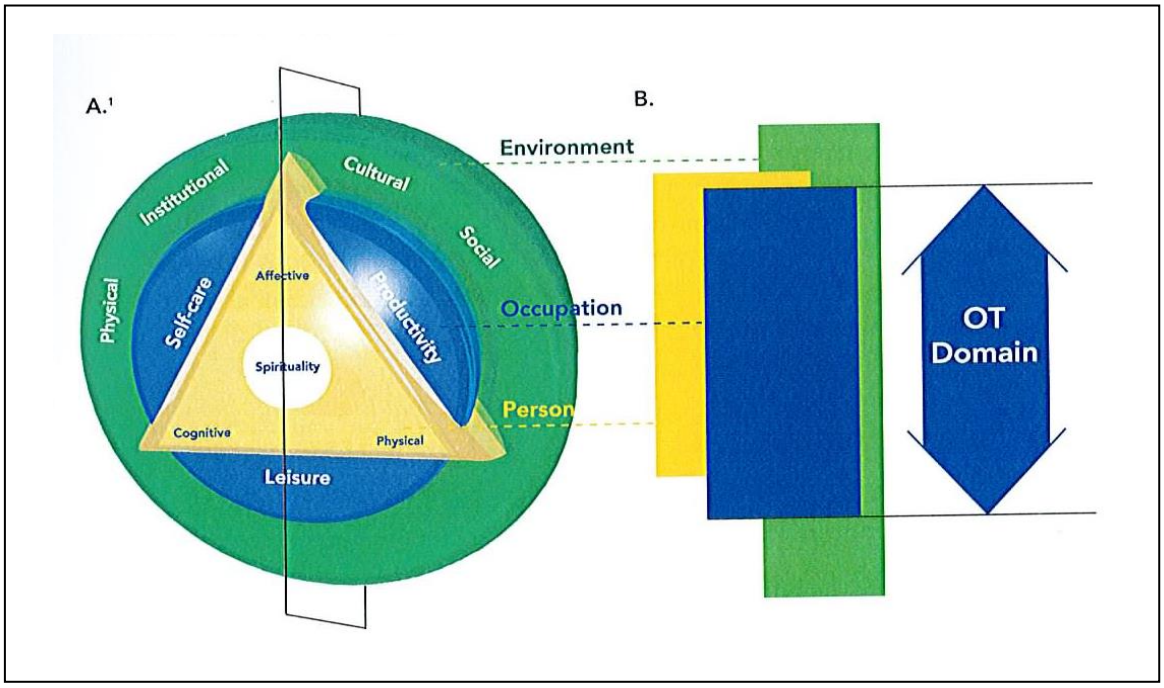

Figure 1.1. The CMOP-E Model. Taken from Townsend and Polatajko (2007), p. 23.[4]

consisting of the physical, institutional, cultural and social factors that influence the person (Polatajko, Townsend & Craik, 2007).

The core principle of the CMOP-E is the dynamic connection between the person, the person's environment, and the person's occupations (Picture B in Figure 1.1). According to this model, the ability of the person to perform and achieve successful occupations meaningful to them, within the communities or environments in which the person lives, and which are culturally and age appropriate, results in successful occupational performance (Canadian Association of Occupational Therapists, 2002; Townsend & Polatajko, 2007). This may influence the effective interaction between the person and the environment and occupation elements required to achieve successful occupation, which in turn might hinder meaningful occupational performance.

[4] Note. Reprinted with permission from the Enabling occupation II: Advancing an occupational therapy vision for health, well-being and justice through occupation, Canadian Association of Occupational Therapists.

People with Disabilities who are Living in Malaysia

The Federation of Malaysia is composed of two parts - Peninsular Malaysia and East Malaysia, separated by the South China Sea, with transportation between the two by air or sea. East Malaysia is located on the northern coast of the Island of Borneo. There are eleven states and two federal territories in Peninsular Malaysia, and two states and one federal territory in East Malaysia. Kuala Lumpur is the capital city, and this is located in the central region of Peninsular Malaysia (Figure 1.2).

Figure 1.2. Map of Malaysia (Peninsular and East Malaysia) (studymalaysiaguide.com, n.d.).

Malaysia has a multicultural and multiracial population consisting of Malays, Chinese, and Indians as the biggest ethnic groups. In addition, there are some other minority ethnic groups and numerous indigenous/tribal ethnic groups. The Malay language is the official language, but other widely spoken languages include Chinese

dialects, Hakka dialect, Mandarin, Cantonese, Tamil, English and several other languages and dialects spoken by the indigenous groups of peoples, particularly in East Malaysia.

According to the Human Development Index (HDI) produced by the United Nations in 2013, Malaysia was reported as having a high human development rank; 64th in the world and 9th in the region (United Nations Development Programme, 2013). The Human Development Index rank given to Malaysia suggests that the country has good human development, and generally good infrastructure for economic development, health, education, and other systems. In this context, there is a need for Malaysia to develop its own evidence, skills and specialities, such as healthcare services and educational systems, which are suitable for its fast-growing population to improve its society' well-being and developed services, such as health care services that are culturally suitable for their population needs.

The 2010 national census (Department of Statistics Malaysia, 2012) showed a total population of Malaysia of 28.3 million, with 22.56 million people living in Peninsular Malaysia and 5.77 million people living in East Malaysia. In terms of people living with disabilities, there were 280,671 and 33,580 people registered in Peninsular and East Malaysia, respectively (Ministry of Women Family and Community Development, 2012). Learning difficulties (including ASD) was the category of disabilities most highly reported with 120,109 cases, an increase on the 109,708 cases reported in the 2008 census. It is likely that there are higher numbers of people who are not identified formally.

Introduction to the Research

In order to study the needs of children with ASD and their families in Malaysia, the research had two phases. Phase one of the study involved data collection by postal surveys to occupational therapists in Victoria (Australia) and both Peninsular and East Malaysia. The reasons for this comparison of services between the two regions will be

explained later in Chapter III. The second phase of the research involved interviews with parents of children with ASD in Peninsular Malaysia.

Identification of the Issues

Occupational therapists are one of the professional groups involved in providing services to children diagnosed with ASD (James, Pizur-Barnekow, & Schefkind, 2014; Provost, Heimerl, & Lopez, 2007). Although much is understood of the clinical criteria and classification of ASD (Glennon, 2010; Rutter, 2011), limited evidence exists as to effective interventions for children with ASD (Prior, Roberts, Rodger, Williams, & Sutherland, 2011). According to Haynes, Devereaux, and Guyatt (2002), there are four essential elements in achieving good clinical decisions. They are (a) the clinical state and circumstances, (b) the individual's and family's concern and priorities, (c) related research findings, and (d) the practitioner's experience and expertise. This model emphasised that in order to achieve good and effective clinical decisions towards client care, the combination of the occupational therapist's knowledge, the client's goals and specific needs and occupational therapy interventions based on good and strong evidence are the most essential elements. Therefore, it is important for occupational therapists to sufficiently equip themselves with suitable assessment and intervention strategies supported by quality evidence to enhance the occupational performance of children with ASD. This evidence is essential in occupational therapy services to ensure effective interventions that are meaningful to the individual (Bowker et al., 2011).

Occupational therapists aim to improve the adaptation to, and quality of life of, children with ASD and their families (McLennan, Huculak, & Sheehan, 2008). However, existing research was found to focus on interventions to control or reduce challenging behaviours and/or sensory processing issues exhibited by children with ASD, rather than on achieving specific daily tasks and the promotion of active engagement (Jasmin et al., 2009; Wallen & Imms, 2006). There is a need for occupational therapy to provide

occupation-based intervention to improve the ability of the children with ASD in managing their daily living activities independently. This should be the focus of every clinician working with children with ASD to provide the most needed and relevant interventions (Rodger, Ashburner, Cartmill, & Bourke-Taylor, 2010; Wagenfeld & Kaldenberg, 2005).

Cognitive skills among children with ASD have been extensively studied (Bölte & Poustka, 2002; Duncan & Bishop, 2013; Ray-Subramanian, Huai, & Weismer, 2011). It was found that some children with ASD who have good cognitive abilities may still experience challenges in performing their daily living activities, also known as adaptive behaviour skills (Anderson, Oti, Lord, & Welch, 2009; Bishop, Richler, Cain, & Lord, 2007; Duncan & Bishop, 2013; Klin et al., 2007).

Adaptive behaviour skills are defined as the ability to adapt and achieve meaningful daily functions in coping with personal and social demands, according to the person's age and developmental level, cultural influences and expectations and basic environmental needs (Sparrow, Cicchetti, & Balla, 2005a). Adaptive skills can be determined by level of performance in activities such as self-care, home living, social skills, communication skills, school readiness skills, community use, self-determination, play/leisure participation and health/safety education (Hagiwara, Cook, & Simpson, 2008; Sparrow et al., 2005a). Occupational performance is defined as ″the result of a dynamic, interwoven relationship between persons, environment, and occupation over a person's lifespan; the ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after oneself, enjoying life, and contributing to the social and economic fabric of a community″ (Canadian Association of Occupational Therapists, 2002, p.181).

The adaptive behaviour skills that children have difficulties with include the ability to socialise as well as manage daily living activities (Anderson et al., 2009; Duncan & Bishop, 2013; Klin et al., 2007; Liss et al., 2001; Perry, Flanagan, Geier, & Freeman,

2009). Studies show that a higher intelligence score cannot predict the ability of the children with ASD to function effectively in their daily living activities (Duncan & Bishop, 2013; Liss et al., 2001; Schatz & Hamdan-Allen, 1995). This means that even though some children with ASD might have acquired the ability to communicate, they may still be having problems in carrying out their daily living skills, communicating their needs properly and expressing their emotions effectively.

The focus of this research has been to examine the adaptive behaviours and occupational performance among children with ASD to understand their difficulties and the challenges in their daily lives (Larson, 2010). Parents and caregivers were the valuable sources (Amar, 2008; Luong, Yoder, & Canham, 2009) used to collect the information in phase two of this research. This is because many of the children were unable to communicate their needs, but also because parents/caregivers are recognised as important in the life and development of children with ASD. Furthermore, they are often the people responsible for providing or carrying through the interventions prescribed, and, thus, should be empowered in order to ensure effectiveness and generalizability of their child's skills into community living (Burrell & Borrego, 2012).

Prior to this study, there was no information available regarding occupational therapy services provided for children with ASD and their families in Malaysia (Amar, 2008). Matters concerning the Frames of Reference (FOR) and Models of Practice (MOP) utilised, assessments and/or outcome measures administered, type of interventions conducted, areas of adaptive behaviour skills targeted, and the professional development needs of occupational therapists in Malaysia had never been explored. Furthermore, parental perspectives about their views of their child's difficulties and priorities for intervention were unknown. There was, and is, an ongoing need for research into the occupational therapy services for children with ASD in Malaysia, as well as an exploration of parents' concern regarding their children with ASD's occupational performance. The information outlined in this thesis demonstrates a benchmark of current practice, and

provides a guide for occupational therapists working in Malaysia to ensure that they are able to achieve client- and family-centred services for children with ASD and their families.

Aims and Research Questions

Although there has been much investigation into the characteristics of ASD, the underlying performance issues and difficulties with understanding effective interventions for children with ASD are of global concern, but remain undefined (Arbesman & Lieberman, 2010; Prior et al., 2011). The effectiveness of occupational therapy interventions for children and adults with ASD is also unclear (Case-Smith & Arbesman, 2008). Therefore, in order to better understand current practice, the occupational therapy services provided to children with ASD in Victoria (Australia) and both parts of Peninsular and East Malaysia were explored in phase one of this research. The services from occupational therapy practitioners in these regions were described and compared, and issues between and within the regions were explored.

To guide this phase of the research, the following research questions were identified:

1. What frames of reference and models of practice do occupational therapists utilise when providing services for children with ASD?
2. What assessments or outcome measures do occupational therapists utilise when providing services for children with ASD?
3. What interventions and areas of adaptive behaviours in daily living activities do occupational therapists utilise and address when providing services for children with ASD?
4. What are the issues of professional development needs as identified by occupational therapists in providing services for children with ASD?

Phase two of the research aimed to get a baseline profile of adaptive behaviour skills of children with ASD in Malaysia from their parents'/caregivers' perspectives. Information was gathered to obtain a picture of parent priorities. This was further compared with the occupational therapy services provided for children with ASD. Phase two of the research was carried out in Peninsular Malaysia in order to identify the priorities for occupational therapy intervention for children with ASD and their families in Peninsular Malaysia. The research questions addressed in this phase were:

1. What is the level and profile of adaptive behaviour skills in children with ASD living in Peninsular Malaysia?
2. What is the occupational performance difficulties identified in children with ASD in Peninsular Malaysia?
3. What is the relationship between the level of occupational performance in children with ASD and their parents' satisfaction level regarding that occupational performance in Peninsular Malaysia?
4. What is the relationship between the adaptive behaviour skills of children with ASD and their occupational performance difficulties, level of satisfactions and priorities in occupational performance as identified by their parents in Peninsular Malaysia?

Structure of the Thesis

This thesis is organised in seven chapters consisting of:

- ***Chapter I*** provides the reader with a broad introduction to the study, the diagnostic criteria of ASD, the theoretical framework used in the study, a brief background to Malaysia where most of the data collection was conducted, and an overview of the research and the organisation of the thesis.
- ***Chapter II*** presents the literature review, which is divided into three sections: (a) occupational therapy services with children with ASD, (b) adaptive

behaviour skills in children with ASD and difficulties in daily occupational performance among children with ASD, and (c) understanding of the challenges for children and adults with ASD, including perspectives on the services needed and aspects of their unmet needs.

- ***Chapter III*** presents the methods for phase one of the research - development of the questionnaire regarding occupational therapy services for children with ASD and collecting data on occupational therapy services for children with ASD in Victoria (Australia) and Malaysia.
- ***Chapter IV*** presents and discusses the findings in phase one regarding the occupational therapy services in Victoria (Australia) and Malaysia.
- ***Chapter V*** presents the methods employed in phase two of the research – Daily living skills in children with ASD – from the parents' perspective.
- ***Chapter VI*** presents and discusses the findings in phase two in terms of the level of adaptive behaviour skills and occupational performance problems among children with ASD, from the parents' perspective.
- ***Chapter VII*** focuses on the discussion of both phases of the research. In this chapter, the findings from phase one and two are compared and discussed in terms of parents' goals for their children with ASD occupational performance abilities as compared to service availabilities provided by occupational therapists. The study limitation, implication, suggestions for future studies and conclusions are also presented.

Summary

This chapter has presented the context of this study, the criteria for the diagnosis of ASD, the Canadian Model of Occupational Performance and Engagement (CMOP-E) adopted and a brief explanation about Malaysia where the main data collection was

conducted as well as the structure of the thesis. The review of the literature is presented in the next chapter.

CHAPTER II

LITERATURE REVIEW

This chapter presents the review of literature relevant to the research aims and questions in this study with regard to the occupational therapy practices with, and occupational performance issues in, children with ASD, as previously discussed. Figure 2.1 provides the overview of the presentation of the literature review.

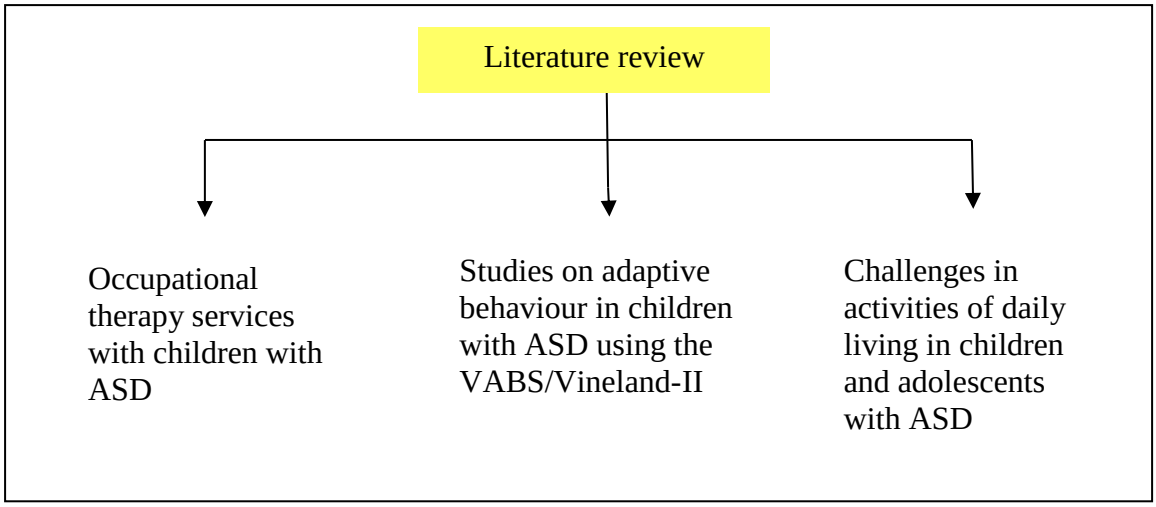

Figure 2.1. Overview of the presentation of the literature review.

Occupational Therapy Services with Children with Autistic Spectrum Disorder

Occupational therapy practitioners provide assessment and intervention for children with ASD in a wide variety of settings such as clinics, schools and the child's own home (Hodgetts & Hodgetts, 2007). A variety of intervention approaches based on the child's specific needs are needed in order to improve the child's abilities to perform his or her daily activities (Arbesman & Lieberman, 2010; Hodgetts & Hodgetts, 2007; Polatajko & Cantin, 2010). Providing a single approach is unlikely to address the children's unique and challenging needs (Flynn & Healy, 2012; LaVesser & Hilton, 2010; Zachor & Curatolo, 2013). It has been shown that the provision of intervention as early as

possible to children with ASD improves their ability to participate in their daily occupational performance activities (Dawson et al., 2010; Douglas & Taylor, 2004; Hébert, Kehayia, Prelock, Wood-Dauphinee, & Snider, 2012). In order for appropriate interventions to be implemented, accurate early diagnosis is needed (Moore & Goodson, 2003; Zachor & Curatolo, 2013).

The ability of children with ASD to generalise the skills that they have learnt in controlled intervention settings is essential to their successful participation and meaningful occupational performance in their daily living activities in community settings (Arbesman & Lieberman, 2010; Burrell & Borrego, 2012; Douglas & Taylor, 2004; Koegel, Matos-Freden, Lang, & Koegel, 2012; Wallen & Imms, 2006). This in turn might assist in successful integration into family routines (DeGrace, 2004). Some of the improvements that have been noted for children with ASD who have received occupational therapy include an increased use of language and significantly greater social interaction (Hébert et al., 2012; Nwora & Gee, 2009; Sams, Fortney, & Willenbring, 2006), positive behavioural changes (Fertel-Daly, Bedell, & Hinojosa, 2001; Nwora & Gee, 2009; Watling & Dietz, 2007) and improved motor-based occupational performance areas (Rodger & Brandenburg, 2009). In order to achieve these improvements, occupational therapy practitioners incorporate a number of different strategies in their interventions for children with ASD (Hodgetts & Hodgetts, 2007; Polatajko & Cantin, 2010; Watling & Dietz, 2007). However, studies that specifically look at improving occupational performance aspects provided in occupational therapy interventions for children with ASD are still limited (Arbesman & Lieberman, 2010; DeGrace, 2004; Jasmin et al., 2009; LaVesser & Hilton, 2010; Wallen & Imms, 2006). Some of the available studies focused more on the intervention needed to address behavioural challenges exhibited by children with ASD, rather than on providing intervention targeting the achievement of successful engagement in daily tasks (DeGrace, 2004; Wallen & Imms, 2006). In addition, many interventions provided to children with ASD lack evidence for their effectiveness, indicative that further

research is required (Arbesman & Lieberman, 2010; Dominguez, Ziviani, & Rodger, 2006; Goldstein, 2000; Hodgetts & Hodgetts, 2007; Parham et al., 2007; Pfeiffer, Koenig, Kinnealey, Sheppard, & Henderson, 2011). According to Case-Smith and Arbesman (2008), sensory integration and sensory-based interventions are the main approaches that have been given emphasis in occupational therapy practice for children with ASD.

Rodger, Brown, and Brown (2005) profiled paediatric occupational therapy practice in Australia that included children with ASD among the clients seen by the survey respondents. The results demonstrated that of the respondents (*n*=330), 52.8% had a specialty qualification in sensory integration therapy, 77.6% used sensory integration, 70.8% used a multisensory approach/sensory processing, and 56.0% used sensory diet interventions/approaches in their services with children with developmental delays. In terms of the treatment methods used by the respondents, 84.4% provided parental/caregiver education, teaching and learning in their services, 80.8% used sensory integration techniques, 76.0% provided activities of daily living/self-care skills training and 73.6% administered sensory stimulation and sensory diet.

Watling, Deitz, Kanny, and McLaughlin (1999a) surveyed occupational therapists practising in the United States of America (US). This was one of the earliest studies published regarding occupational therapy services specifically for children with ASD. The authors found that the most common intervention provided by occupational therapy practitioners for children with ASD was sensory integration and positive reinforcement and that the services were most commonly delivered on a one-to-one basis. In the survey, 88.0% of the respondents indicated that they most frequently provided services for children with ASD aged two to five years. In terms of the specific assessments and interventions used, the majority of the respondents in the Watling et al. (1999a) study stated that they utilised sensory-based approaches most frequently; and hands-on mentoring was the method of obtaining knowledge preferred by the greater number of the respondents. The authors stated that 50.0% of the respondents utilised outpatient clinics as

their site of occupational therapy service delivery and six to ten years was the longest work experience with children with ASD reported. However, since then, the huge advancements in research and information regarding children diagnosed with ASD, in terms of its diagnostic criteria, available assessments, and interventions, have demanded that more current investigations be carried out. More recently, Ashburner, Ziviani, and Rodger (2010, unpublished report) surveyed occupational therapists practising in Queensland, Australia and found that the greatest number of respondents in their study used visual supports with children and adults with ASD and most frequently saw children between three to six years of age (68.0%). The authors reported that the sensory profile (Dunn, 1996, 2006) was the formal assessment tool most frequently used by the majority of the respondents and sensory processing was among the areas of knowledge and training placed as a priority by the respondents. Occupational therapy utilising sensory-based intervention strategies for children with learning difficulties has also been reported as widely used in school settings (Bonggat & Hall, 2010; Worthen, 2010).

Levels of Evidence of the Interventions Provided for Children with Autistic Spectrum Disorder in Occupational Therapy Practice

Case-Smith and Arbesman (2008) conducted a comprehensive systematic review of interventions for children and adolescent with ASD used in, or of relevance to, occupational therapy practice. Table 2.1 contains the criteria used by Case-Smith and Arbesman (2008) in evaluating the studies. They found studies with levels of evidence I, II and III, suggesting that there is evidence for occupational therapy practitioners to implement comprehensive, individualised analysis of the child's performance to develop suitable occupational therapy intervention strategies. In their review, they developed six emerging themes of occupational therapy interventions provided to children and adolescent with ASD:

1. Sensory integration and sensory-based interventions

2. Relationship-based, interactive interventions
3. Developmental skill-based programs
4. Social cognitive skill training
5. Parent-directed or parent-mediated approaches
6. Intensive behavioural intervention.

Table 2.1

The level of evidence of studies in the systematic review conducted by Case-Smith and Arbesman (2008)

Level of evidence	Criteria
Level I	Randomised controlled trials, systematic reviews, meta analyses.
Level II	Nonrandomised clinical trials – two group, such as cohort, case-control studies.
Level III	Nonrandomised clinical trials – one group pre-test and post-test.
Level IV	Case series and single-subject design.
Level V	Case reports, expert opinion, such as narrative literature reviews and consensus statements

The first three interventions were found to be the most commonly used by occupational therapy practitioners in their services with children and adolescents with ASD (Case-Smith & Arbesman, 2008). Summaries of some of the studies involved in the systematic review relevant to the six interventions most commonly used by occupational therapy practitioners in their services with children with ASD can be located in Appendix A.

Case-Smith and Arbesman (2008) concluded that although some studies show evidence of improvement in children with ASD, further research is still needed which should include measurement of both physiological and performance effects to determine the influence of the interventions on behavioural and performance outcomes. Case-Smith and Arbesman (2008) suggest that future research should be conducted to investigate the effect of environmental modifications for children with ASD, taking into consideration

that these children are able to respond more effectively in a highly structured environment (Kinnealey et al., 2012). This highlighted a role for occupational therapy practitioners when providing services for such children. In general, based on the reviews performed, although some interventions utilised in occupational therapy services provided for children with ASD show evidence of their effectiveness, further research is still needed before any claim can be made on the most effective interventions for children with ASD. Moreover, the limited study of the utilisation of occupation-based practices in occupational therapy services in improving occupational performances in children with ASD should be given serious attention (Arbesman & Lieberman, 2010; Diamantis, 2010).

The Debate around the Implementation of Sensory-Based Interventions in Occupational Therapy Practice with Children with Autistic Spectrum Disorder

The theory behind the use of sensory processing states that the human brain and nervous system receive sensory information from the surroundings through senses of sight, hearing, touch, smell, and taste. The brain and nervous system also receive sensory inputs from within the body through the vestibular system, which gives information relating to balance and the proprioceptive system that gives the sense of knowledge of body position in space. Authors who advocate for sensory issues suggest that the process of interpreting this information by the brain and nervous system is called sensory processing (Kranowitz, 2005; Miller, 2006).

Miller (2006) and others suggest that the failure of the brain and nervous system to effectively process and organise all the sensory inputs received through all the senses could result in sensory processing disorder (SPD). However, this is highly controversial, and it has recently been suggested that SPD should not be a diagnosis on its own but other developmental disorders should be considered and thoroughly evaluated when these sensory symptoms are present (American Academy of Pediatrics, 2012). The suggestion to include SPD as a disorder in the DSM-V (American Psychiatric Association, 2013a)

was excluded, as the symptoms cannot be clearly conceptualised and often coincided with other disorders (Koziol, Budding, & Chidekel, 2011).

What is known about children with ASD is that they do have issues with sensory sensitivities such as hyper- and hypo-sensitivity to touch and sound in particular, as included in the DSM-V (APA, 2013), which could affect their responses and interaction with their surroundings, including people around them, and affect the quality of their occupational performance (Cermak, Curtin, & Bandini, 2010; Polatajko & Cantin, 2010; Richdale & Baglin, 2013; Robinson & Magill-Evans, 2009; Schaaf & Nightlinger, 2007). However, what is not proven by evidence in this population is the effectiveness of the sensory-based interventions (Arbesman & Lieberman, 2010). Following the American Academy of Pediatrics (2012) policy statement that there is limited and inconclusive research evidence to support sensory-based intervention, further debate within the occupational therapy profession on the use of sensory-based intervention for children with ASD is warranted (Bundy et al., 2013; Burrows, 2013; Rodger, Ashburner, & Hinder, 2012). The occupational therapy profession needs to reach a clear definition of the term used in explaining sensory-based interventions, performing studies using robust design and determining the appropriateness of the sensory-based interventions. Occupational therapy practitioners should be able to provide goal-directed intervention that can help the children with ASD manage their daily activities more effectively (Arbesman & Lieberman, 2010). One of the options is to focus on the aspect of occupation as the means of intervention.

Given the limited evidence for sensory-based interventions, the intervention should be paired with occupation-based tasks targeted on increasing performance outcome in children with ASD, such as play and self-care activities, rather than as a standalone intervention (Arbesman & Lieberman, 2010; Case-Smith & Arbesman, 2008; Case-Smith & Bryan, 1999). It is also important that occupational therapy practitioners should not lose their focus on providing occupation-based intervention with children with ASD and

that interventions based on achieving successful daily living occupation should be given priority (Diamantis, 2010; Jasmin et al., 2009; Rodger et al., 2010).

Polatajko and Cantin (2010) conducted a systematic literature review on occupational therapy interventions other than sensory integration in children and adolescents with sensory processing and integration disorders, including children and adolescents with ASD. The authors classified intervention approaches used by occupational therapy practitioners as: (a) impairment-oriented approaches in which the interventions targeted the reduction of the impairment and restoration of function to the impaired body structure and function, which in turn would result in increased occupational performances, and (b) performance-oriented approaches where the interventions directly focused on increasing occupational performance and participation abilities without being directly concerned with the underlying disability in body structure and function (Polatajko & Cantin, 2010).

Effectiveness in using sensory-based interventions for children with ASD was reported in some studies. Among the changes observed were improved behavioural responses, increased social and communication abilities and improved occupational performance skills and abilities (Arbesman & Lieberman, 2010; Case-Smith & Bryan, 1999; Fertel-Daly et al., 2001; Iwanaga et al., 2014; Nwora & Gee, 2009; Schaaf, Hunt & Benevides, 2012; Schaaf, 2013; Watling & Dietz, 2007). Although some studies reported on the effectiveness of the sensory-based intervention strategies, the quality of the studies generally was flawed, including by small study participant number, heterogeneity of the participants, or mixed or preliminary results only reported (Arbesman & Lieberman, 2010; Case-Smith & Bryan, 1999; Miller, Coll, & Schoen, 2007; Pfeiffer et al., 2011; Polatajko & Cantin, 2010; Schaaf et al., 2013).

Recently, an attempt was made to evaluate the effectiveness of sensory integration (SI) intervention in a pre- and post-test randomised control trial (RCT) study of children diagnosed with ASD or PDD by assigning them to a fine motor or SI treatment group

which focused on the areas of sensory processing/regulation, functional fine motor skills, and social-emotional skills. In this pilot RCT study conducted by Pfeiffer et al. (2011) with 37 participants aged between 6 and 12 years, decreased autistic mannerisms, and improvements in the area of sensory processing and regulation abilities and fine motor skills were reported among children who received SI intervention as opposed to children who received fine motor skills intervention only. Among the measures used in the study were standardised assessment of Quick Neurological Screening Test, 2nd Edition (QNST-II) (Mutti, Martin, Sterling, & Spalding, 1998) and the Goal Attainment Scaling (GAS) (Mailloux et al., 2007). The implementation of RCT study design in the Pfeiffer et al. (2011) study provided greater evidence for the use of sensory-based intervention with children with ASD in terms of its effectiveness. Most recently, Schaaf et al. (2013) also observed improvement in occupational performance abilities among children with ASD receiving SI intervention in occupational therapy services in their study. In the Schaaf et al., (2013), RCT study, 17 children with ASD, aged 4 – 8 years, assigned into the SI intervention in occupational therapy scored significantly better in self-care and socialisation skills compared to the 15 children with ASD placed in a control group. The findings from these studies should be interpreted cautiously by occupational therapy practitioners to guide their intervention with children with ASD, provided that there remains an occupational focus. Further studies are required regarding not only the effectiveness of SI and sensory-based interventions but also in which contexts these approaches make meaningful change - or - not - for the children and their families (Baranek, 2002; Case-Smith & Bryan, 1999).

The weak relationship, that could be owing to the small numbers of study participants, between sensory processing disorders and daily living skills indicates that there are other factors that may cause poor self-care skill performance among children with ASD (Robinson & Magill-Evans, 2009). Therefore, various assessments and intervention strategies need to be conducted by occupational therapy practitioners with

their clients of children with ASD, considering the multiple factors that may influence reduced occupational performance among those children (American Academy of Pediatrics, 2012). It can be concluded that there is limited evidence on the effectiveness of interventions based on a sensory approach to improve occupational performance abilities in daily living skills among children with ASD (Robinson & Magill-Evans, 2009). There is a need to explore not only whether the sensory-based approach used in occupational therapy practices is effective but also how it is effective in order to deliver quality services to children with ASD and their families, and also when it is not effective (Arbesman & Lieberman, 2010; Tomchek, 2010).

Other Related Approaches and Strategies in Occupational Therapy

In managing children with ASD, occupational therapy practitioners often use different strategies to achieve goals and targets (Hodgetts & Hodgetts, 2007), with the preferred strategies based on high-level strong evidence (Polatajko & Cantin, 2010). There are increasing numbers of studies that investigate improvement of occupational performance of children with ASD (Rodger & Brandenburg, 2009).

The Cognitive Orientation for daily Occupational Performance (CO-OP). The Cognitive Orientation for daily Occupational Performance (CO-OP) is a task-orientated problem-solving approach that utilises cognitive skills to improve occupational performance (Rodger, 2004). This approach has been reported as used with children diagnosed with various conditions, such as Asperger's syndrome, Developmental Coordination Disorder (DCD), acquired brain injury, as well as children with pervasive developmental disorder (Chan, 2007; Hyland & Polatajko, 2012; Missiuna et al., 2010; Phelan, Steinke, & Mandich, 2009; Rodger, 2004; Rodger & Vishram, 2010; Vun, 2008).

Although promising results were obtained from the studies using CO-OP approaches with children with ASD, further research is required to be able to use the approach with confidence (Rodger & Brandenburg, 2009).

The use of technology for children with autistic spectrum disorder. The implementation of technologies, such as video or DVD technology (DiGennaro Reed, Hyman, & Hirst, 2011) have been observed to improve communication, social, play and daily living skills among children with ASD (Flynn & Healy, 2012; Reichow & Volkmar, 2010; Weiss & Gal, 2011). A meta-analysis conducted by Akullian and Bellini (2007) found that the use of video modelling and video self-modelling were effective intervention strategies for addressing the social-communication skills, behavioural functioning, and functional skills of children with ASD.

These strategies can also be implemented in a variety of settings (Akullian & Bellini, 2007; Flynn & Healy, 2012). In a systematic review of treatments for deficits in social skills in children with ASD conducted by Flynn and Healy (2012), it was concluded that the use of video modelling had many strengths including:

1. It can be implemented with children with ASD with varying severity of symptoms
2. It appears to be an effective intervention across a range of settings
3. It does not require initial instruction or specific training
4. It is effective in decreasing social and problem behaviours during the interventions among children with ASD.

Video modelling has also been reported as suitable for use with a broad age range of children and adolescents and has shown promising results for its effectiveness (Reichow & Volkmar, 2010).

Social stories for children with autistic spectrum disorder. The use of social stories with children with ASD, especially with children with communication and social difficulties, has been reported by some occupational therapy practitioners (Karkhaneh et al., 2010; Marr & Nackley, 2010; Reynhout & Carter, 2008). Social stories are used to help children to mentally prepare for certain social situations by understanding the consequences of their behaviours and also of others around them. The aim is to help children to execute correct and appropriate responses in typical everyday situations (Reynhout & Carter, 2008; Rust & Smith, 2006). The social stories approach was most frequently used in school settings (Barry & Burlew, 2004; Kokina & Kern, 2010).

However, the studies demonstrating benefits of social stories used to improve occupational participations have significant limitations in study design, such as small sample size and lack of experimental control (Barry & Burlew, 2004; Kuocha, Mirenda, & Ozdemir, 2008; Prior et al., 2011; Spencer, Simpson, & Lynch, 2008). Owing to the limited evidence of the effectiveness of social stories due to the weaknesses in the study designs, caution should be observed by occupational therapy practitioners in implementing social stories in their intervention programmes (Karkhaneh et al., 2010; Kokina & Kern, 2010; Rust & Smith, 2006; Sansosti, Powell-Smith, & Kincaid, 2004).

In a recent review of the research to identify the most effective early interventions for children with ASD performed by The Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), the conclusion was that there was weak evidence for social stories, and that it must be used with other eligible intervention/approach (Prior et al., 2011).

Family-Centred Practice and Occupational Therapy

Having a family member with ASD brings challenge and adjustment in family routines (Altiere & von Kluge, 2009; Cermak et al., 2010; Joosten & Safe, 2014; Luong et al., 2009; Pottie & Ingram, 2008; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter,

2008). Parents have stated that their life is affected in many ways, such as a decrease in their own social life, and difficulties in dealing with public and community perceptions (Altiere & von Kluge, 2009; Benson & Karlof, 2009; Grey, 2002; Richdale & Baglin, 2013; Woodgate, Ateah, & Secco, 2008). They also face challenges in meeting educational demands for their children with ASD (Cassimos, Polychronopoulou, Tripsianis, & Syriopoulou-Delli, 2013; Luong et al., 2009; Renty & Roeyers, 2006). Parents have indicated a need for increased collaboration with professionals and educators to achieve optimum functional ability of their child in the context of their family life (Miller-Kuhaneck & Britner, 2010; Naseef, 2009; Thomas, Morrissey, & McLaurin, 2007).

Parents reveal their experience in dealing with children with ASD as time and energy consuming (Altiere & von Kluge, 2009; Flynn & Healy, 2012; Ling-Yi, 2010; Luong et al., 2009; Phelps, McCammon, Wuensch, & Golden, 2009). Social supports are important to decrease the stress related to caring for their child (Benson & Karlof, 2009; Twoy, Connolly, & Novak, 2007). Some parents also reported feeling guilty for having to sacrifice their attention to their other children (Phelps et al., 2009), and some siblings reported a difficult relationship with their sister or brother with ASD (Petalas, Hastings, Nash, Lloyd, & Dowey, 2009; Rivers & Stoneman, 2008).

Taking this into consideration, effective services for individuals with ASD need to be client- and family-centred (Fernell, Eriksson, & Gillberg, 2013; Joosten & Safe, 2014; Miller-Kuhaneck & Britner, 2010; Zachor & Curatolo, 2013). Whilst early intervention and treatment can improve the functional ability of people with ASD (Aldred, Green, & Adams, 2004; Fernell et al., 2013) it also has the potential to increase or reduce stress among parents (Karst & Van Hecke, 2012; McConache & Diggle, 2006; Twoy et al., 2007).

Smith et al. (2008) studied the level of well-being and ability to cope among mothers of children with ASD, and specifically compared parents of toddlers and those with adolescent children. The study found that both groups of mothers experience

significant level of stress compared to the general population, and that the level of stress did not differ according to the type or severity of their child's ASD symptoms (Pottie & Ingram, 2008). However, the mothers of the adolescents demonstrated higher levels of anger and disengagement, compared to mothers of toddlers with ASD (Smith et al., 2008). It was hypothesised that this may be due to the greater challenges in managing and caring for their adolescent children with ASD as opposed to younger children (Smith et al., 2008).

Mothers reported that the symptoms that they found most stressful included (a) rigid rhythmicity in daily habits, (b) high task orientation which put extreme emphasis on sameness and resisting changes, and (c) inability to communicate (Cermak et al., 2010; Konstantareas & Papageorgiou, 2006). Other than repetitive behaviours among children with ASD, lower adaptive behaviours were among the factors which put stress on mothers (Bishop et al., 2007; Ling-Yi, 2010). Children who had low nonverbal and/or verbal IQ scores did not have a negative impact on the stress levels of mothers (Bishop et al., 2007).

Parents or caregivers of children with ASD have been reported to be living in social isolation (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011; Woodgate et al., 2008). Parents described their social isolation as emerging from four sources: (a) a lack of understanding of ASD by the community, (b) the inability of the family to lead a 'normal life', due to the extensive time and attention needed in managing and caring for their child, (c) feeling disconnected from other family members, including their spouses, and (d) being not sufficiently supported by the available services needed by their children with ASD (Woodgate et al., 2008).

Parents expressed dissatisfaction in a number of areas that they felt disrupted their family life. Firstly, the age of diagnosis, which is often late, but then a long waiting list to receive a service. A study by Twoy, Connolly, and Novak (2007) found that it took six months or even longer from the time parents expressed concern about developmental delay in their child for professionals to provide a diagnosis of ASD.

Secondly, difficulty in finding suitable schooling for their child, both in placement and education and, thirdly, insufficient information regarding ASD (Renty & Roeyers, 2006). Furthermore, parents identified difficulty and unmet needs when searching for support in managing their children's daily activities (Larson, 2009).

Parents also expressed concern regarding their children's future needs and supports. To ensure effectiveness of occupational therapy interventions for children with ASD, the needs and goals of the child's social system should be considered and addressed (Burrell & Borrego, 2012; Fingerhut, 2013; Hanna & Rodger, 2002). The affected people will live within their social system – that is, their immediate and extended family for the whole of their life. It is essential, therefore, that active involvement and partnership with parents/caregivers and other family members are keys to ensure the successfulness of any recommendations (Dempsey & Keen, 2008; Fingerhut et al., 2013; Hanna & Rodger, 2002; Karst & Van Hecke, 2012). This is especially true when considering the continuity of care and any recommendations that are in the home environment (Burrell & Borrego, 2012; Espe-Sherwindt, 2008; Rouse, 2012).

Family-centred practice has been recognised as important in services for children with special needs. Ideally, this means that family members' roles in managing their children's unique needs based on their family priorities are recognised and respected (Burrell & Borrego, 2012; Karst & Van Hecke, 2012; Rouse, 2012). Under the principles of family-centred practice, active collaboration between occupational therapy practitioners and parents/caregivers and other family members in the decision-making process are vital in delivering services that are individualised, sensitive and responsive to the needs of the child in his or her context as a family member (Dunst, Trivette, & Hamby, 2010; Fingerhut, 2013; Rouse, 2012, Joosten & Safe, 2014).

Although it was reported that the implementation of family-centred practice can be difficult (Crais, Roy, & Free, 2006; Hanna & Rodger, 2002) and in need of further development and improvement (Dempsey & Keen, 2008; Kilmer, Cook, & Palamaro

Munsell, 2010), occupational therapists assisting the child's family members (especially main caregivers) have a responsibility to formulate or plan interventions that address the concerns and priorities of the families (Hanna & Rodger, 2002; Jaffe, Humphry, & Case-Smith, 2010, Joosten & Safe, 2014). Hence, families, as decision makers regarding the interventions their child receives, should be empowered to assist them to improve their quality of life (Dunst, 2002; Fingerhut, 2013; Rouse, 2012). The empowerment of families to be actively involved and decide on what is important for their children and family, and the planning of interventions based on their needs and priorities, has been found to lead to improved cooperation and satisfaction (Dempsey & Keen, 2008; Dunst, 2007).

The reported positive effects resulting from the implementation of family-centred practice with children with special needs include improved access and use of services, improvements to the health of family members, improvement in family functioning, improved development of their child with special needs and an increase in adherence to interventions designed to help and support the child (Burrell & Borrego, 2012; Dunst et al., 2010; Espe-Sherwindt, 2008; Kuhlthau et al., 2011). The observed benefits are likely to be from the cooperation and determination shown by the family members as they feel responsible for ensuring that their child with special needs achieves intervention goals that are meaningful and purposeful to them, not defined or directed by health or educational professionals (Burrell & Borrego, 2012). Hence, based on the significant benefits of family-centred practices as reported in the literature, as well as the core principles of occupational therapy models [such as the Person Environment Occupation (PEO) model] (Law et al., 1996), all occupational therapists practicing in the area of ASD should be encouraged to employ such practices in their service provision for children with ASD and their families (Joosten & Safe, 2014).

Studies and Methods of assessment for Adaptive Behaviour in Children with Autistic Spectrum Disorder

There have been many studies on adaptive behaviour among children with ASD, often with the purpose of determining their abilities to successfully function in their daily lives (Flynn & Healy, 2012; Kanne et al., 2011). Adaptive behaviours skills, such as the ability to manage personal-care activities and active community participations are also said to be one of the indicators of successful achievement of independence in daily living activities among children with ASD (Duncan & Bishop, 2013; Flynn & Healy, 2012; Paul et al., 2004). Sparrow et al. (2005a, p. 6) defined adaptive behaviour as the "ability to adapt and achieve meaningful daily functions in coping with personal and social demands according to person's age and developmental level, cultural influences and expectations and basic environmental needs."

It is reported that the adaptive behaviour displayed by children with ASD was significantly impaired, compared to children with other diagnoses (Perry et al., 2009; Kanne et al., 2011). Lord and Schopler (1989a) demonstrated in their study, that children with ASD consistently scored lower in adaptive behaviour skills as opposed to non-autistic children matched on chronological age and cognitive level, and this is consistent throughout the literature (Kanne et al., 2011).

Assessment of adaptive skills in this population is through three mechanisms – (1) standardised assessments, (2) norm-referenced assessments, and (3) informal assessments, such as structured observations. Standardised assessments such as the Adaptive Behaviour Assessment System-Second Edition (ABAS-II) (Harrison & Oakland, 2003) and the Scales of Independent Behavior-Revised (SIB-R) (Bruininks, Woodcock, Weatherman, & Hill, 1996) that are used to assess and measure behaviour, also have an adaptive skills assessment to them. Informal assessment tends to be via either an interview with children themselves or their parents/caregivers or via structured observation in their natural settings, such as home, school and community.

The most commonly used assessments that are specifically developed to measure adaptive behaviour in this group are the Vineland Adaptive Behaviour Scales (VABS) (Sparrow, Balla, & Cicchetti, 1984) and the Vineland Adaptive Behaviour Scales-Second Edition (Vineland-II) (Sparrow, Cicchetti, & Balla, 2005b) which is widely reported in the research literature (Duncan & Bishop, 2013; Kanne et al., 2011; O'Donnell, Deitz, Kartin, Nalty, & Dawson, 2012; Scattone, Raggio, & May, 2011).

In the VABS/Vineland-II (Sparrow et al., 1984; Sparrow et al., 2005b), adaptive behaviour skills can be profiled based on either the standard scores measure or the age-equivalent measure. The standard scores describe an individual's overall functioning, as well as his or her level of functioning in each of the adaptive behaviour domains – "… a standard score relates one person's performance to the performance of a pertinent reference group" (Sparrow et al., 2005a, p. 63). Whereas, the age-equivalent scores "indicate the age level at which the average person in the population performs the same as the individual who is being assessed" (Sparrow et al., 2005a, p. 65).

The Vineland-II (Sparrow et al., 2005b) assesses adaptive behaviour skills in four major domains of (a) communication, (b) daily living skills, (c) socialisation, and (d) motor skills, and the optional domain of maladaptive behaviour.

Autism Profile in Individuals with Autistic Spectrum Disorder

Some studies reported a typical "autism profile" of adaptive behaviour in children and adults with ASD as significantly impaired in socialisation skills, relatively impaired in communication skills with adaptive behaviour as a relative strength (Bölte & Poustka, 2002; Carter et al., 1998; Loveland & Kelly, 1991; Tomanik, Pearson, Loveland, Lane, & Shaw, 2007). A study conducted by Carter et al. (1998) on 684 children with ASD of both verbal and non-verbal children, found that children aged below 10 years scored higher in all Vineland Adaptive Behaviour Scales - survey form (VABS) (Sparrow et al., 1984) standard scores as opposed to the group of older children. The authors also found a typical

“autism profile” of adaptive behaviour obtained with age-equivalent scores in which the socialisation aspect was most impaired in children with ASD in their study population and the aspect of daily living skills was the area of relative strength. A similar “autism profile" of adaptive behaviour was also found in a more recent study by Kanne et al. (2011) based on a standard score measures. An important finding was that the daily living skills in children with ASD were significantly impaired but to a lesser extent than the other domains.

In a more recent study conducted by Ray-Subramanian et al. (2011), the result obtained from the Vineland-II (Sparrow et al., 2005b) administered to 125 children with ASD aged below three years shows that the communication skills were most impaired, followed by socialisation skills, daily living skills and motor skills. The pattern of delayed adaptive behaviour levels in children with ASD can be detected as young as below three years (Ray-Subramanian et al., 2011). What is important when thinking about ASD is that early communication abilities, both verbal and nonverbal skills are among the important predictors of outcome in adaptive behaviour skills in preschool children with ASD (Szatmari, Bryson, Boyle, Streiner, & Duku, 2003). All children with ASD tend to fall behind their peers as they get older, but children who do not develop fluent language fall further behind even if they are higher functioning and have good nonverbal skills compared to other children with ASD who manage to acquire ability to communicate (Szatmari et al., 2003).

Relationship between Age Levels and/or Cognitive Abilities and Adaptive Behaviour Skills

The relationship between age levels and/or cognitive abilities and adaptive behaviour skills among children with ASD was reported to be negatively associated (Duncan & Bishop, 2013; Gabriels, Ivers, Hill, Agnew, & McNeill, 2007; Kanne et al., 2011). This means that the deficits in adaptive behaviour skills among children with ASD

become more apparent as they grow older, when the differences between children with ASD and typically developing children become more obvious, although some of the children with ASD might be reported to have higher cognitive ability compared to others (Duncan & Bishop, 2013; Jacobson & Ackerman, 1990; Kanne et al., 2011; Klin et al., 2007; Lord & Schopler, 1989b).

Children with ASD were reported to show very little improvement in certain areas of adaptive behaviour skills, such as socialisation and daily living skills, even when their cognitive abilities increase as predicted by their intelligence scores (Liss et al., 2001). They were also reported to experience difficulties in daily living skills even for those who have higher cognitive abilities (Duncan & Bishop, 2013; Perry et al., 2009) and this uneven profile of development is shown only in children with ASD (Anderson et al., 2009; Gillham, Carter, Volkmar, & Sparrow, 2000). The summaries of the studies included in this review are located in Table 2.2.

Generally, children with ASD face difficulties in their adaptive behaviours skills, particularly with managing daily living activities regardless of their age and cognitive abilities. As they get older, their occupational demands and expectations increase which widens the gap between them and children of typically development (Kanne et al., 2011).

Adaptive Behaviour Skills and Their Implication for Occupational Therapy Practice

This review demonstrates that the adaptive behaviour skills abilities, such as personal care and socialisation activities among children with ASD do not improve as they grow older, even if they show above average cognitive abilities. As children grow older, the demands of their daily living skills – in particular their developing socialisation becomes more challenging. For children with ASD, this means that the gap between their adaptive living skills and those of their peers widens. Thus, there is a need to strengthen and prioritise interventions related to adaptive behaviour skills in children with ASD as they move into adolescence and adulthood in order to help them to adapt successfully to

Table 2.2

Studies on adaptive behaviour skills, autism profiles, and the relationship between adaptive behaviour and age and/or cognitive level

Author	Participant/design	Autism profile/relationship between adaptive behaviour and age and/or cognitive level
Carter et al. (1998)	684 individuals with ASD of both verbal and nonverbal, divided into 4 groups of below and above 10 years.	Autism profile was attained with age-equivalent measure, with the results showing that the socialisation domain was most impaired and the daily living skills was the area of strength in individuals with ASD.
Tomanik et al. (2007)	129 participants - children and adolescents, aged between 7 and 18 years, who were evaluated for autism. The tools used were the ADI-R and ADOS. The Vineland Adaptive Behaviour Scale was included in the analysis for the purpose of classification accuracy.	Adaptive functioning was significantly lower in the autism group as opposed to the non-autism group across all Vineland domains (i.e.: communication, daily living skills and socialisation), as well as the Vineland composite scores.
Paul et al. (2004)	40 children with autism and PDD-NOS aged between 4 and 11 years functioned in the mild to moderate range of intellectual impairment. The purpose of the study was to provide a microanalysis of differences in adaptive functioning seen between well-matched groups of school-aged children with autism and those diagnosed as having PDD-NOS.	Generally, children diagnosed with ASD show deficits in adaptive behaviour functioning. However, significant differences in raw scores were observed between the autism group and the PDD-NOS group on the Vineland domains of communication and socialisation, especially on the expressive subdomain, interpersonal and play/leisure subdomains. Children with autism scored poorly in the areas involving more elaborated language usage.

Table 2.2

Studies on adaptive behaviour skills, autism profiles, and the relationship between adaptive behaviour and age and/or cognitive level (continued)

Author	Participant/design	Autism profile/relationship between adaptive behaviour and age and/or cognitive level
Bölte and Poustka (2002)	The association between adaptive behaviour and cognitive level in 67 individual with ASD with and without comorbid mental retardation was examined. Data from the screening version of the Vineland Adaptive Behaviour Scales and the Wechsler Intelligence Scales were analysed.	The individuals with ASD show higher intellectual functioning than adaptive behaviour skills. In terms of the typical autism profile as measured on the Vineland Adaptive Behaviour Scales, individuals with ASD typically score highest on daily living skills, lowest on socialisation and intermediate on communication. The overall adaptive behaviour and IQ (Intelligence Quotient)-level differed significantly only in the subgroup of non-mentally retarded individuals with ASD.
Gabriels et al. (2007)	A 5-year follow-up study examining the stability of adaptive functioning in two cognitive ability groups of 14 children with ASD.	Children with ASD with both normative and impaired nonverbal IQ scores show significantly delayed adaptive behaviour skills as measured with the Vineland Adaptive Behaviour Scales composite standard scores over time. The group of children with ASD with cognitive impairments did not demonstrate an increase in adaptive behaviour skills over time.
Klin et al. (2007)	187 high functioning children with ASD, all boys, aged between 7and18 years were investigated in terms of their ability and disability using the Vineland and Autism Diagnostic Observation Schedule (ADOS).	Adaptive skills in the participants were substantially below typically developing children despite cognitive potential. A weak relationship was found between ability and disability, and negative relationships were found between age and Vineland scores and no relationships were found between age and ADOS scores.

Table 2.2

Studies on adaptive behaviour skills, autism profiles, and the relationship between adaptive behaviour and age and/or cognitive level (continued)

Author	Participant/design	Autism profile/relationship between adaptive behaviour and age and/or cognitive level
Szatmari et al. (2003)	To assess the extent to which measures of cognitive abilities taken in 68 higher-functioning preschool children with autism and Asperger's syndrome predict outcomes after two and six years.	Early communication abilities, both verbal and nonverbal skills are important predictors of outcome in adaptive behaviour in preschool children with ASD. Those who do not develop fluent language as they grow older fall further behind, even if they are higher functioning and have good nonverbal skills compared to other children with ASD who acquire communication skills.
Ray-Subramanian et al. (2011)	To assess the relationship between adaptive behaviour and cognitive skills for 125 toddlers on the autism spectrum, aged below 3 years. The tools used were the Vineland-II and Bayley-III.	Delays in adaptive skills could be detected as early as 2 years of age. Children with ASD show an autism profile of Vineland-II standard scores in which motor skills were greater than daily living skills, which, in turn, was greater than socialisation, and socialisation was greater than communication skills.

the skills they need for adult life (Klin et al., 2007). The gap between peers and children with ASD in terms of daily living skill may further widen due to the decrease in access to services to help them address these needs as the children grow older (McConachie & Robinson, 2006).

This is an important point that is reflected in the literature: as the gap between the person's skills and the skills of peers widens, the access to services that may address these needs is reduced. This phenomenon is likely to reduce the functional ability and independent skills among children with ASD, as the children with ASD's challenging behaviour seems to increase as they exit the school systems and enter adulthood (Taylor & Seltzer, 2010), or do not receive the services that they need to successfully transition to adult life. Services that specifically address leaving the school system and entering adulthood are important to ensure the most successful transition possible (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012). Ongoing access to developmentally-appropriate occupationally-targeted interventions should be available throughout the lifespan of the individual.

Occupational therapy practitioners are one of the health care professionals involved in helping children with ASD to experience smooth transition into adolescent and adult life successfully. The maximum level of independence possible for the individual in daily living intervention is an essential part of this, and intervention for children with ASD should be aimed at achieving success in daily living occupations - a core occupational therapy skill (Flynn & Healy, 2012; Kanne et al., 2011; Perry et al., 2009). Since higher levels of cognitive functioning among children with ASD did not reflect their level of competence in daily living activities, intervention should be goal-directed, and focused on enabling children to be successful in their meaningful daily occupations, that include generalising skills to function better in their natural environment (Klin et al., 2007).

Given this area of practice, occupational therapy practitioners should be placed to perform intervention in the community and use their clients' own natural environments as

the intervention settings, in order to provide services that are most effective as well as meaningful for children with ASD and their families. Daily living activities are best addressed in the environment(s) in which they are carried out, not in a controlled therapy setting, in order for the interventions to be effective (Klin et al., 2007) and also for adaptive outcomes to be investigated (Klin et al., 2007).

Challenges in Activities of Daily Living for Children and Adolescents with Autistic Spectrum Disorder

According to the DSM-V(American Psychiatric Association, 2013a), the core characteristics to obtain a diagnosis of ASD are - impairments in communication and socialisation, the presence of restrictive, repetitive patterns behaviours, interests, or activities, and this is likely to influence the ability of the children and adolescents with ASD to perform effectively in their daily living occupations (see Table 1.1 for the full characteristics).

As emphasised under the CMOP-E model (Polatajko, Townsend & Craik, 2007), the ability of the person to perform and achieve successful occupations in their life results in the achievement of successful occupational performance. However, there has been little research to specifically investigate occupational performance problems related to children and adolescents with ASD. All of the associated impairments of ASD, such as those in communication, deficits in socialisations and restricted, repetitive behaviours (American Psychiatric Association, 2013a) influence children's occupational performance abilities in their day-to-day lives (Goldingay et al., 2013; Hilton, Crouch, & Israel, 2008), but this area of research is still scarce (Duncan & Bishop, 2013; Jasmin et al., 2009; LaVesser & Hilton, 2010). Given the lack of information, in order to understand the challenges in occupational performance experienced by children with ASD, insights from personal accounts are highly relevant.

Managing Daily Living Skills by Parents of Children with Autistic Spectrum Disorder

Parents of children with ASD have unmet needs in managing the daily activities of their children with ASD (Brown et al., 2011; Dabrowska & Pisula, 2010; Miller-Kuhaneck & Britner, 2010), and, as above, insights from parents and families are important to understand this area (DeGrace, 2004; Larson, 2010).

According to the CMOP-E model (Townsend & Polatajko, 2007), to be considered as having successful occupational performance, children and adolescents with ASD should be able to:

1. Care for themselves
2. Satisfactorily perform at school, play and leisure.

These are elements of childhood occupations that need to be harmoniously integrated with factors within the environment, such as the physical, institutional, social, and cultural aspects that are unique to individuals (refer to Figure 1.1). What has been shown is that the level of active participation in all aspects of occupational performance is impaired in children and adolescents with ASD (Larson, 2010), and, thus, achieving successful and meaningful occupational performance can be a challenge for them (Flynn & Healy, 2012; Hilton et al., 2008; Watling & Dietz, 2007). The type of occupational performance issues that can present in various contexts in everyday occupations of children with ASD, such as in personal care, school/academic activities, social, and play contexts (LaVesser & Hilton, 2010), are reviewed and presented below.

Occupational Performance Issues in Personal Care Activities

Children with ASD have been consistently reported to experience difficulties in personal care activities (Allik, Larsson, & Smedje, 2006; Cermak et al., 2010; Flynn & Healy, 2012; Twachtman-Reilly, Amaral, & Zebrowski, 2008). Personal care activities

are the basic self-care tasks that people usually do daily and these include the personal care aspects of daily living activities, which include feeding, sleeping, self-hygiene, dressing, bathing, toileting, and ambulating (Flynn & Healy, 2012). These aspects of personal care activities can be a challenge to the person with ASD and can interrupt their daily living skills (Cermak et al., 2010; Duncan & Bishop, 2013; Flynn & Healy, 2012; Jasmin et al., 2009). The following personal care tasks have been identified as potential areas of difficulty for people with ASD.

Eating and self-feeding. It has been reported that 90% of children diagnosed with ASD have feeding difficulties (Zachor & Curatolo, 2013). Feeding problems among children with ASD can be divided into physiological and behavioural factors (Bandini et al., 2010; Twachtman-Reilly et al., 2008). There are two main difficulties identified: (a) food selectivity and refusal, and (b) disruptive mealtime behaviours.

Food selectivity and refusal. Nearly 70% of children with ASD are reported as having eating difficulties present with food selectivity (Zachor & Curatolo, 2013), and predominantly a lack of food variety (Gale, Eikeseth, & Rudrud, 2011; Nadon, Feldman, Dunn, & Gisel, 2011; Sharp, Jaquess, Morton, & Miles, 2011). More than 50% of feeding problems in children with ASD were reported to be problems in terms of trying new foods, taking medicine, limited food choices, and mouthing objects (Gale et al., 2011; Williams, Dalrymple, & Neal, 2000). As well, insisting on routine, playing with food, eating one brand, eating non-edible items and licking objects were also common difficulties with this group (Williams et al., 2000). These problems in feeding were observed even in young children with ASD aged 3-6 years (Provost, Crowe, Osbourn, McClain, & Skipper, 2010; Sharp, Jaquess, & Lukens, 2013). Some individuals with ASD will limit their choices of food to certain kinds and numbers of food only (Bandini et al., 2010; Dunn & Donaldson, 2001; Gale et al., 2011; Sharp et al., 2011). This fussiness often places extra strain on

parents or caregivers (Gale et al., 2011; Lecavalier, Leone, & Wiltz, 2006; Suarez, Atchison & Lagerwey, 2014). One participant's experience as describe by Jones, Quigney, and Huws (2003) exemplifies this:

> And I don't like the texture of some foods, especially foods that are hard to chew, like steak. I don't like food that is slimy like shrimp, or the fat part of chicken, food that wiggles, like Jelly-O. All these foods feel bad on my mouth and tongue and teeth (pp. 115-116).

Schreck and Williams (2006) found that 48.6% of the children with ASD in their study (N=138) showed food refusal due to using different utensils, or if different food items were touching on a plate as well as due to food texture. Oral motor problems were reported in 23.2%. The food preferences of children with ASD were generally related to their family food preferences (Schreck & Williams, 2006). Preferences for using certain utensils among children with ASD were also found in an earlier study by Schreck, Williams, and Smith (2004), besides narrow food selection and limited acceptance of food textures such as refusal to eat new food textures and flavours, for example when moving from pureed to solid food as the child grows older (Cermak et al., 2010; Gale et al., 2011). Vegetables were among the most reported rejected food in children with ASD (Sharp et al., 2013).

Limited food selection and eating refusal exhibited by some children with ASD has been reported to cause medical complications such as malnutrition and lethargy to the extent that emergency treatment was needed by some of them (Bandini et al., 2010; Cermak et al., 2010; Graf-Myles et al., 2013; Piazza, Dolezal, & Stein, 2011; Zachor & Curatolo, 2013).

Disruptive mealtime behaviours. Other problems include not only food selectivity and refusal, but refusal to participate in mealtime rituals such as sitting at the table and the display of disruptive behaviours, for examples running away from the eating area,

screaming, crying, hitting, spitting and pushing food away (Koegel et al., 2012; Provost et al., 2010; Sharp et al., 2011; Suarez, Atchison & Lagerwey, 2014).

Parents become increasingly concerned about their child's disruptive behaviour as the child reaches the age of 1 year (Provost et al., 2010). Disruptive behaviours during mealtime exhibited by children with ASD make it difficult for their family to dine out (Provost et al., 2010) and negatively impact on the families' quality of life (Cermak et al., 2010; Groden et al., 2001). The repetitive and ritualistic behaviours of many children with ASD were also reported to contribute to difficulties in participation during mealtime, as well as impairment in social and language skills (Twachtman-Reilly et al., 2008). Disruptive mealtime behaviour was also associated with sensory sensitivities in children with ASD (Cermak et al., 2010).

Toileting. Toileting is an important aspect of independence in later life. In terms of the difficulties in toileting, school-aged children with ASD were reported to still wear diapers and had urination accidents daily both in the home and school settings (Cicero & Pfadt, 2002; Keen, Brannigan, & Cuskelly, 2007; Kroeger & Sorensen, 2010; LeBlanc, Carr, Crossett, Bennett, & Detweiler, 2005).

Toilet training appears to be very important. Some children failed toilet training attempts and continue to face difficulties in toileting (Keen et al., 2007; Kroeger & Sorensen, 2010; LeBlanc et al., 2005). Thus, there are a number of approaches in the literature to try and ensure success, and those that are reported include a modified intensive toilet training protocol (Kroeger & Sorensen, 2010; LeBlanc et al., 2005) and also the use of animated toileting video modelling (Keen et al., 2007). The use of video modelling may facilitate urinary control among children with ASD, together with the use of operant conditioning strategies (Keen et al., 2007).

Self-hygiene. Children with ASD were reported to have difficulties in their daily living skills with personal care aspects being the most affected, such as the ability to care for their own hygiene, for example, washing or cleaning their own hands (Jasmin et al., 2009; Rosenberg, Schwartz, & Davis, 2010). Furthermore, the presence of motor coordination problems among some children with ASD can also interfere with their ability to achieve independence in daily living occupations (Kopp, Beckung, & Gillberg, 2010). The type of daily living skills engaged by children with high functioning ASD were reported to be limited to the personal care activities not involving people, such as cleaning or tiding-up after oneself and less involved activities associated with others, such as caring for others (Reynolds, Bendixen, Lawrence, & Lane, 2011).

Sleeping difficulty. Sleeping patterns were found to be disturbed in some children with ASD which affected their occupational performance, and that of their family (Allik et al., 2006; Giannotti, Cortesi, Cerquiqlini, Vaqnoni, & Valente, 2011; Kozlowski, Matson, Belva, & Rieske, 2012). Difficulty falling asleep and daytime sleepiness were among the sleeping problems reported in literature in children with ASD (Allik et al., 2006; Richdale & Schreck, 2009). Anxiety, autism symptom severity, sensory sensitivities, and gastro-intestine problems were among the issues associated with sleeping difficulty in children with ASD (Holloway, Aman, & Butter, 2013; Richdale & Baglin, 2013; Richdale & Schreck, 2009).

Occupational Performance Issues in School/Academic Activities

Among the identified difficulties in participating in school activities for children with ASD were: (a) hand function difficulty, (b) behavioural problem, and (c) communication impairment (Cassimos et al., 2013; Fuentes, Mostofsky, & Bastian, 2009; Hsu & Ho, 2009; Ming, Brimacombe, & Wagner, 2007; Yianni-Coudurier et al., 2008), as

well as poor engagement in school or classroom activities and with peers (Falkmer, Granlund, Nilholm, & Falkmer, 2012).

Hand function difficulty. It was observed that children with ASD had overall poorer performance on handwriting tasks compared to their typically-developing peers (Fuentes et al., 2009). Difficulties with motor control might influence their ability to perform better letter formation which might result in performance difficulty at school (Fuentes et al., 2009; Kushki, Chau, & Anagnoustou, 2011). Other hand writing difficulties including holding pens and writing were an issue (Ming et al., 2007). Occupation based intervention, that are directed by the person and their family such as training in letter formation and fine motor control might be beneficial in improving handwriting skills among children with ASD (Fuentes et al., 2009). This may help the child to achieve successful occupational performance in school/academic skills (Kushki et al., 2011).

Generally, children with ASD were found to exhibit poor handwriting quality in terms of their writing speed, letter formation, alignment, spacing and sizing (Kushki et al., 2011; Mayes & Calhoun, 2007), and these problems tend to persist through to adulthood (Fuentes, Mostofsky, & Bastian, 2010).

Behavioural issues. Children with ASD often demonstrated significant difficulties related to their academic and social functioning and have been rated as having lower school performance than their peers (Montes & Halterman, 2006). Parents of children with ASD were reported as having the greatest amount of contact with teachers regarding problem behaviours of their children (Montes & Halterman, 2006). Problem behaviours exhibited by children with ASD include hyperactivity, withdrawal from activities, disruptive behaviour, poor attention and irritability (Cassimos et al., 2013; Mayes & Calhoun, 2007; Yianni-Coudurier et al., 2008). Children with ASD who exhibited

behaviour problems were reported to have fewer hours in school and this in turn influenced their inclusion into the main-stream classroom (Yianni-Coudurier et al., 2008).

In a study by Estes, Rivera, Bryan, and Dawson (2011) on 30 higher functioning school-aged children with ASD, the authors found that there was no relationship between the children's problem behaviours and their level of academic achievement. The authors observed that improvement in social ability skills among children with ASD was associated with increases in their academic performance. This can be because the educational activities in school provided more intellectually stimulating activities which resulted in higher improvements in the students as opposed to those who have already exited the school system, who show less improvement (Taylor & Seltzer, 2010).

One of the diagnostic criteria for ASD (American Psychiatric Association, 2013a) is the emphasis on order and sameness in routine. When changes occur in routine, considerable stress may be experienced by individuals with ASD (Wing, 1997). Rigid ritual behaviours were reported to contribute to lower academic performance in children with ASD and cause disruption in classroom routines (Hsu & Ho, 2009). Repetitive behaviour, which is one of the core characteristics in children with ASD as listed under the DSM-V (American Psychiatric Association, 2013a), is likely to affect their occupational performance in school activities (Hsu & Ho, 2009).

Stereotypic and repetitive motor mannerism, such as fingers flapping or body rocking is synonymous with ASD, but individuals with high functioning autism and Asperger's syndrome seem to be better able to control these behaviours (Ghanizadeh, 2010). Motor mannerisms can occur at almost any time and may increase in intensity when such children are in stress or even when they are excited (Ghanizadeh, 2010).

Communication. Children with ASD can demonstrate impairments in communication that can be either verbal and/or non-verbal (Ganz et al., 2012). This is one of the major characteristics associated with ASD (Arnold et al., 2000; Charman, Howlin,

Berry, & Prince, 2004; Kjellmer, Hedvall, Fernell, Gillberg, & Norrelgen, 2012) with greater than half of the children diagnosed with ASD presenting with communication impairments (CDC, 2007, 2010). Typically-developing toddlers will turn when they hear their names as early as before their first birthday and can use at least 2-3 simple word sentences by the age of 3 years. However, this is not the case in individuals with ASD. Some do gain language communication later in life but some might remain uncommunicative throughout their life; for example, Sinclair (1992) explained:

> …I didn't communicate by talking, not because I was incapable of learning to use language, but because I simply didn't know that was what talking was for (p. 296).

This statement made by an individual with ASD clearly shows that such individuals have difficulties understanding language and conversation. These situations often lead to the suspicion that they have a hearing impairment. They might appear to be not attending to conversation or ignoring requests. Another statement that clearly shows how language can be achieved in the learning process of individuals with ASD was made by Lissner (1992). She noted:

> I didn't start talking until I was 4…Dad also used Coke to stimulate my language. He placed a Coke on the table in front of me and made me say "Coke" before pouring a drink. His techniques must have worked because soon after that I began talking… (p. 304).

In order for individuals with ASD to learn language they require explicit instruction as to what a word means and its context (Kjellmer et al., 2012). This highlights that such individuals may learn differently from typically-developing peers (Cassimos et al., 2013; Lang et al., 2011). It has been reported that some children learn language using pictures and symbols and others may gain verbal communication but may have differences such as unusual voice pitch and pedantic speech. This may then lead to difficulties in obtaining and maintaining social conversations (Paul, Augustyn, Klin, & Volkmar, 2005).

This is known as semantic-pragmatic use of language, which is knowing what to say and when is it appropriate to say it (Paul et al., 2005; Toichi & Kamio, 2001). These deficits might then add to the perception of high-functioning individuals as 'weird' by others (Paul et al., 2005).

Some individuals with ASD, who are unable to acquire language and have reduced communication ability, may exhibit challenging behaviours (Kjellmer et al., 2012; Noens & Berckelaer-Onnes, 2004). These may take the form of self-injury, temper tantrums, destructive and aggressive behaviours that are used as an outlet for their anger and frustrations (Lecavalier et al., 2006). Inability to express and communicate their needs, feelings and emotions may put tremendous stress and anxiety on individuals with ASD.

Some individuals with ASD may have the ability to receive and understand instructions, but they may understand words literally. In terms of social situations, this may make them appear to be attention seekers, disturbing to others' attention or perceived as being rude (Janzen, 2003). An example of literal understanding provided by Lawson shows:

> Young man takes too much time to eat breakfast in the morning. Carer complains that because he is so slow, they are often late. However, when they go out for 'fast food', the young man eats his food quickly and attempts to clear the food from other people's tables too! I suggested telling the young man at breakfast time 'this is fast food', might mean he eats his breakfast more quickly! (Lawson, 2001, p. 30).

Communication problems were also reported to affect participation in school activities (Asberg, 2010). Similarly, children diagnosed with high-functioning autism and Asperger's syndrome with a full-scale IQ of at least 80 (without any history of hearing and sight problems) were also reported to experience expressive and receptive language difficulties, even though they had reported a typical development in terms of early language development. The presence of echolalia and pronominal reversal were also reported among those children (Noterdaeme, Wriedt, & Hohne, 2010). The problems with

receptive and expressive language make it difficult for children with ASD to participate in academic occupations.

Occupational Performance Issues in Socialisation and Play Activities

One of the criteria to obtain a diagnosis of ASD is impairment of socialisation skills (American Psychiatric Association, 2013a; Goldingay et al., 2013). It has been demonstrated repeatedly that social skills are an area of challenge for children with ASD compared to their typically-developing peers (Goldingay et al., 2013; Macintosh & Dissanayake, 2006). The topic on which this work has concentrated includes social and community activities, socialisation skills, range and type of play activities, peer reactions and interventions to address this area.

Social and community activities. Children with ASD have less involvement in social and community activities, and that may lead to a reduced quality of life (Goldingay et al., 2013; Lee, Harrington, Louie, & Newschaffer, 2008). Children with ASD were observed to show ability in helping adults to achieve the adults' goals; however, they might show a lack of cooperative ability in achieving shared goals (Liebal, Colombi, Rogers, Warneken, & Tomasello, 2008; Shields, King, Corbett, & Imms, 2013). Even though children with ASD may show the ability and motivation, they are likely to need to be guided to enable engagement in active community activities (Shields et al., 2013). It was also observed that children and adolescents with ASD spend considerably less time engaged in social conversation or doing social activities with their peers (Orsmond & Kuo, 2011) as well as less time engaged in physical activities than their peers (Shields et al., 2013). Some children and adolescents with ASD preferred to be alone or chose to spend time with their mothers or other adults instead (Lang et al., 2011; Orsmond & Kuo, 2011).

Socialisation skills. Individuals with ASD lack the ability to demonstrate and understand non-verbal communication conventions (Anderson et al., 2009; Kjellmer et al., 2012). Body language such as facial expressions, body postures, and gestures that form part of an important aspect in socialisation skills generally hold no meaning to them (Goldingay et al., 2013), and this often leads to difficulties in social interactions (Kjellmer et al., 2012; Sperry & Mesibov, 2005). The ability to understand and use appropriate social interaction convention in conversation is essential to obtaining and maintaining successful social relationships. The impact of this is demonstrated through an insight from Phillips (2009, March 29) when he explained:

> In the past, I would ramble on about a topic or subject that interested me. I often failed to notice that the person or persons I was addressing didn't quite share my enthusiasm for the subject. This also occurred because I couldn't read other people's body language and facial signals. I could only recognise when someone was happy because they smiled when they were happy. Hence I couldn't tell that the person or persons I was talking to were bored. I also would go on and on about the same thing over and over again because it felt, to me, reassuring to talk about it. When I was younger, recognising facial expressions and body language to me, was like you being asked to read Chinese (Unless you can read Chinese of course!) Totally incomprehensible (para. 1).

The inability to understand body language and facial expression means that individuals with ASD may be perceived as insensitive to other people's feelings (Beall, Moody, McIntosh, Hepburn, & Reed, 2008; Goldingay et al., 2013). Sometimes individuals with ASD are aware of other's expressions but don't have the ability to understand them or know what is the appropriate response for those expressions, as explained by Sinclair (1992):

> Sometimes I'm not aware of social cues because of the same perceptual problems that affect my understanding of other aspect of environment. My visual-processing problems are no more the result of indifference than blindness is – are blind people considered insensitive if they fail to recognize people or to respond to others' facial expressions? Sometimes I notice the cues but I don't know what they mean (p. 300).

Behavioural problems were found to affect children with ASD in their social context (Macintosh & Dissanayake, 2006). Children with ASD were reported to have greater problem behaviours and reduced social skills compared to their typically-developing peers (Macintosh & Dissanayake, 2006). Furthermore, lack of socialisation skills may contribute to the limited social participation shown in children with ASD (Goldingay et al., 2013; Hilton et al., 2008).

Individuals with ASD not only may appear insensitive to other people's feelings, but they also show limited understanding of their own feelings and emotions (Sperry & Mesibov, 2005). This may make it hard to predict their feelings towards something or events that happen in their life because such individuals show reduced ability in sharing enjoyment and interest with other people. Jackson (2002) explained,

> Despite what Mum says, I do have fun at it even though it doesn't show on my face. My face never does seem to do the right thing! (p. 49).

This statement demonstrates how individuals with ASD do have feelings but may lack the ability to show them. For individuals with ASD, in order to understand body language, expressions and feelings used in social conversation and to learn the appropriate response to those expressions or how those expressions feel, the feelings need to be taught and described in detail. Sinclair (1992) in his personal essay on understanding the feelings and emotions of individuals with ASD, and how to help them, explains:

> And through all this condescending concern about feelings and emotional issues, no one ever bothered to explain to me what the words meant! No one ever told me that they expected to see feelings on my face, or that it confused them when I used words without showing corresponding expressions. No one explained what the signals were or how to use them. They simply assumed that if they could not see my feelings, I could not feel them. I think this shows a serious lack of perspective taking! (p. 297).

Range and type of play activities. Children with ASD have been found to participate in a limited range of activities, with a narrow group of friends and their social

participations were also limited in terms of geographical locations (Goldingay et al., 2013; Hilton et al., 2008). Some children with ASD were also reported to have at least one secondary condition such as attention deficit and hyperactivity disorder (ADHD), anxiety disorder, learning disability, depression, Tourette syndrome or epilepsy which might contribute to or worsen their challenges in socialisation activities (Hilton et al., 2008).

Children with ASD have been considered as less attractive playmates by their peers (Reynolds et al., 2011), which is likely to be associated with their social interaction difficulties and/or due to repetitive behaviours (Ghanizadeh, 2010; Hartley & Sikora, 2009; McLennan, Lord, & Schopler, 1993). Furthermore, parents report that their children do not play like other children, which again creates a barrier to forming relationships with their peers (Gillberg et al., 1990; Zandt, Prior, & Kyrios, 2007). Among the challenging play behaviours reported in children with ASD were:

1. Limited ability to communicate and less turn-taking behaviours during play (Reynolds et al., 2011; Rodman et al., 2010).
2. Limited exploration during play, such as looking at the play object (Kawa & Pisula, 2010; Rodman et al., 2010).
3. Focusing on sensorimotor play, such as banging or swinging of the play object without playing with it functionally (Blanc, Adrien, Roux, & Barthelemy, 2005; Dominguez et al., 2006; Rutherford, Young, Hepburn, & Rogers, 2007).
4. Stereotypic play - such as focusing on ritualistic and repetitive behaviours during play was also reported in some children with ASD, especially those who present with lower functioning abilities (Reed et al., 2012; Ghanizadeh, 2010; Zandt et al., 2007).
5. Delayed development of functional play and very limited symbolic play, such as less or limited creativity during play (Baranek et al., 2005; Blanc et al., 2005).

6. Significantly more gross motor play and less construction toys than peers (Dominguez et al., 2006).
7. Engagement in solitary play (Orsmond & Kuo, 2011; Reynolds et al., 2011).
8. Narrow range of play activities and less imaginative and/or dramatic play (Reynolds et al., 2011).

When exploring the types of play that children with ASD preferred, the following were identified in literatures as the ones most commonly engaged in:

1. Playing video games, or with transportation vehicles, and reading/books, as well as other types of solitary play (Reynolds et al., 2011; Rotheram-Fuller, Kasari, Chamberlain, & Locke, 2010).
2. Games that do not involve complex rules (Reynolds et al., 2011; Rotheram-Fuller, Kasari, Chamberlain, & Locke, 2010).
3. Watching television and using a computer (Orsmond & Kuo, 2011).

The choices of play activities clearly demonstrate passive and solitary activities. The choices of play activities among children with ASD have been hypothesised as impacted by their sensory responsiveness and also associated with their difficulties in relating to other people, which affected their performance in play (Reynolds et al., 2011; Williams, Reddy, & Costall, 2001). However, the social development ability among children with ASD without co-morbidity of intellectual disability was reported to significantly correlate with their symbolic play abilities (Stanley & Konstantareas, 2007); that is, those with better social skills tended to have more independent symbolic play.

Fascinations and fixations of interests, behaviours and activities shown by individuals with ASD can be varied among certain events, animals, figures, numbers and sounds (Ghanizadeh, 2010). These fascinations seem to change over time and it can also

affect occupational performance and also social areas of functioning of such individuals, as explained by Jackson (2002);

> The arguments over the PlayStation are ongoing in our house. When I am on it I forget to eat, to get dressed or do anything other than work out where my character is going or what it is supposed to be doing next (p. 49).

The above insight clearly shows how obsessive play behaviours may interrupt functional aspects of daily activities among individuals with ASD. Although the general population may have interests with extreme fascination (Reed et al., 2012), the levels of fascination intensity in individuals with ASD are extremely high; attempts to disrupt their engagement may result in aggressive behaviours and irritations (Dunn & Donaldson, 2001; O'Donnell et al., 2012).

Many individuals with ASD, especially children, will always have something in their hands, usually a small object (Jackson, 2002). They are not going to properly play with it or use that object according to its purposes. Instead, they might just enjoy its smell, taste, texture, making a sound with the object by tapping it almost everywhere or just for the sake of having it with them. They seem to relax and are in full control when the object is with them, as explained by Jackson (2002): "I remember all this well, and the feeling of insecurity when I was without one" (p.52).

Others may show persistent preoccupation in play with parts of objects; for example, instead of playing with the toy car appropriately, they may only concentrate and focus on the toy car's wheels. They might spend hours repeatedly turning and spinning the wheels and this behaviour may be generalised to other things also (Reed et al., 2012).

Peer reaction to children with Autistic spectrum disorder. Children with ASD might be prone to choose to be alone or only engage in solitary play (Orsmond & Kuo, 2011). Children with ASD often experience peer rejection (Spinrad et al., 2004) and have been found to be less accepted by their peers and have less reciprocal friendships

compared to typically-developing children (Cappadocia & Weiss, 2010; Flynn & Healy, 2012; Rotheram-Fuller et al., 2010). The children with ASD were more likely observed to be isolated in social relationships within the classroom context and the social isolation becomes greater as their grade level increases (Rotheram-Fuller et al., 2010).

Interventions to improve engagement in play and socialisation. As individuals with higher social skills have been found to have better adaptive skills, it is important to help children to engage in social play with peers where possible. A study by Dominguez et al., (2006) found that including play objects or toys based on well-known television programmes or cartoon characters may assist in increasing play performance and motivation among children with ASD. The inclusion of adults and/or other people in play might also assist in increasing functional and symbolic play ability among children with ASD, as well as increasing their social and communication abilities, but interferes with independent interaction with other children and therefore must be carefully balanced (Blanc et al., 2005; Shields et al., 2013; Williams et al., 2001).

Social interaction abilities among children with ASD and their peers at school for example, behaviours such as offering of objects, communicating and turn-taking were reported to increase as parents arranged more frequent play dates for them at home (Frankel, Gorospe, Chang, & Sugar, 2011). Socialisation skills can be increased by providing those children with the opportunity to practice their skills. Furthermore, involving typically-developing peers as models through play dates or therapists also seems to be effective in promoting the learning of target skills among children with ASD (Lang et al., 2011).

Motor Difficulties in Children with Autistic Spectrum Disorder

Motor difficulties are present in some children diagnosed with ASD and cause occupational performance problems that exacerbate other skills problems (Green et al.,

2009; Liu, 2013; Rinehart & McGinley, 2010; Shetreat-Klein, Shinnar, & Rapin, 2012, Stackhouse, 2010). The presence of motor problems among children with ASD is debatable; at present, it is considered an associated symptom and not part of the core characteristics of the disorder (American Psychiatric Association, 2013a; Fournier, Hass, Naik, Lodha, & Cauraugh, 2010; Ming et al., 2007), however, it has been proposed that it should be included as one of the core features of ASD (Mattila et al., 2011).

In a systematic review conducted by Fournier et al. (2010) on 51 studies, both published and unpublished, regarding motor impairments in children and adults with ASD, including both high and low functioning autism and Asperger's syndrome, the authors analysed the aspect of motor coordination consisting of: (a) movement preparation or planning, (b) upper extremity motor function, and (c) gait and balance. Findings show that children and adults with ASD present with significant motor coordination impairments, both in upper and lower extremities, when compared to typically-developing control groups. The authors concluded that the motor coordination impairments are significant characteristics of ASD. The presence of motor coordination impairment in children and adults with ASD interferes with their daily occupational performances and potentially reduces their quality of life (Fournier et al., 2010; Green et al., 2009; Stackhouse, 2010).

Among the motor difficulties observed in children with ASD were: (a) hypotonia, (b) apraxia, (c) toe-walking, (d) gross motor delay, (e) reduced ankle mobility, and (f) difficulties in fine motor skills (Green et al., 2009; Ming et al., 2007). Some suggested that the motor impairments in children with ASD seem to improve as they get older, either with or without interventions (Ming et al., 2007; Shetreat-Klein et al., 2012).

The aspect of movement planning in children with ASD was also reported to be impaired where they were unable to plan the goal of the direction, the orientation towards the goal and the trajectory when they were asked to walk to a specified location (Stackhouse, 2010; Vernazza-Martin et al., 2005). Noterdaeme et al. (2010) reported that motor impairments was present in 53% and 47% of the children with Asperger's syndrome

and high-functioning autism, respectively, and an earlier study by Provost et al. (2007) also reported that 50-73% of children with ASD showed motor delays.

Thus, even though, at present, motor impairment is not part of the diagnosis of ASD, the majority of children with ASD are likely to have some sort of motor difficulties, suggesting that motor assessment should be considered as part of the ongoing assessment in children with ASD (Green et al., 2009; Stackhouse, 2010). This, combined with their social and communicative difficulties will further influence the children's abilities in performing ADL and self-care tasks (Flynn & Healy, 2012; Shetreat-Klein et al., 2012).

Summary and Conclusion

This chapter has reviewed studies of occupational therapy services with children with ASD, adaptive behaviour skills and occupational performance problems among children with ASD, and reviews of the challenges in managing daily living skills among children and adolescents with ASD.

In this review, problems related to managing daily living activities in children and adolescents with ASD in terms of personal care, school, socialisation, and play, were explored and it was found that the level of cognitive abilities in children and adolescents with ASD does not always predict their functional and adaptive behaviour skills. Hence, children and adolescents with ASD who presents with higher cognitive abilities cannot be assumed to be better able to manage their daily living skills needs, such as personal care, school and social interactions, than people with less cognitive ability. The presence of sensory sensitivities and motor impairments in some children with ASD were also reported as contributing to decreased ability to perform daily occupational performance activities independently among those children and adolescents. Studies show negative correlation between age and ability to adaptively function successfully in everyday activities among children with ASD, suggesting that those children might need continuous support throughout their life. Assessment and intervention for children and adolescents with ASD

should be individually planned to suit the child's current abilities and specific needs, and the involvement of families is highly recommended. Interventions should be started as early as possible and interventions with high-level evidence of its effectiveness should be the priority.

Given the difficulties with occupational performance demonstrated by children and adolescents with ASD and the effects on their daily living activities, it is worth exploring occupational therapy services provided for them in managing these issues. It has been valuable to look at the interventions provided by occupational therapy practitioners for children and adolescents with ASD. It is also essential to investigate what the priorities are in the interventions most needed by parents and families in order to determine the type of services and interventions that are really useful and valuable for the children and adolescents with ASD and their family members.

Some of the studies reported that occupational therapy interventions for children and adolescent with ASD shows promising improvement in terms of their ability to function in everyday life. However, there needs to be an investigation of the extent of focus on the provision of occupation-based intervention by occupational therapy practitioners in managing occupational performance issues faced by children with ASD in their daily living skills and for functioning effectively in communities. This could be achieved by conducting interventions with stronger study design, as the existing studies are unable to support the effectiveness of the interventions provided, due to the methodological difficulties of the studies that exist at present, as well as the lack of firm evidence for support of these interventions.

CHAPTER III

INTRODUCTION TO THE METHODS USED IN PHASE ONE OF THE RESEARCH: DEVELOPMENT AND DELIVERY OF A QUESTIONNAIRE TO INVESTIGATE OCCUPATIONAL THERAPY SERVICES FOR CHILDREN WITH AUTISTIC SPECTRUM DISORDERS

Children with ASD and their families require a range of services either directly or indirectly throughout their lives. These services depend on the needs of the children with ASD and their families, as well as on the goal that needs to be achieved and can be influenced by service availability. The service might involve direct interventions for the children or be in the form of emotional and psychological support to the child and/or the child's family. Occupational therapy practitioners are one of a range of health professionals involved in providing services to children with ASD and their families (Case-Smith, 2005; Case-Smith & Arbesman, 2008). However, information on what services are available and provided internationally are scant, and are not available in Malaysia and still limited in Australia (Amar, 2008; Prior et al., 2011). To address this, a questionnaire was developed to investigate what services are provided to these children and their family in both jurisdictions.

Development of a Questionnaire to Investigate Existing Occupational Therapy Services for Children with Autistic Spectrum Disorder

Watling et al. (1999a) designed a questionnaire to investigate occupational therapy practices for children with ASD entitled *'*Current practice of occupational therapy for children with autism: A national survey of practitioners©' (Watling, Deitz, Kanny, & McLaughlin, 1999b). The questionnaire was designed to investigate occupational therapy services in the US for children 3-9 years of age (R. Watling, personal communication,

May 28, 2009). This questionnaire was selected as the basis for the questionnaire developed in this study. Considerable modification was required, as the original questionnaire was: (a) designed for therapists based in the US, and (b) designed and carried out prior to 1999. Permission for this was granted by the author, Dr. Renee Watling (Appendix B). Figure 3.1 illustrates the whole process of the questionnaire development.

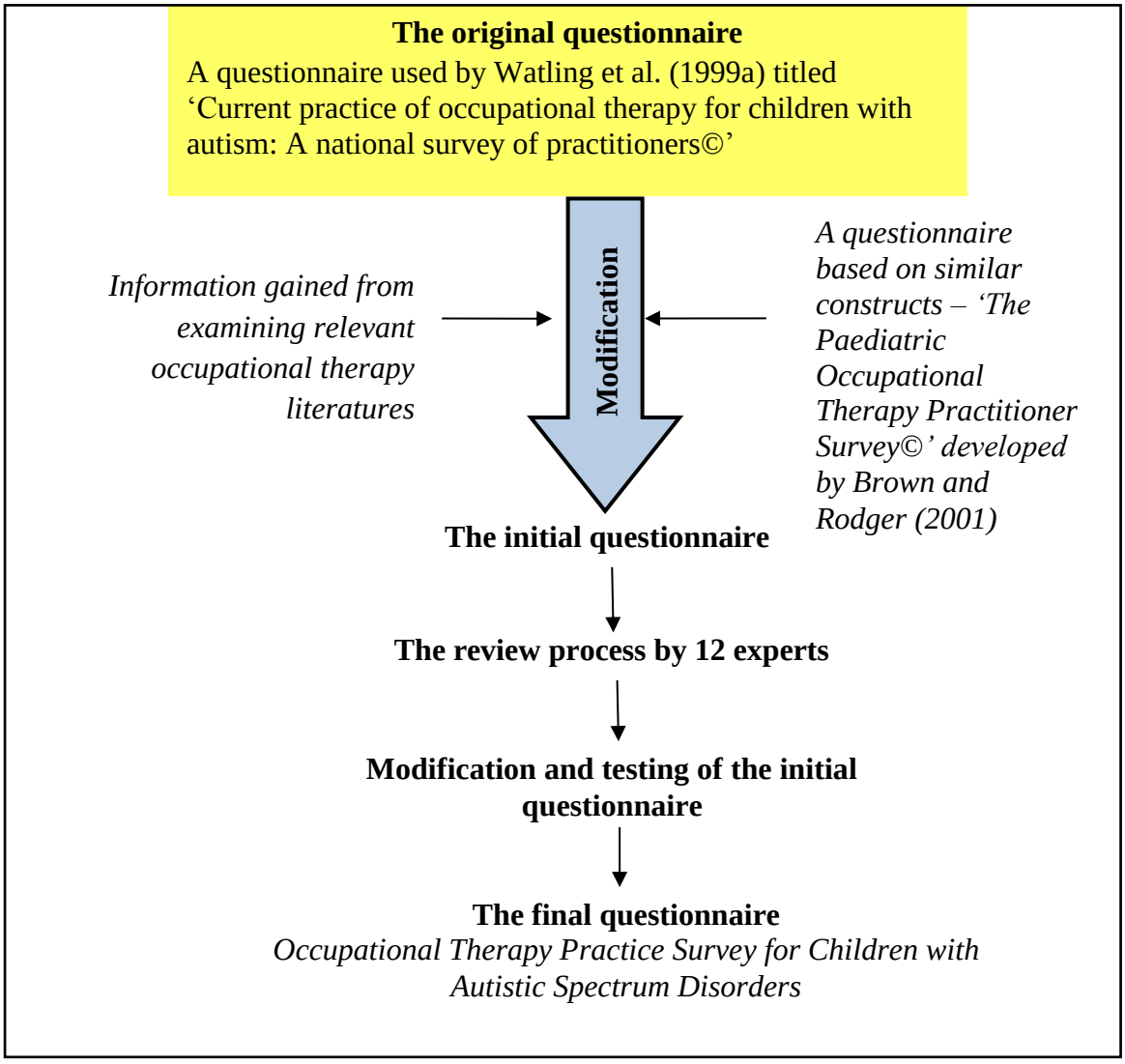

Figure 3.1. The process of the questionnaire development used in this study.

Modification and Testing of the Initial Questionnaire

The contents of the original questionnaire were modified based on information from relevant occupational therapy literature, and was based on *The Paediatric Occupational Therapy Practitioner Survey*© developed by Brown and Rodger (2001), owing to its similar constructs. The questionnaire designed for this study was constructed in English and was sent to experts for their comment (Salant & Dilman, 1994). The purpose of sending the initial questionnaire to the experts was to (a) review whether the design of the questionnaire would work in practice, (b) to identify problematic questions in order to amend and refine those questions, and (c) to identify problems relating to the content, wording, layout, length, and instructions in the questionnaire. Seventeen experts were approached to review the modified questionnaire and 12 were recruited to act as reviewers.

The experts consulted were sent the following documents:

1. Introductory letter (Appendix C)
2. The initial design of the questionnaire (Appendix D)
3. Operational definitions of terms used in the survey (Appendix E)
4. Questionnaire for expert reviewer (Appendix F).

The questionnaire for the expert reviewer was designed to assist reviewers with the process.

Expert Feedback and Modifications

Out of the 17 experts consulted, 12 experts provided feedback and the details are presented in Table 3.1. The involvement of native English and Malay language experts in the review process was considered vital, as the questionnaire was used with participants in both countries. The experts responded to 13 questions (refer to Appendix F for the questions) regarding the face and content validity of the initial questionnaire.

Table 3.1

Origin, numbers and details of experts approached to review the modified questionnaire and the numbers of experts provided feedbacks and their details

Origin of experts approached	Numbers	Details	Number of experts provided feedbacks and their details
Malaysia	5	Four experts were lecturers in occupational therapy. One expert was a medical doctor with specialisation in rehabilitation field.	Four experts responded and all experts were native Malay language speakers with proficiency in English language.
Australia	5	Four experts were lecturers in occupational therapy. One expert was a rehabilitation manager in the ASD field.	Four experts responded and all experts were English language speakers.
United States of America (US)	4	Three experts were lecturers in occupational therapy. One expert was an occupational therapy practitioner and consultant.	Three experts responded and all experts were English language speakers.
United Kingdom (UK)	2	All experts were occupational therapists and doctoral students at the time of consultation.	None.
Taiwan	1	The expert was working as an occupational therapist.	One expert responded and the expert was a native speaker of Taiwanese language with proficiency in English language.

A total of 65 comments were received regarding the questionnaire and all the questions, comments from experts, changes made and its discussions are presented in full in Appendix G.

Table 3.2 provides a summary of the questions asked and modifications made to the initial questionnaire. All comments received from the experts were studied and the suggestions were considered in refining the questionnaire.

Table 3.2

Summary of the comments received and modifications made to the initial questionnaire

Questions	Modifications made
Question 1: Were the study objectives stated clearly in the introductory letter to the respondents?	Content of introductory letter changed and statement of approval from ethics committee included.
Question 2: In question A1, we listed a few frames of reference and models of practice for the respondents to choose from. However, the respondents also have the choices of writing their own answer in the spaces given. Should we: - List more frames of reference and model of practice for the ease of answering to the respondents. - Do not list any frames of reference and models of practice; however, leave it as an open ended questions. - Our initial design was appropriate and acceptable. - Other; please give comments:	Names of authors typically associated with the frames of reference, models of practice listed in the questionnaire were included, and space provided for respondents to specify which occupational frame of reference that they are referring to.
Question 3: We separated the frames of reference and models of practice in two different tables. Should we: - List the frames of reference and models of practice in just one table. - Our initial design was appropriate and acceptable. How can we improve our design in this section?	No modification made.
Question 4: In question B1, we listed the methods of assessments/outcome measures which can be used when assessing children with autistic spectrum disorders. There are also spaces for	Another method of assessments/outcome measures of interview with other health professionals was included in the list.

Table 3.2

Summary of the comments received and modifications made to the initial questionnaire (continued)

Questions	Modifications made
the respondents to include other methods if any. Are there any other methods of assessments/outcome measures that we should include in the list?	
Question 5 (5a): Question B2 (B2.1 to B2.8) in section B are asking respondents about the specific type of standardised assessments they use in their occupational therapy services for children with autistic spectrum disorders. 5a) Are there any to exclude?	Respondents only have to name one assessment tool that they used most frequently and some short definition of diagnostic assessment was included in the questionnaire.
Question 5 (5b): Question B2 (B2.1 to B2.8) in section B are asking respondents about the specific type of standardised assessments they use in their occupational therapy services for children with autistic spectrum disorders. 5b) Are there any to include?	The questionnaire was restructured by asking the respondents about the age group of the children with autistic spectrum disorders that they serve most frequently and to have them answer the following questions based on that age group. Activity of daily living and school related-skills assessments were included and the respondents only had to give one tool that they used the most.
Question 6: In question C1, we listed a few commonly identified interventions/ programmes which are used by occupational therapists and other professional for children with autistic spectrum disorders. However, the respondents also have the choices of writing their own answer in the spaces given. Should we: - List more interventions/programmes for the ease of answering to the respondents. - Do not list any interventions/programme; however,	Respondents have to rank their answers in term of the frequency that they use the interventions or programmes listed. As well, an additional interventions and programmes were added to the list and the activity of daily living was excluded from the list.

Table 3.2

Summary of the comments received and modifications made to the initial questionnaire (continued)

Questions and responses received	Modifications made
leave it as an open ended question. - Our initial design was appropriate and acceptable.	
Question 7 (7a): In question C5, we listed a few areas of adaptive behaviours in daily living activities. However, the respondents also have the choices of writing their own answer in the spaces given. 7a) Are there any to exclude?	1. Modification were made to question C2 by asking the respondents to lists the three most common short term occupational therapy intervention goals. 2. Question C4 was amended by asking specifically for the challenges with children with ASD that the respondents encountered when providing services for them. 3. Work or vocational skills was another area added to the list.
Question 7(7b): In question C5, we listed a few areas of adaptive behaviours in daily living activities. However, the respondents also have the choices of writing their own answer in the spaces given. 7b) Are there any to include?	No modification made.
Question 8: Question D1 is asking regarding the level of confidence among respondents when providing services for children with autistic spectrum disorders. We are using the five point Likert scale in order to elicit response to this question. Is this method appropriate?	No modification made.
Question 9: In question D4, we listed a few methods of obtaining knowledge and skills in increasing occupational therapists' competencies when providing services for children with autistic spectrum disorders.	Advanced post-professional academic degrees and online courses as methods of obtaining knowledge and skills to increase occupational therapists' competencies were included and continuing education courses in question D2 in the questionnaire was also included.

Table 3.2

Summary of the comments received and modifications made to the initial questionnaire (continued)

Questions and responses received	Modifications made
However, the respondents also have the choices of writing their own answer in the spaces given. Are there any to include?	
Question 10: Are there any other questions pertaining to professional development needs that we should include in the questionnaire?	No modification made.
Question 11: The section on the demographic information should be put: - At the beginning of the questionnaire. - Our initial design was appropriate and acceptable.	The clinical doctorate and research doctorate in occupational therapy were put as two separate answer choices to generate data that are more useful.
Question 12: We will include the separate sheet of operational definitions on the terms use in the questionnaire for respondents' guideline when answering the survey. Is this necessary?	Based on the comments received, it was decided not to include the separate sheet of operational definitions in the questionnaire.
Question 13: Are there any other suggestions on what we should do in order to improve the quality of our questionnaire?	1. The questions were put in regular type and the answers in bold. 2. The statement at the end of the survey was amended to include that the return of the questionnaire will be considered as the respondents' consent to participate in the study. 3. The questionnaire developers' names and copyright were included on the front cover. 4. The screening question at the beginning of the survey was amended.

Each comment was reviewed and discussed by the researcher, together with supervisors. Most comments were taken on board in order to improve the questionnaire's content and format. Other questions were reviewed and rejected as they involved making the questionnaire much longer and more cumbersome. The revised questionnaire was then sent to six qualified occupational therapists in Malaysia for testing and also for their feedback on the ease of answering. The revised questionnaire was sent to these six Malaysian occupational therapists for testing in order to evaluate whether the English language used in the questionnaire was appropriate for occupational therapists in Malaysia. None of the therapists involved suggested that the questionnaire should also be produced in Malay language to be used in Malaysia or that the respondents should be allowed to answer the open-ended questions in either Malay or English language. It took them a range of 15-20 minutes to answer the survey, and could take longer to answer the open-ended questions depending on the amount of responses provided.

The Final Questionnaire

The final draft of the questionnaire, *Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders* (Appendix H) consisted of 31 open- and close-ended questions designed to elicit responses to explore what occupational therapy services were delivered for children with ASD. There was one screening question asking whether the respondents are currently working, have worked or have never worked with children with ASD in their occupational therapy services at the beginning of the questionnaire. Those who indicated that they had never worked with children with ASD were asked to return the incomplete questionnaire to the researcher using the stamped self-addressed envelope provided. The objectives of the study were explained in the introductory letter to the respondents (Appendix I).

The final questionnaire was divided into six sections:

1. Section A explored the frame(s) of reference and model(s) of practice utilised by the respondents
2. Section B explored which assessments or outcome measures were used
3. Section C explored the interventions utilised
4. Section D investigated what areas of adaptive behaviours were addressed in their occupational therapy services for children with ASD
5. Section E explored the professional development topics desired by occupational therapists
6. Section F covered demographic details.

The developed questionnaire was used to collect data regarding the occupational therapists' practices with children with ASD that will be discussed below.

Occupational Therapy Services for Children with Autistic Spectrum Disorder

Internationally, occupational therapists working with children with ASD provide a wide variety of interventions (Miller-Kuhaneck, 2004). However, currently, there is no published information available regarding occupational therapy practice in Malaysia with children with ASD. Information on occupational therapy practice has been published in the US (Watling et al., 1999a), and Australia (Ashburner et al., 2010, unpublished report; Rodger et al., 2005). However, findings from these studies are not transferable to the Malaysian context as the impact of the socioeconomic, cultural and geographical diversity of Malaysia on the services available to children with ASD and their families will be different from both the US and Australian contexts (Amar, 2008; Dolah et al., 2011; Dolah, Wan Yahaya, Chong, & Mohamed, 2012; Fong & Mohd Jelas, 2010; Wilder et al., 2004).

In any case, studies reported in the literature on the effectiveness of interventions for children with ASD and occupational therapy have been found to be of variable (and

often low) quality in terms of study design; generally small numbers of participants and descriptive designs (Case-Smith & Arbesman, 2008), with recommendations that the findings should be used with caution owing to these limitations (Dawson & Watling, 2000; Hodgetts & Hodgetts, 2007; Wallen & Imms, 2006). Even if the findings from the research studies were valid and reliable, it would be inappropriate to generalise this to the Malaysian context. Little is known about the best mechanisms for occupational therapy interventions for children with ASD in Malaysia and their families (Amar, 2008). Attempts have been made to transplant Western therapies and techniques directly to occupational therapy services in Malaysia (Amar, 2008). Given the inadequate evidence base for many of the interventions attempted for people with ASD in the West (Bowker, D'Angelo, Hicks, & Well, 2011), it is inappropriate to apply them directly to the Malaysian population. The Malaysian population is very diverse in terms of socioeconomic factors, culture and geography. Indeed; it is ethically wrong to implement therapy that does not have an evidence base. Furthermore, many of these interventions are very costly, and places a high economic cost on both public funding, and family resources, more alarming when there is so little evidence (Amar, 2008; Dolah, Wan Yahaya, & Chong, 2011; Wilder, Dyches, Obiakor, & Algozzine, 2004). Considering that Malaysia is a country that falls in the high category of the Human Development Index in terms of its fast-growing development in the education and health care sectors (United Nations Development Programme, 2013), it is time for Malaysia to develop its own relevant practice for children with ASD and their family. This is the rationale for the comparison between Victorian (Australia) and Malaysian occupational therapy services to see whether the Malaysian occupational therapists are providing services that are unique and culturally appropriate to the Malaysian population, or whether the practices are heavily adopted from Western culture. It was hypothesised that studying practice of therapists in Victoria (Australia) could add valuable information as to what the contemporary nature of practice in occupational therapy with children with ASD is in related neighbour in Oceana, and

provides a basis for comparison of occupational therapy services between culturally diverse neighbours. To date, the only available studies reporting specifically on occupational therapy practices for people with ASD have only been from the US (Watling et al, 1999a) and Queensland (Australia) (Ashburner et al., 2010, unpublished study), both from Western based studies, and none from Asian culture.

The following outlines the methods for the data collection in order to summarise and compare occupational therapy services for children with ASD in Victoria (Australia) and Malaysia. The state of Victoria (Australia) was chosen as a basis for service comparison due to the almost equal number of registered occupational therapists in Malaysia and Victoria (Australia) during the data collection period (The Malaysian Occupational Therapists Association & The Occupational Therapy Australia Limited, Victoria Division, 2009, personal communications).

Participants and Recruitment

The participants in this study were qualified occupational therapists who were either registered members of The Occupational Therapy Australia Limited, Victoria Division (OTAL, Vic.) or registered members of the Malaysian Occupational Therapists Association (MOTA). To be included in the study, the participants must have either been currently working with children with ASD, or had previously done so, in their occupational therapy practice in either setting.

The Victorian cohort. The Victorian division of OTAL was consulted for their help in identifying the potential participants for the study. Permission was granted by the Victorian Executive Director to send a letter out to members on their database. To comply with the members' privacy policy of the OTAL, Vic., no details of the participants in Victoria were given to the researcher and identification of the potential participants and preparation the names and addresses labels to mail out the surveys were all performed by

the OTAL, Vic. There were 323 occupational therapists identified who worked in the paediatric area. One potential participant was excluded from the study, as the participant did not work in Victoria. Hence, surveys were mailed to 322 participants in Victoria, Australia, hereafter called Victoria.

The Malaysian cohort. For the Malaysian cohort, MOTA was consulted for their help in identifying the potential participants for the study and a formal application letter was mailed to the president of the MOTA and permission was granted to send a survey out to their registered members. The MOTA members' information was given to the researcher. It contained their membership number, name, date of birth, address, contact number, email address, area of interest and academic qualification. This information were given to the researcher for the purpose of mailing out the survey only.

Student and international members were excluded from this survey. There were some issues with this method of recruitment in 2009 when this survey was undertaken. The MOTA database contained 459 ordinary members; however, only 362 members had their full names and addresses recorded in the database. The remaining members either did not have their full name recorded (missing surnames), records were incomplete or had no physical or email addresses available. Furthermore, the currency of the information was unclear, and a number of the mail outs were returned to sender. The MOTA database held no information as to the members' service areas or specialties; so, all 362 MOTA members in both parts of Peninsular and East Malaysia, hereafter called Malaysia, were mailed the surveys. Appendix J contains the correspondence with both organisations.

Data Collection

Monash Human Research Ethical Committee (MUHREC) approval was applied for and ethical approval was granted in November 2009 (Reference number CF09/3131 – 2009001710, Appendix K). In order to conduct research in Malaysia, ethical approval was

also gained from The Research Promotion and Co-Ordination Committee, Economic Planning Unit (EPU), Prime Minister's Department, Malaysia and ethical approval was given in December 2009 (Reference number UPE: 40/200/19/2505, Appendix L). To ensure the privacy and confidentiality of the participants, no identifying information was kept or recorded by the researcher; hence, the return of the surveys remained anonymous. It was not known to the researcher which participants did or did not return the surveys.

The data collection took place in a three month period in each region - between January and April 2010 in Victoria and between July and October 2010 in Malaysia. An introductory letter, explanatory statement and a questionnaire (Appendices I, M and H) were mailed to the participants together with a stamped self-addressed envelope to facilitate the return of the questionnaires to the researcher.

Two weeks after the distribution of the questionnaires, a first reminder was send to the participants requesting them to complete and send the survey to the researcher if they have not already done so, and also to thank them if they have already returned the survey. Two weeks after the first reminder, a second reminder was send (refer to Appendix N for the first and second letter of reminder). No further reminder was sent thereafter.

A numerical code was given as participants returned their survey. An initial letter 'V' was put prior to the numerical code to indicate respondents from Victoria and an initial letter 'M' was given to specify respondents from Malaysia.

Statistical Tests and Methods of Data Analysis of the Questionnaire

The results from the surveys were analysed according to the type of data yielded by the question. The questionnaire was designed to include some categorical/nominal (yes/no), ordinal and qualitative questions. Nominal and ordinal data were analysed using either a chi square test of independence (Pett, 1997) and the Man-Whitney U test (Pett, 1997) as appropriate to the categorical data.

In performing the chi square test, categorical data were collapsed into categories that fit into a 2-way table. The null hypothesis for this test is that there is no association between the two variables; the alternative research hypothesis is that there was an association between the two variables.

A two-tailed Mann-Whitney U test was performed, as it could not be predicted whether occupational therapist respondents in Victoria or Malaysia would score higher than the corresponding group. The Man-Whitney U test was chosen due to the nature of the scaled data in the study. The null hypothesis for this test is that there is no difference between occupational therapist respondents in Victoria and Malaysia on each of the scaled questions. In both tests, the level of probability is less than 0.05 for a significant result. The Predictive Analytics software (PASW) Version 18.0 for Windows (formerly SPSS-The Statistical Package for the Social Sciences) was used to store the data and perform the analysis.

The responses from open-ended questions were grouped according to their identified categories based on their answered themes and presented in terms of the number of replies received from the participants based on content analysis procedures (Liamputtong, 2009) and descriptively (frequencies and percentages). The questionnaires were analysed to determine occupational therapy services for children with ASD by describing the services in both regions and comparing it between Victoria and Malaysia in terms of similarities and differences. Table 3.3 presented the level of measurements, statistical tests, and methods of data analysis for each question in the questionnaire.

In analysing Question B2, the age group of the children with ASD was collapsed into three categories of: (a) below 5 years old, (b) between 6 to 18 years old and (c) both age groups.

Table 3.3

The level of measurement, statistical tests, and methods of data analysis for each question in the questionnaire

Questions	Level of measurements	Statistical test and method of data analysis
A1, B2, B3, and E2.	Nominal	The chi square test of independence
B1, C1, C3, D1, D2, E1, and E4.	Ordinal	The Mann-Whitney U test
B4, C2, C4, the open-ended response options in questions B3 and E2, and E3.	Qualitative responses	Content analysis
F1-F7	Nominal	Descriptive statistics to present the characteristics of the occupational therapist respondents involved in the study (frequencies/percentages)

Summary

This chapter has described the development of the questionnaire to survey occupational therapy practitioners in Victoria and Malaysia; the details of the development are in Appendices C, D, E, F, G, H, and I. The questionnaire was developed based on a previous questionnaire and further developed, with the permission of the originator (R. Watling, personal communication, May 28, 2009, Appendix B).

To ensure that the questionnaire was addressing the issues, the questionnaire was reviewed by experts. Twelve experts in occupational therapy and related health fields were engaged in the process of establishing face and content validity for the developed questionnaire, and this not only enriched but also clarified the content of the questionnaire.

The final questionnaire enabled cross-cultural comparisons of the occupational therapy services provided to children with ASD and their family. The final questionnaire was maintained in English, as the Malaysian participants involved in the testing of the questionnaire indicated that this was the most satisfactory.

Occupational therapy practices with children with ASD in Malaysia were compared with practices in Victoria to find their similarities and differences; hence, two cohorts of occupational therapy respondents were recruited – the Victoria and Malaysia cohorts. Due to the various levels of data measurements obtained in the survey, a number of data analysis and statistical test methods were chosen based on the type of data gathered – a nonparametric alternative of a statistical test of the chi square test of independence, the Mann-Whitney U test, descriptive analysis, and content analysis. The results obtained of phase one of this research and their implications are presented in Chapter IV.

CHAPTER IV

PHASE 1: RESULTS AND DISCUSSION ON A CROSS-CULTURAL COMPARISON OF THE OCCUPATIONAL THERAPY SERVICES TO CHILDREN WITH AUTISTIC SPECTRUM DISORDERS: VICTORIA AND MALAYSIA

This chapter presents and discusses the results of the questionnaires to therapists regarding their practices with children with ASD and their families. The results are firstly presented for each region, and then compared, in order to elucidate both the similarities in practice, but also to highlight differences.

Response Rates

The initial question on the questionnaire was a screening question to identify whether or not therapists had worked with children with ASD. Sixty-six participants in Victoria and 52 participants in Malaysia indicated that they either worked or had worked, in this area (Table 4.1), and all of these participants were included in the analysis.

Of the 322 surveys mailed to the participants in Victoria, 118 replies were received, a response rate of 36.6%. Of these however, there were 52 negative responses, yielding 24.4% for the participants in Victoria. In Malaysia, the figures were more difficult, due to the inaccuracy of the database. However, of the 362 surveys, 78 were received - a response rate of 21.5%. However, there were 26 negative responses and when these were withdrawn; the valid response rate was 15.5% for the participants in Malaysia.

Participants' Characteristics

The demographic information was derived from Section F of the survey, and are presented in Table 4.2.

Table 4.1

Replies on screening question received from the participants

	Participants in Victoria, Australia (N=118)		Participants in Malaysia (N=78)	
	Frequency	Percentage	Frequency	Percentage
I have worked and/or currently are working with children with autistic spectrum disorders	66	55.9	52	66.7
I have never worked with children with autistic spectrum disorders	52	44.1	26	33.3
Total	**118**	**100.0**	**78**	**100.0**

Malaysian Cohort

The participants in the Malaysian cohort were mainly from Peninsular (West) Malaysia (82.7%), with only 17.3% from the Borneo part of Malaysia. The majority of entry-level qualifications were Diploma/Certificates in Occupational Therapy with 29.0% having higher qualifications, and they typically worked in a hospital settings, with between 1 and 5 years of post-graduate experience (Table 4.2). The majority had worked with children with ASD for less than a year, and none had worked with children with ASD for more than 10 years. Patterns of working were reported to be mainly individual intervention sessions with children and consultations with parents and/or caregivers.

Victorian Cohort

The participants from Victoria all held a Bachelor's degree in Occupational Therapy, with 22.7% reporting further qualifications. The practice area most commonly reported were in early intervention settings and private practices and the length of post-graduate practice was generally between 1 to 5 years, and the majority of Victorian participants had worked with children with ASD between 1 and 5 years. The most

Table 4.2

Characteristics of the participants

Participants' characteristic	Participants in Victoria		Participants in Malaysia		
	Frequency	Percentage	Frequency		Percentage
Participants' origin	66	100.0	Peninsular Malaysia	43	82.7
			East Malaysia	9	17.3
Total	**66**	**100.0**		**52**	**100.0**
Highest academic qualification					
Diploma/certification in occupational therapy	1	1.5		37	71.0
Bachelors degree in occupational therapy	50	75.8		14	27.0
Graduate-entry masters degree in occupational therapy	6	9.1		0	0.0
Coursework/research masters	7	10.6		1	2.0
Research doctorate in occupational therapy	1	1.5		0	0.0
Other (Master in clinical family therapy)	1	1.5		0	0.0
Total	**66**	**100.0**		**52**	**100.0**
Setting of current practice					
Hospital	2	3.0		43	82.7
School	11	17.0		0	0.0
Community-based care	11	17.0		2	3.8
Early intervention	14	21.2		0	0.0
Private practice	17	25.8		1	2.0
Other	0	0.0		2	3.8
More than one settings	11	17.0		4	7.7
Total	**66**	**100.0**		**52**	**100.0**

Table 4.2

Characteristics of the participants (continued)

Participants' characteristic	Participants in Victoria		Participants in Malaysia	
	Frequency	Percentage	Frequency	Percentage
Years of practising as an occupational therapist				
Less than 1 year	1	1.5	6	11.5
1-5 years	19	28.8	30	57.7
6-10 years	14	21.2	9	17.3
11-15 years	10	15.2	6	11.5
16-20 years	9	13.6	1	2.0
More than 21 years	13	19.7	0	0.0
Total	**66**	**100.0**	**52**	**100.0**
Years of working with children with ASD				
Less than 1 year	7	10.6	31	59.6
1-5 years	30	45.4	18	34.6
6-10 years	14	21.2	3	5.8
11-15 years	7	10.6	0	0.0
16-20 years	4	6.1	0	0.0
More than 21 years	4	6.1	0	0.0
Total	**66**	**100.0**	**52**	**100.0**
Direct occupational therapy services				
Individual intervention sessions	40	60.6	34	65.4
Group intervention sessions	15	22.7	3	5.8
Both individual and group sessions	11	16.7	15	28.8
Total	**66**	**100.0**	**52**	**100.0**
Indirect occupational therapy services				
Consultation with parents/caregivers	32	49.2	33	64.7

Table 4.2

Characteristics of the participants (continued)

Participants' characteristic	Participants in Victoria		Participants in Malaysia	
	Frequency	Percentage	Frequency	Percentage
Indirect occupational therapy services (continued)				
Consultation with education staff	8	12.3	0	0.0
Multidisciplinary team conference	3	4.6	4	7.8
Professional development	0	0.0	1	2.0
Other	1	1.5	0	0.0
More than one answers	21	32.3	13	25.5
Total	**65**	**100.0**	**51**	**100.0**

common methods of service delivery were individual intervention sessions and consultations with parents and/or caregivers.

Results from the Questionnaire: Individual Questions

Section A: Frames of Reference and Models of Practice

Question A1 – Please indicate which frames of reference and models of practice you use with children with autistic spectrum disorders in your occupational therapy practice.

Both cohorts (87.9% from Victoria and 98.1% from Malaysia) used Frames of Reference (FOR) to guide practice, with no statistically significant difference between the participants in both regions in the use of FOR (p = .085).

The majority of participants used a sensory integration frame of reference (Kimball, 1999) to guide their practice, although this was more common in Malaysia with nearly 100% of the cohort using this FOR. Detailed results are presented in Table 4.3. It

is interesting that there were a number of other FOR used in both cohorts, including the Developmental-Individual Differences-Relationship-based approach (DIR®)/Floortime™ (Weider & Greenspan, 2003), Family centred, occupational adaptation, sensory processing, developmental, behavioural, neuro-developmental and biomechanical frames of references. Statistically significant differences between the cohorts were demonstrated in the coping frame of reference (Williamson & Szczepanski, 1999), psychosocial frame of reference (Olson, 1999) and sensory integration frame of reference (Kimball, 1999) .

As with FOR, Models of Practice (MOP) were used by the majority of participants in both regions (87.9% in Victoria and 92.3% in Malaysia) to guide their practice, and this was not statistically different (p = .629).

However, there were marked differences between participants in Malaysia and Victoria with the types of model used. Both used a range of models to guide practice, but the majority of Malaysian practitioners preferred the Model of Human Occupation (MOHO) (Kielhofner, 2008; Kielhofner & Burke, 1980), whereas, higher percentages of participants from Victoria preferred the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko, Townsend & Craik, 2007) (Table 4.3).

More than 24% of the respondents in Victoria (almost a quarter), but none of the Malaysian cohort stated that they used other model of practices (other than the models listed in the questionnaire) in their services. These models of practice included cognitive behavioural therapy, narrative therapy, DIR®/Floortime™ (Weider & Greenspan, 2003), sensory integration (SI) (Kimball, 1999), occupational adaptation, occupational performance model-Australia (OPM-A), occupational therapy intervention process, family centred practice, strength based practice and transdisciplinary model of practices.

There were no statistically significant differences between the participants in the two regions when using the CMOP-E (Polatajko, Townsend & Craik, 2007), Cognitive Orientation to daily Occupational Performance (CO-OP) (Polatajko & Mandich, 2004), ecology of human performance model (Dunn, Brown, & McGuigan, 1994) and also

Person-Environment-Occupation (PEO) (Law, et al., 1996). The use of the MOHO (Kielhofner, 2008; Kielhofner & Burke, 1980) was the only model of practice that shows a statistically significant difference between the participants in the two regions.

Table 4.3

Results on the types of Frames of Reference (FOR) and Models of Practice (MOP) utilised with children with ASD

Types of Frames of Reference (FOR) and the statistical result	Using FOR (%)		*p*
	Victorian (n=66)	Malaysian (n=52)	
Coping FOR	4.5	46.2	<.001*
Acquisitional FOR	13.6	26.9	.115
Psychosocial FOR	27.3	63.5	<.001*
Occupational FOR	19.7	7.7	.0114
Sensory Integration FOR	72.7	92.3	.013*
Types of Models of Practice (MOP) and the statistical result	**Using MOP (%)**		***p***
	Victorian (n=66)	**Malaysian (n=52)**	
Canadian Model of Occupational Performance and Engagement (CMOP-E)	43.9	40.4	.841
Cognitive Orientation to daily Occupational Performance (CO-OP)	24.2	21.2	.860
Ecology of Human Performance Model	9.1	13.5	.648
Model of Human Occupation (MOHO)	30.3	73.1	<.001*
Person –Environment-Occupation (PEO)	34.8	26.9	.471

Note. Percentages total is higher than 100% because participants could choose more than one answers. *p <.05

Section B: Assessments/Outcome Measures

Question B1 – How often do you use each of the following methods of assessments/outcome measures when assessing children with autistic spectrum disorders?

This question describes the methods of assessment or outcome measures administered by occupational therapists. The greatest percentages of the participants in each region indicated that they 'often' administered standardised assessment or screening tools in their services (43.9% participants in Victoria and 37.5% participants in Malaysia), with 4.5% participants in Victoria and 2.1% participants in Malaysia reported that they had 'never' administered standardised assessment across their region. Using informal assessments was answered by all but four (7.7%) therapists from Malaysia.

In terms of observation in multiple environments, there was a difference between the cohorts (Table 4.4), where all of the Victorian cohort used multiple environments and frequently worked with educational staff, but, in the Malaysian cohort, a small number (10.0%) never went outside of their clinic, and seldom or never worked with educational staff. Both cohorts worked with other health professionals. The detailed results are shown in Table 4.4.

In summary, the above results are also placed in context when comparing the numeric data where there are statistically significant differences between the participants in the two regions when observing children with ASD in multiple environments, interview with teachers or education staff and in interviews with other health professionals.

Table 4.4

Results on the methods of assessments/outcome measures used when assessing children with autistic spectrum disorders by the participants in Victoria and Malaysia

Methods of assessments/outcome measures used and the statistical result	n†		Never (%)		Seldom (%)		Sometimes (%)		Often (%)		Always (%)		*p*
	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	
Standardised assessments or screening tools	66	48	4.5	2.1	3.0	16.7	34.8	25.0	43.9	37.5	13.6	18.8	.837
Informal assessments or screening tools	66	48	3.0	0.0	1.5	10.4	19.7	18.8	40.9	47.9	34.8	22.9	.204
Observation in multiple environments	66	50	0.0	10.0	15.2	28.0	16.7	16.0	37.9	36.0	30.3	10.0	.001*
Interview with parents/caregivers	66	50	0.0	0.0	1.5	4.0	4.5	6.0	16.7	24.0	77.3	66.0	.174
Interview with teachers/education staff	66	50	0.0	8.0	3.0	40.0	28.8	30.0	34.8	12.0	33.3	10.0	<.001*
Interview with other health professionals	66	49	0.0	6.1	9.1	26.5	36.4	40.8	39.4	22.4	15.2	4.1	<.001*

Note. n† Represents number of participants providing rating. In a five-point Lickert scale ranging from 1 (Never), 2 (seldom), 3 (sometimes), 4 (often) and 5 (always). *$p < .05$

Question B2 – What is the age group of children with autistic spectrum disorders you serve most frequently?

Question B2 focused on the age group of children with ASD who participants served most frequently. The majority of the participants in both regions reported that they served children with ASD aged below 5 years in their services (69.7% and 69.2% participants in Victoria and Malaysia, respectively). Although there were no statistically significant differences between participants in the two regions in children's age groups below 5 years ($p = 1.000$), between 6 to 18 years of age ($p = 0.769$) and for both age groups ($p = 1.000$), the under 5 group was most frequently serviced.

Question B3 – In this question, participants were asked to state the type of standardised assessment they used with the age group of children with ASD they serve most frequently.

The standardised assessments used varied between the regions. Participants in Victoria and Malaysia used four main standardised assessments in the areas of: (a) sensory processing or sensory integrations, (b) gross or fine motor skills, (c) developmental screenings and evaluations and (d) school-related skills.

Participants in Malaysia also reported that they used standardised assessments in the area of Activities of Daily Living skills – the Australian cohort did not identify this. The lists of the top five standardised assessments tools used most frequently by the participants, where applicable, are presented in Appendix O, Table O.1.

Question B4 – If you use non-standardised assessments, please describe them.

The greater number of responses was received from the participants in both regions concerning the method of using assessments created by their workplace or self-developed (27.3% participants in Victoria and 23.1% participants in Malaysia) and also regarding the use of reports from interviews or observations (36.4% participants in

Victoria, 30.8% participants in Malaysia). Using a section of the items derived from the standardised assessments informally to guide the assessment process garnered fewer responses from the participants in both regions (7.6% and 17.3% from participants in Victoria and Malaysia, respectively).

Section C: Intervention

Question C1 – Please indicate which of the following interventions/ programmes you use/have used with children with autistic spectrum disorders in your occupational therapy practice.

Interventions used by therapists working in Victoria were - early intervention programme, environmental modifications, Picture Exchange Communication System (PECS) (Bondy & Frost, 2001), sensorimotor stimulation, sensory diet and sensory integration, which were 'often' utilised in their work. Participants in Malaysia most commonly use play therapy, sensory integration training and snoezelen therapy in their services.

The ones which are common to both include early intervention, modification of environment, therapeutic listening, floortime™ techniques and facilitated communication. However, thirty-four different types of interventions were indicated, with only those five interventions common to both regions. The detail results are shown in Appendix O, Table O.2.

Question C2 – Please list your three (3) most common short-term occupational therapy intervention goals when working with children with autistic spectrum disorders.

Information gathered from this question was categorised accordingly and a number of responses were presented. Seventeen categories were identified based on the

participants' responses and these are listed in Appendix O, Table O.3. The top three most common short-term goals that received more responses from the participants in Victoria were:

1. Managing issues related to sensory difficulties (26 responses or 39.4%)
2. Improving attention and concentration skills (19 responses or 28.8%)
3. Improving self-care skills (16 responses or 24.2%).

The top three most common short-term goals that received more responses from the participants in Malaysia were:

1. Improving communication and social skills (26 responses or 50.0%)
2. Improving attention and concentration skills (26 responses 50.0%)
3. Managing issues related to sensory difficulties (18 responses 34.6%).

It is interesting to see that the participants in both regions provided similar qualitative responses on two short-term goals - managing issues related to sensory difficulties and improving attention and concentration skills.

Question C3 – How often do you work with the following people/ professionals?

The participants were asked to circle one number for their answers ranging from 1-5 (never to always) and asked to name other people or professionals they worked with who are not listed in the questionnaire.

Table 4.5 presents the detailed results on the participants' working with other people or professionals in their services in Victoria and Malaysia. Working with parents or caregivers received the majority responses from the participants in both regions as 'always' been worked with in their services.

Table 4.5

Results on the collaboration with other people or professionals in services with children with autistic spectrum disorders by the participants in Victoria and Malaysia

Working with other people or professionals and the statistical result	n†		Never (%)		Seldom (%)		Sometimes (%)		Often (%)		Always (%)		*p*
	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	
Working with parents/caregivers	66	52	0.0	0.0	3.0	1.9	4.5	1.9	18.2	28.8	74.2	67.3	.520
Working with teachers/educational staff	66	51	0.0	5.9	1.5	19.6	16.7	51.0	39.4	19.6	42.4	3.9	<.001*
Working with speech therapists/speech pathologists	66	50	1.5	14.0	4.5	20.0	12.1	38.0	47.0	20.0	34.8	8.0	<.001*
Working with psychologists	65	50	6.2	38.0	20.0	24.0	32.3	26.0	32.3	10.0	9.2	2.0	<.001*

Note. n† Represents number of participants providing rating. In a five-point Lickert scale ranging from 1 (Never), 2 (seldom), 3 (sometimes), 4 (often) and 5 (always). *p <.05

Statistical analysis showed no significant difference between the participants in the two regions in working with parents or caregivers. This result is consistent with the result obtained in Question B1 where interviews with parents/caregivers were reported as being 'always' administered by the majority of the participants in both regions. However, there is a statistically significant difference between the participants in the two regions in - working with teachers or education staff, speech therapists or speech pathologists and also in working with psychologists (Table 4.5).

Forty-seven participants indicated that they worked with other people or professionals such as medical doctors including paediatricians, general practitioners, psychiatrists, and other health professionals such as psychologists, neuropsychologists, nurses, physiotherapists, movement therapists, family therapists, audiologists, dieticians, and social workers. Other behavioural or educational professionals including counsellors, play therapists, Applied Behavioural Analysis (ABA) therapists, behaviour management specialists, and integration aides.

Question C4 – What are three of the most common challenges you experience when working with children with autistic spectrum disorders?

This question received one hundred responses from 66 participants in the Victorian cohort and 71 responses from 52 participants in the Malaysian cohort as to what the practitioners found the most difficult. Both cohorts stated that the condition itself was challenging and identified "difficulties in dealing and working with children with ASD" as their major issues. The other two issues were also common, with the Victorian participants identifying challenges with providing occupational therapy services as their second issues and Malaysian participants identifying this as their third issues, and "difficulties with working with parents/caregivers" identified as the third issues in Victoria and second issue in Malaysia. These detailed results can be located in Appendix O, Table O.4.

Points of interest here are the great similarities observed in terms of the challenges experienced by the participants in both regions in providing services for children with ASD, especially in those three areas stated above.

Section D: Adaptive Behaviours

Question D1 – How often do you address the following adaptive behaviours with children with autistic spectrum disorders in your occupational therapy practice?

In order to answer this question, participants were asked to (a) complete a Likert scale of the areas of adaptive behaviours addressed in their services for children with ASD, and (b) identify areas of adaptive behaviours that were not listed elsewhere in the questionnaire.

Table 4.6 shows the results and comparison of results between the two cohorts, demonstrating a statistically-significant difference between the regions in health and safety and work/vocational skills. No further adaptive behaviours were identified by either cohort.

Question D2 – How often do you utilise the following settings when providing adaptive behaviour interventions for children with autistic spectrum disorders?

The participants were asked to circle one number on a Likert scale and asked to name other settings they employed that are not listed in the questionnaire. Utilising clients' natural environments was stated as 'always' and 'sometimes' utilised by the highest percentages of the participants in both cohorts, as shown in Table 4.7.

Statistical analysis showed no significant difference between the respondents in the two regions in utilising community facilities as their intervention settings when providing adaptive behaviour interventions. However, there are statistically-significant differences between the respondents in both regions when using occupational therapy setting and

Table 4.6

Results on the area of adaptive behaviours addressed with children with ASD by the participants in Victoria and Malaysia

Area of adaptive behaviours addressed by the participants in their services with children with ASD in Victoria and Malaysia													
Area of adaptive behaviours addressed and the statistical result	n†		Never (%)		Seldom (%)		Sometimes (%)		Often (%)		Always (%)		*p*
	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	
Self-care activities (e.g., bathing, toileting)	65	51	1.5	0.0	1.5	7.8	20.0	25.5	58.5	43.1	18.5	23.5	.606
Home living (e.g., make bed, prepare breakfast)	65	51	15.4	15.7	29.2	31.4	38.5	29.4	12.3	15.7	4.6	7.8	.840
Social skills	65	50	0.0	0.0	1.5	0.0	18.5	20.0	47.7	52.0	32.2	28.0	.754
Communication skills [including Alternative and Augmentative Communication (AAC)]	63	52	14.3	9.6	9.5	21.2	34.9	17.3	19.0	38.5	22.2	13.5	.988
School readiness skills (e.g., hand writing skills, modifications to accommodate limitations in functional academic activity)	65	52	1.5	7.7	3.1	5.8	10.8	19.2	50.8	42.3	33.8	25.0	.050

Table 4.6

Results on the area of adaptive behaviours addressed with children with ASD by the participants in Victoria and Malaysia (continued)

Area of adaptive behaviours addressed by the participants in their services with children with ASD in Victoria and Malaysia													
Area of adaptive behaviours addressed and the statistical result	n†		Never (%)		Seldom (%)		Sometimes (%)		Often (%)		Always (%)		*p*
	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	
Community use (use of facilities in the community, e.g., transportation, recreational centre, local shop)	65	50	20.0	32.0	36.9	36.0	27.7	22.0	12.3	4.0	3.1	6.0	.133
Self-determination (e.g., problem solving skills, making decision and choices)	65	52	6.2	7.7	16.9	23.1	35.4	26.9	24.6	36.5	16.9	5.8	.412
Play/leisure participation (e.g., attend & participate in games)	65	51	0.0	0.0	4.6	2.0	18.5	5.9	46.2	54.9	30.8	37.3	.199
Health and safety education	65	51	35.4	15.7	33.8	35.3	13.8	33.3	13.8	7.8	3.1	7.8	.029*
Work or vocational skills	64	51	60.9	39.2	23.4	17.6	9.4	27.5	4.7	9.8	1.6	5.9	.004*

Note. n† Represents number of participants providing rating. In a five-point Lickert scale ranging from 1 (Never), 2 (seldom), 3 (sometimes), 4 (often) and 5 (always). *$p < .05$

Table 4.7

Results on the setting utilised when providing adaptive behaviours interventions with children with ASD by the participants in Victoria and Malaysia

Area of adaptive behaviours addressed by the participants in their services with children with ASD in Victoria and Malaysia													
Area of adaptive behaviours addressed and the statistical result	n†		Never (%)		Seldom (%)		Sometimes (%)		Often (%)		Always (%)		*p*
	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	
Occupational therapy settings/clinics	64	52	14.1	0.0	9.4	1.9	9.4	9.6	35.9	23.1	31.3	65.4	<.001*
Clients' natural environments	66	52	0.0	11.5	7.6	21.2	25.8	40.4	31.8	23.1	34.8	3.8	<.001*
Community facilities	66	50	40.9	38.0	27.3	42.0	28.8	20.0	3.0	0.0	0.0	28.0	.583

Note. n† Represents number of participants providing rating. In a five-point Lickert scale ranging from 1 (Never), 2 (seldom), 3 (sometimes), 4 (often) and 5 (always). *$p < .05$

clients' natural environments in their services. Other settings utilised when addressing adaptive behaviour interventions listed by the participants included multidisciplinary settings; i.e. using other profession's settings, e.g., speech therapy clinics, hospital facilities, e.g., playground, and community-based rehabilitation (CBR) centres.

Section E: Perceived Professional Development Needs

Question E1 – Please rate your level of confidence when providing occupational therapy services for children with autistic spectrum disorders.

The participants were asked to circle one number ranging from: 1 (Very low), 2 (Low), 3 (Moderate), 4 (High) and 5 (Very high) in order to define how confident they felt in providing occupational therapy services. No therapists registered very low confidence, with the majority feeling moderately or highly confident (Figure 4.1). Statistical analysis showed no significant difference between the participants in the two regions regarding their level of confidence when providing services for children with ASD (p = .434).

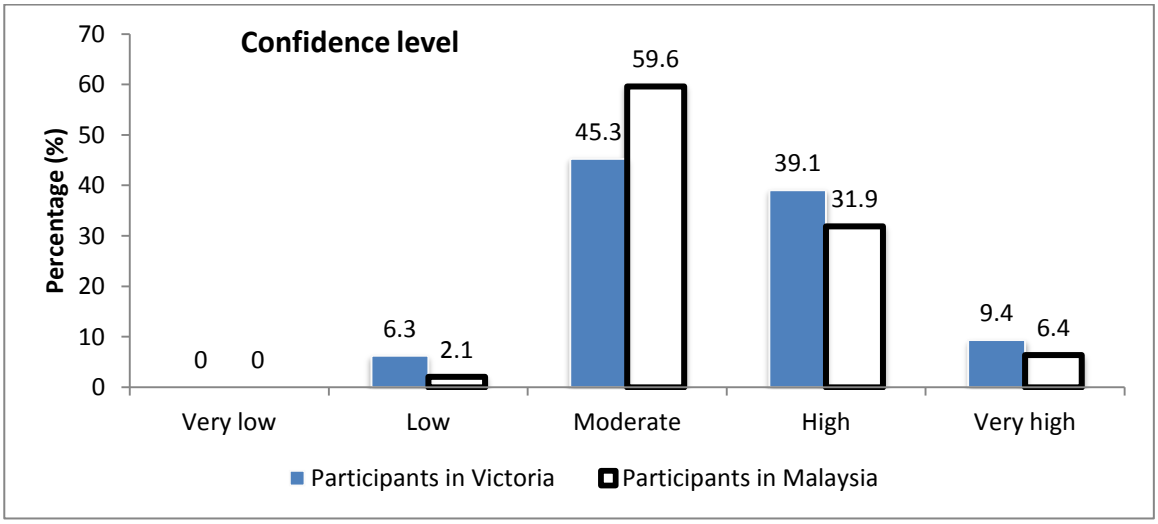

Figure 4.1. Bar chart showing the percentages of the level of confidence when providing occupational therapy services for children with ASD.

Question E2 – Have you attended any training/certification courses or continuing education courses that are relevant to your occupational therapy services for children with autistic spectrum disorders?

The result shows that high numbers of therapists have attended relevant courses (80.3% for respondents in Victoria and 46.2% for respondents in Malaysia), although the Victorian cohort were double that of the Malaysian group, which is statistically significant ($p = <.001$). Participants were also asked in a qualitative question to list the courses and years attended. The detailed qualitative information is presented in Appendix O, Figure O.1. The type of courses most attended in both regions included sensory related courses (25.8% and 42.3% of participants in Victoria and Malaysia, respectively). Participants in Malaysia named behavioural management courses as the second most attended and social skills training as the third courses most attended (28.8% and 15.4%, respectively). Social skills training was reported by the Victorian cohort as the second most attended (19.7%), with training on assessment tools and knowledge about ASD as the third courses most attended by them. Attending courses on activities of daily living/self-care skills was only reported by 1.5% and 3.8% of the participants in Victoria and Malaysia, respectively. The detailed results of this question can be found in Appendix O, Figure O.1.

Question E3 – Please name the training/certification courses that are relevant to your occupational therapy services for children with autistic spectrum disorders which you plan to attend in the table below.

The detailed results in this question are consistent with the results in Question E2 where participants in both regions stated that the sensory-based related courses were attended the most by them. This question demonstrates that most practitioners would like to attend courses related to sensory-based intervention for children with ASD (Appendix O, Figure O.2).

The top five courses that the participants in Victoria would like to attend were:

1. Sensory-based related courses (17 responses or 25.8%)
2. Social skills (13 responses or 19.7%)
3. Training on assessments tools (5 responses or 7.6%)
4. Courses/seminars on gaining knowledge about ASD (5 responses or 7.6%)
5. Interventions on activities of daily living/self-care skills (3 responses or 4.5%).

The top five courses that the participants in Malaysia would like to attend were:

1. Sensory-based related courses (22 responses or 42.3%)
2. Behavioural management (15 responses or 28.8%)
3. Social skills (8 responses or 15.4%)
4. Play skills (6 responses or 11.5%)
5. Handwriting skills or school related skills (6 responses or 11.5%).

Question E4 – Please indicate your preferences in the method of obtaining knowledge and skills.

In this question, participants were asked to identify their preferred learning style (Table 4.8). The greatest percentages of the respondents in Victoria indicated that they had 'high preferences' in the method of (a) hands-on mentoring by expert or experience therapists, (b) multidisciplinary workshop with discussion and problem solving, (c) short courses of specialised certification on a certain technique or programme, and (d) conferences or seminars.

The highest percentages of the respondents in Malaysia reported that they preferred (a) hands-on mentoring by expert or experienced therapists and (b) attending short courses of specialised certification on certain techniques or program in obtaining knowledge and skills.

Table 4.8

Results on the preferences on the method of obtaining knowledge and skills reported by the participants in Victoria and Malaysia

Area of adaptive behaviours addressed by the participants in their services with children with ASD in Victoria													
Method of obtaining knowledge and skills and the statistical result	n†		Not preferred (%)		Low preferences (%)		Moderate (%)		High preferences (%)		Preferred the most (%)		*p*
	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	
Hands-on mentoring by expert/experienced therapists	64	51	1.6	0.0	1.6	3.9	17.2	21.6	51.6	31.4	28.1	43.1	.414
Case presentation of intervention and technique	64	51	1.6	0.0	14.1	3.9	45.3	31.4	35.9	49.0	3.1	15.7	.001*
Multidisciplinary workshop with discussion and problem solving	64	51	0.0	2.0	7.8	0.0	31.3	21.6	54.7	49.0	6.3	27.5	.004*
Short courses of specialised certification on certain technique/program	65	51	4.6	2.0	4.6	3.9	21.5	29.4	43.1	31.4	26.2	33.3	.759
Online courses	64	49	26.6	10.2	23.4	30.6	21.9	44.9	20.3	8.2	7.8	6.1	.572
Conferences or seminars	66	50	4.5	6.0	16.7	6.0	31.8	30.0	37.9	50.0	9.1	8.0	.268
Literature reviews	64	50	17.2	10.0	25.0	20.0	37.5	38.0	20.3	28.0	0.0	4.0	.082
Advanced post-professional degrees	63	47	22.2	14.9	25.4	14.9	25.4	27.7	22.2	23.4	4.8	19.1	.029*

Note. n† Represents number of participants providing rating. In a five-point Lickert scale ranging from 1 (not preferred), 2 (low preferences), 3 (moderate), 4 (high preferences) and 5 (preferred the most). *$p < .05$

Other methods of obtaining knowledge and skills listed by the respondents were:

1. Video conferences which might benefit occupational therapy practitioners who are located in remote areas
2. Distance education learning

Summary

This chapter has presented the results and discussion on two surveys regarding the occupational therapy services provided for children with ASD in Victoria and Malaysia. The purpose of this was to compare current practice, and to see whether or not Malaysian occupational therapists were acting in a way that was either imitating the practice in a near but culturally different nature, or starting to develop independently and contextually appropriate services for Malaysian children and families. Some similarities can be seen in the services provided by the participants in these regions, such as in terms of the assessments and interventions/programmes provided and also on the practitioners' goals in their service provisions for children with ASD and their families. Malaysian and Victorian participants indicated that they have attended, and would like to attend, courses and training related to sensory-based interventions, whereas hands-on mentoring and short courses on specialised certifications were their most preferred methods of acquiring knowledge and skills in their services for children with ASD and families. It was highly indicated by the participants in both cohorts that they are working closely with parents/caregivers in their services. However, in both regions, it was unclear as how the therapists worked with parents/caregivers, in terms of planning for the services based on the child with ASD's unique needs and abilities. This was then explored in the second phase of the study.

CHAPTER V

PHASE 2: DAILY LIVING SKILLS IN CHILDREN WITH AUTISTIC SPECTRUM DISORDER IN PENINSULAR MALAYSIA – PARENTS' PERSPECTIVE - METHODOLOGY

As stated previously, children with ASD have difficulty managing daily living activities, and there is no published information in this area of children with ASD in the Malaysian context. In order to address this, the following research questions were identified:

1. What is the level and profile of adaptive behaviour skills in children with ASD living in Peninsular Malaysia?
2. What are the occupational performance difficulties that children with ASD living in Peninsular Malaysia display?
3. What is the relationship between the level of occupational performance in children with ASD and their parents' satisfaction level regarding that occupational performance, and
4. What is the relationship between the adaptive behaviour skills in children with ASD and their occupational performance difficulties, level of satisfactions and priorities in occupational performance as identified by their parents in Peninsular Malaysia?

In order to address these questions, a mixed methods approach, consisting of survey and semi-structured interviews, was developed. Figure 5.1 provides an overview of the methods employed in phase two of this research.

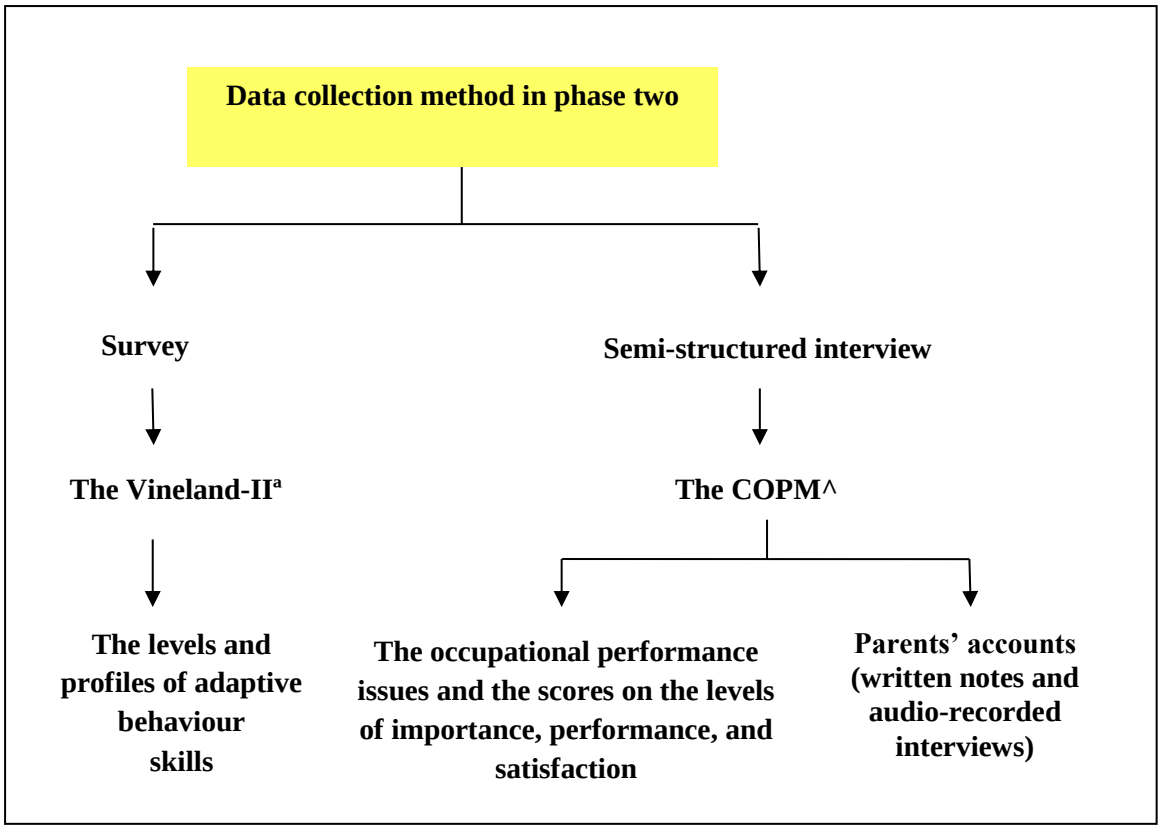

Figure 5.1. The overview of the data collection methods employed in phase two of the research.[5]

Analytical tools

The two data collection tools used to address the research question include the Canadian Occupational Performance Measure, hereafter called the COPM (Law et al., 2000, 2008) and the Vineland Adaptive Behaviour Scales (Second edition) (Parent/Caregiver Rating Form), hereafter called the Vineland-II (Sparrow et al., 2005b) (refer to Appendices P and Q).

[5] *Note.* [a] The Vineland Adaptive Behaviour Scales – Second Edition (Parent/Caregiver Rating Form) (the Vineland-II) (Sparrow et al., 2005b).
^ The Canadian Occupational Performance Measure (COPM) (Law et al., 2000, 2008).

The Canadian Occupational Performance Measure (COPM)

The COPM is a client-centred outcome measure, in which a person identifies his/her priorities in occupational performance within the areas of self-care, productivity and leisure, with three further categories in each area (Table 5.1). For each of these categories, the person identifies the importance of the activity, and also satisfaction, performance and importance of the activity, on a ten-point scale. It is generally delivered in a semi-structured interview format, and has been used as a proxy measure successfully in research and practice with children (Cusick, Lannin, & Lowe, 2007; Lowe, Novak, & Cusick, 2006; Stewart & Neyerlin-Beale, 2000; Verkerk, Wolf, Louwers, Meester-Delver, & Nollet, 2006). The COPM semi-structured interview was developed to promote a client-centred occupational therapy approach. It identifies problems encountered by clients in the areas of self-care, productivity and leisure, which are called occupational performance issues. Engagement in meaningful occupation through the successful interaction between the person and his or her environment and occupation enhances his or her performance and maintains cognitive and physiological wellbeing.

Table 5.1

The areas and categories contained in the Canadian Occupational Performance Measure (COPM)

The Canadian Occupational Performance Measure (COPM)		
	Areas	Categories
1.	Self-care	- Personal care - Functional mobility - Community management
2.	Productivity	- Paid/unpaid work - Household management - Play/school
3.	Leisure	- Quiet recreation - Active recreation - Socialisation

The COPM semi-structured interview was developed to be used with adult clients; however, it has successfully been used with paediatric clients with parents or caregivers used as proxies (Cusick, Lannin, & Lowe, 2007; Lowe, Novak, & Cusick, 2006; Stewart & Neyerlin-Beale, 2000; Verkerk, Wolf, Louwers, Meester-Delver, & Nollet, 2006).

A study conducted by Verkerk et al. (2006) concluded that the use of the COPM semi-structured interview would identify the child's unique individual issues and also that it is a valuable tool in defining the intervention goals for the child, based on a parent's or caregiver's perspective. Moreover, a literature review conducted by Carswell et al. (2004) found that the COPM semi-structured interview has been successfully used with a wide variety of clients, including children with disabilities and their family members, and also in a variety of different countries and cultural backgrounds. The review concluded that the COPM semi-structured interview is a valid, reliable, clinically useful, and responsive outcome measure for use by occupational therapy practitioners and researchers (Carswell et al., 2004). Thus, the COPM was chosen for this study in order to identify the priority areas for this group of children and their families.

The Vineland Adaptive Behaviour Scales-Second Edition (Vineland-II)

The Vineland-II (Sparrow et al., 2005b) is the most commonly used standardised assessment used to identify difficulties in adaptive behaviour for children with ASD (Scattone et al., 2011). The results of the Vineland have been used to facilitate educational and vocational planning for those with ASD (Carter et al., 1998; Tomanik et al., 2007). The Vineland-II is considered the gold standard assessment tool in assessing adaptive behaviours in children with special needs (Scattone et al., 2011). Hence, the Vineland-II, the most recent version of the Vineland Adaptive Behaviour Scales (VABS), was used in this study.

The Vineland-II (Sparrow et al., 2005b) consists of a survey interview and parent/caregiver rating form, and has an extended interview form and a teacher rating form, as well. It assesses sub-domains within the four domains of Communication, Daily Living Skills, Socialisation and Motor skills (Table 5.2).

Table 5.2

The domains and sub-domains contained in the Vineland Adaptive Behaviour Scales – Second Edition (Vineland-II)

The Vineland Adaptive Behaviour Scales – Second Edition (Vineland-II)		
	Domains	Sub-domains
1.	Communication	- Receptive (Listening and understanding) - Expressive (Talking) - Written (Reading and writing)
2.	Daily living skills (Daily living)	- Personal (Caring for self) - Domestic (Caring for home) - Community (Living in the community)
3.	Socialisation (Social skills and relationships)	- Interpersonal relationships (Relating to others) - Play and leisure time (Playing and using leisure time) - Coping skills (Adapting)
4.	Motor skills (Physical activity)	- Gross motor (Using large muscles) - Fine motor (Using small muscles)

The domains and sub-domains shown in brackets are the terms used in the booklet intended for use by parents or caregivers. The Parent/Caregiver Rating Form is a survey form using simple terms and sentences.

The motor skills domain consists of fine and gross motor skills, and is administered only to children up to 6 years of age. The optional domain of the maladaptive behaviour index can also be scored using the Vineland-II. It consists of internalising, externalising and other types of undesirable behaviours that may interfere with adaptive functioning. However, in this study, the motor skills domain was not

included, owing to the age limitations put on it; the optional maladaptive behaviour domain was also excluded, because this study focused on the daily living abilities of the children with ASD.

The four broad domains cover essential adaptive skills across the lifespan. Parents or caregivers rate their child's performances in day-to-day activities under the four broad domains using the score of 2 (usually), 1 (sometimes or partially), or 0 (never). The Vineland-II survey is able to identify strengths and weaknesses in children with ASD; however, it does not include what is important to parents or caregivers. For this reason, the COPM semi-structured interview was incorporated in the study in order to attain the daily living activities that are most important to parents or caregivers. Therefore, in this study, findings from the Vineland-II (Parent/Caregiver Rating Form) on the children with ASD's adaptive behaviour abilities were compared with findings from the COPM semi-structured interview, which addressed parents' or caregivers' concern and priorities for achieving meaningful occupational performance for their children with ASD. Findings in terms of the difficulties in adaptive behaviours of the children with ASD as identified in the Vineland-II were compared to the priorities of the parents or caregivers. In this way, the usefulness of both measures (the Vineland-II and the COPM) can be considered in terms of occupational therapy practice.

The Translation Process

Both instruments, the COPM (the interview form and its score cards) and the Vineland-II (Parent/Caregiver Rating Form survey) were translated into the Malay language for use with the Malaysian populations involved in this study. Permission to translate the instruments into the Malay language and use them in the study was granted from the copyright holders for (a) The main author of the COPM, Prof. Mary Law (Appendix R), and (b) The NCS Pearson, Inc. for the Vineland-II (Parent/Caregiver Rating Form survey) (Appendix S).

The forward-backward translation procedure was applied to translate both instruments from the original English into the Malay language version (Beaton, Bombardier, Guillemin, & Ferraz, 2000; Hunt & Bhopal, 2004). Two translators independently performed the forward translation process of both instruments from the English into the Malay language. A certified translator did one translation and an occupational therapy lecturer who is a native speaker of the Malay language and also a proficient speaker of the English language did another. The translation was aimed at achieving the most relevant meaning and intent of the English terms and translating them into the conceptually equivalent Malay language accordingly (Beaton et al., 2000; Hunt & Bhopal, 2004).

Once the researcher, who is a native speaker of the Malay language and a proficient speaker of the English language, received the forward translation from both translators, comparisons were made and discussions were held with both translators. The discussions were made in order to decide on the words or expressions used to maintain their meaning before the harmonised version of the forward translations of both instruments were produced (Beaton et al., 2000; Hunt & Bhopal, 2004). Both translators agreed that items containing people's names, sports or games and use of currency in the Vineland-II (Parent/Caregiver Rating Form) should be replaced with commonly used people's names, and sports or games commonly played, in the Malaysian cultures, and the currency used in Malaysia.

The harmonised version of both translated instruments was then translated back into the English language as a process of validity checking to ensure content consistency (Beaton et al., 2000). The other qualified translator, who was unfamiliar with the instruments to reduce bias in the translation process, did the backward translation. The researcher reviewed the backward translation of both instruments and compared them with the original English language instruments. Any differences in the meaning and intent between the backward translations and the original instruments were reviewed.

Consequently, any items in the forward translation that did not reflect the original intent of the English language instruments were re-worded into Malay to produce the final forward translations of both instruments.

These were then sent to seven Malaysian occupational therapy clinicians and a tutor specialising in early childhood development to review the final forward translation in order to ensure its content accuracy and cultural validity in terms of each item's appropriateness to be used with the Malaysian population. Initially, seven reviewers agreed to conduct the review; however, one withdrew for personal reasons. The six clinicians who conducted the review included one occupational therapy practitioner with more than 20 years' work experience, and another with nearly 15 years' experience in various areas of occupational therapy services for children and adult clients and also experience in administrative tasks. The four others had between six to 10 years' work experience in occupational therapy services with children and adult clients in Malaysia. All of them were native speakers of the Malay language.

No suggestions for modification were received from the clinicians regarding the content of the instruments. However, one comment was received regarding the format of the 'date of assessment' and 'date of birth' located on the front cover of the Vineland-II where both were written in 'day:month:year' format. These have been changed to 'year:month:day' format for both date of assessment and date of birth as this is how it is written in the original English language form.

Correcting this was important as this specific format of the date is used to calculate the child's chronological age. This error had gone unnoticed during the translation process. Consequently, the final forward translation of both instruments was produced according to the same format and layout as in the original instruments and was then sent to the copyright holders, together with a copy of the backward translation, for their reference and as requested in the permission agreement. Refer to Appendices T and U for the final forward translation of the Malay language version of the COPM and the

Vineland-II, respectively. The steps involved in the translation process of both instruments were simplified as in Figure 5.2.

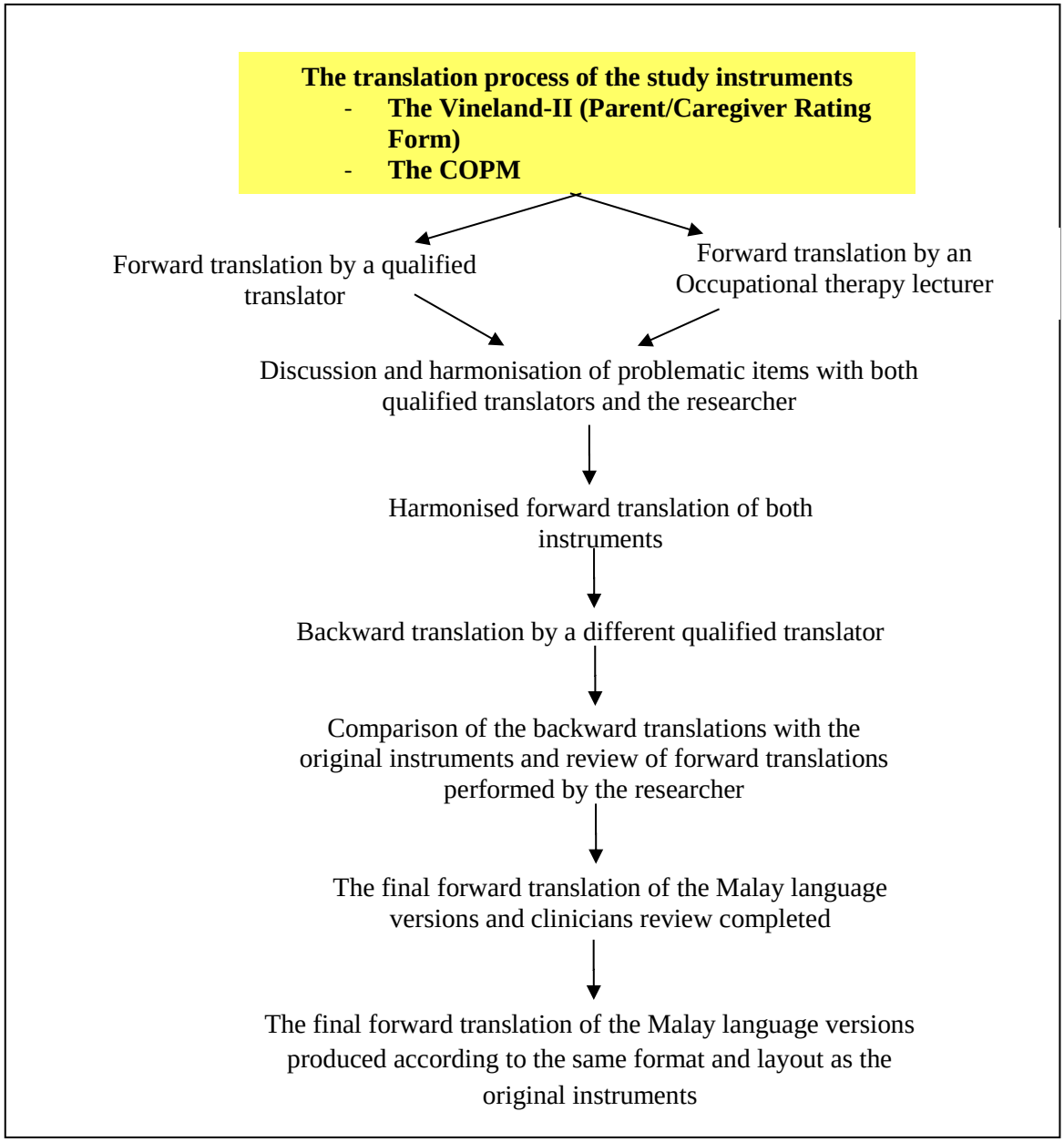

Figure 5.2. The forward-backward translation process of the Vineland-II and the COPM.

Participants and Recruitment

Respondents in this phase of the research were parents of children with ASD in Peninsular Malaysia. The decision made to conduct the surveys and interviews in phase two of the study in Peninsular Malaysia only, as opposed to the whole of Malaysia (Peninsular and East) was due to language and geographical factors. It was also found from phase one of

the research that there were more occupational therapy respondents from Peninsular Malaysia compared to East Malaysia. The student researcher's main native language was Malay and she was able to understand the majority of the Malay dialects spoken in Peninsular Malaysia. There was also a geographical factor in that East Malaysia is located on the island of Borneo. The possibility of collecting data in East Malaysia was limited by language, financial, and time constraints. A final influencing factor was that, according to the 2010 national census produced by the Department of Statistics Malaysia (2012), the population of persons with disabilities, which included children with disabilities was reported to be higher in Peninsular Malaysia as opposed to East Malaysia, as explained in the introduction chapter previously (Chapter I, p. 11).

The inclusion criteria for participants (hereafter called the parents) were that they had:

1. A child with ASD who was diagnosed with ASD between 3 to 12 years of age
2. The parents were able to read, comprehend and write in the Malay language.

The parents were recruited from two centres:

1. The Universiti Kebangsaan Malaysia Medical Centre (UKMMC), which is one of the teaching hospitals in Malaysia
2. The National Autism Society of Malaysia (NASOM), which is a non-government organisation (NGO) that provides various services to children and adults with ASD and also to their families.

The Head of the Occupational Therapy Department, UKMMC and the Chairman of the NASOM were first contacted in person to inform them about the study and explain the selection criteria for the parents for the study. This was then followed with a formal application letter (Appendix V for the application letter to NASOM and UKMMC) sent

together with the explanatory statements of the study (Appendix W for an explanatory statement of the survey and the explanatory statement for the semi-structured interview) to the Head of the Occupational Therapy Department, UKMMC and the Chairman of the NASOM. Permission was received from both bodies to recruit parents from their centres (Appendix X for the permission letters from both centres).

Ethics

The Monash Human Research Ethics Committee (MUHREC) approval was applied for and granted in September 2010 – project number CF10/1520 – 2010000818 (Appendix Y). In order to conduct research in Malaysia, another approval was sought from the Research Promotion and Co-Ordination Committee, Economic Planning Unit (EPU), Prime Minister's Department, Malaysia. This ethics approval was granted in December 2009 – reference number UPE: 40/200/19/2505. This approval from EPU was for data collection performed in phases one and two of the research (Appendix L). A separate human ethic approval was applied for to recruit parents from the UKMMC from the Medical Research and Industry Secretariat. This was granted in 15 November 2010 – reference number: UKM 1.5.3.5/244/SPP/NN-102-2010 (Appendix Z). No separate ethical approval was needed to recruit parents from the NASOM as the approval from EPU and MUHREC were considered satisfactory and applicable to this research by the Chairman of the Centre.

Data Collection

Data collection took place between July and September 2010 and in January and February 2011. The parents were recruited from those whose children with ASD were attending occupational therapy clinics in the UKMMC and NASOM. In order to reduce the perception of pressure on the parents to participate in the research in relation to receiving therapy, the researcher herself approached the parents, instead of asking their

occupational therapists to approach them. Each parent, while waiting for his or her child's turn to receive an occupational therapy service, or when just finished their interventions, was approached by the researcher and was firstly given a verbal explanation about the objectives of the study followed by an explanatory statement to read about the study. There were two explanatory statements given to parents: one for the Vineland-II Parent/Caregiver Rating Form survey and another for the COPM semi-structured interview (Appendix W). Those parents who gave their verbal agreement to voluntarily participate in the research were then given a consent form to complete and sign. Two consent forms were given, one for the Vineland-II Parent/Caregiver Rating Form survey (Appendix AA) and another for the COPM semi-structured interview (Appendix AB). All the explanatory statements and consent forms used were prepared in English and translated into the Malay language by a qualified translator.

Each parent completed both the Vineland-II Parent/Caregiver Rating Form survey and the COPM semi-structured interview. In order to avoid bias from the parents' answers due to the order of the data collection employed in this study, a randomisation process was performed to determine which assessment was performed first. The first parent recruited completed the survey and followed with the interview session, whereas the second parent recruited was interviewed first and followed with the survey. The randomisation process continued with odd number recruitments performing the survey first followed by the interview session and even number recruitments being interviewed first followed by the survey. All parents were given a numerical code for de-identification purposes and no names or other identification details were written on the survey forms, interview notes, and transcriptions other than in the consent forms completed and signed by the parents.

The Vineland-II Survey

The parents were instructed in how to complete the self-administered survey of the final forward translation of the Malay language version of the Vineland-II

(Parent/Caregiver Rating Form) (Appendix U), particularly, in how to rate the abilities of their child with ASD according to the criteria as set out in the form. The parents completed three domains in the form (a) communication, (b) daily living, and (c) social skills and relationships. As mentioned, the physical activity domain was excluded from the study due to the age limitations put on it, as it was only used to measure motor skills for children up to six years of age. The optional domain of maladaptive behaviour was also omitted in the study. The parents indicated whether their child with ASD "can usually perform the tasks", "are sometimes or partially able to perform the tasks" or "are never able to perform the tasks" as listed in the form. To facilitate this process, the researcher calculated the child's chronological age. This chronological age was used as the starting point for parents to begin their ratings. The parents were free to complete the survey at the place or location of their choice and they were also offered the opportunity to complete them in vacant rooms in the occupational therapy department, such as the individual intervention room or staff rest room. They were asked to return the survey form to the researcher once it had been completed.

The Canadian Occupational Performance Measure Semi-Structured Interview

Data were collected using the final forward translation of the Malay language version of the Canadian Occupational Performance Measure (Appendix T). The parents who agreed to be involved in the interview were also asked for their permission for the session to be audio-recorded and were asked to show their agreement by indicating this in the consent form. Audio-recording of the interview sessions allowed the researcher to pay more attention to the parent; the information provided could be heard again for data analysis purposes (Kvale, 2007). However, those who were not feeling comfortable about the session being audio-recorded had their decision respected and notes were taken using pen and paper.

The interviews were performed on a one-to-one basis. To ensure privacy and to encourage parents to speak freely, the interviews were performed in the vacant individual intervention or staff rest room in the occupational therapy department where the conversation could not be overheard (Liamputtong, 2009). These settings also provided a quiet place for the interview to be audio-recorded in order to ensure the quality of the recording (Bryman, 2008). However, it was not possible to carry out all interviews in the individual intervention or staff rest room. Interviews with some parents had to be performed in the waiting area or in the occupational therapy activity rooms/clinics while their children with ASD were receiving occupational therapy sessions. Where the interviews had to be performed in these settings, the interviews were not recorded due to the background noise which inhibits quality audio recording and notes were taken using pen and paper. Some interviews were also not audio-recorded although they were performed in the individual intervention or staff rest room. This was because some parents had to bring along their child with ASD and/or their siblings to the interview room, which made it impossible to get a quiet situation to ensure quality audio-recording. Some children with ASD and/or their siblings were also distracted by and attracted to the audio-recording devices and tried to touch them, which consequently interfered with the parents' concentration and the interview process.

The interview content was guided by the three main occupational performance areas in the COPM consisting of (a) self-care, (b) productivity, and (c) leisure. There are three categories under each occupational performance area in the COPM, but only one category under each area was asked of the parents; the selections consisted of (a) self-care - personal care, (b) productivity - play and/or school, and (c) leisure - socialisation. This selection is illustrated by the shaded boxes in Figure 5.3. The reasons for these selections of the COPM categories are that these areas were the focus of the research questions and it closely match with the domains and sub-domains in the Vineland-II survey (parents/caregivers rating form) (see Table 5.2 for the content).

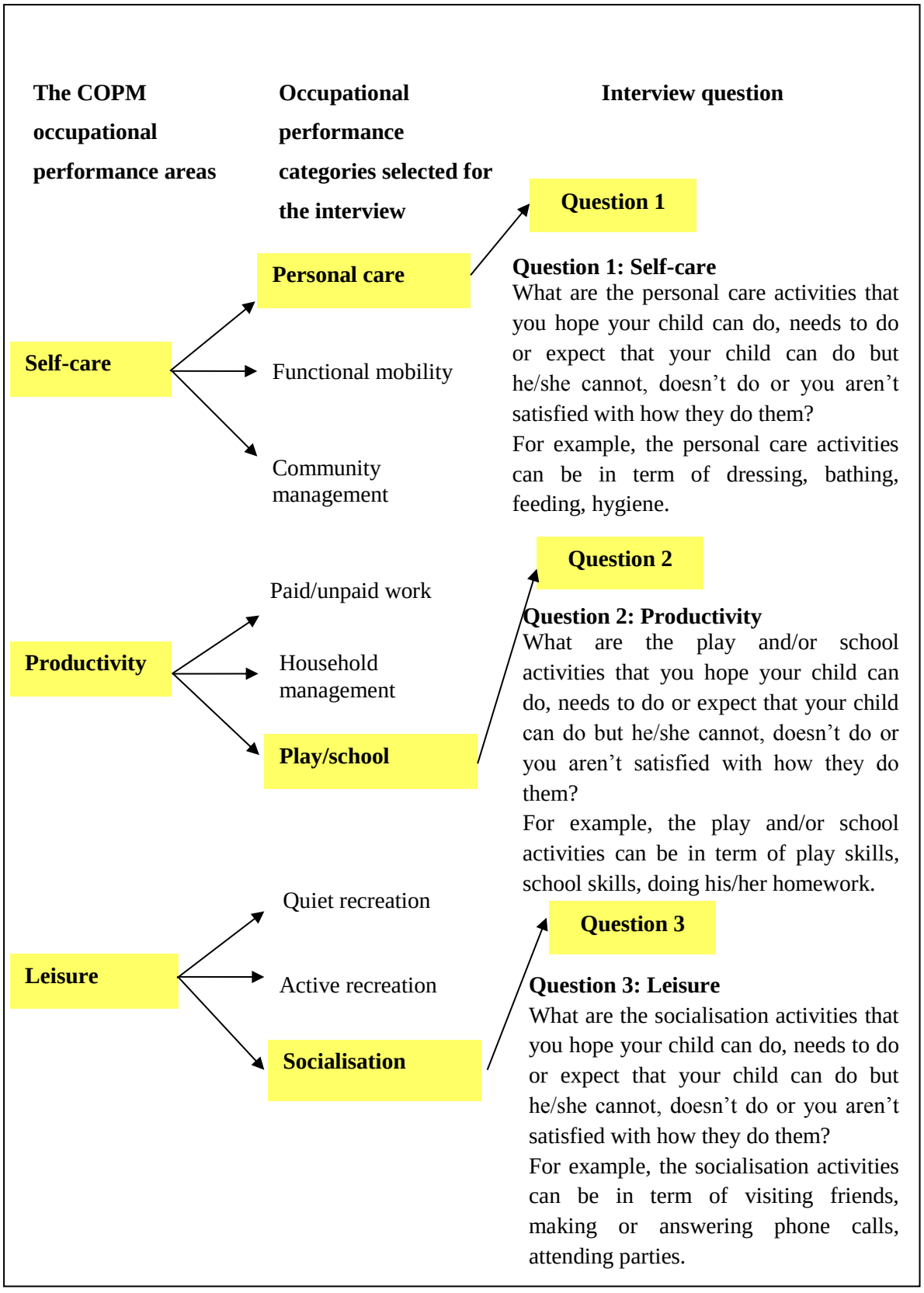

Figure 5.3. Shaded boxes shows the occupational performance domains and sub-domains in the COPM asked in the semi-structured interview.

In order to establish the accuracy of the comments noted by the student researcher, a form of member checking was performed at the end of each interview. All the interview sessions were conducted in the Malay language. The parents were asked for their opinion about the problems faced by their children with ASD in performing daily living activities according to the interview questions listed (see Figure 5.3, p. 116).

A form of member checking is important to gain accuracy on the information given by the parents and at the same time ensuring that the researcher captured the correct intentions from the parent's feedback as well (Lincoln & Guba, 1985; Mays & Pope, 2000). In the member checking process, the researcher stated and summarised the information regarding the occupational performance problems faced by the children with ASD given by the parents during the interview. The parents were given an opportunity to confirm the occupational performance problems summarised by the researcher and they were also asked if there was anything else that they wanted to add. Then, the parents were asked to choose the five most important occupational performance problems among all the problems stated. Using the score cards provided the parents were then asked to rate the level of importance and performance of their child with ASD in each of the five areas and also their level of satisfaction in terms of their child's performance for each of the five areas.

Methods of Data Analysis

The methods of data analysis conducted in phase two of this research are divided into two separate stages:

1. Stage 1 – The method of data analysis on:
    1. The level and profile of adaptive behaviour skills gained from the Vineland-II survey

2. The occupational performance difficulties and the scores on the importance, performance and satisfaction levels obtained from the COPM semi-structured interview
3. Analysis of the relationship between the COPM level of performance and satisfaction
4. Analysis of the relationship between the Vineland-II adaptive behaviour skills and the COPM level of performance, satisfaction, and importance.

2. Stage 2 – the method of data analysis of parents' accounts gathered from the written notes of comments and audio-recorded interviews obtained during the COPM semi-structured interviews.

As such, the results obtained from the above data analysis were also divided into two separate stages and are presented in the next chapter. All the results were described separately and then compared in a triangulation process to see the links between them (Figure 5.4).

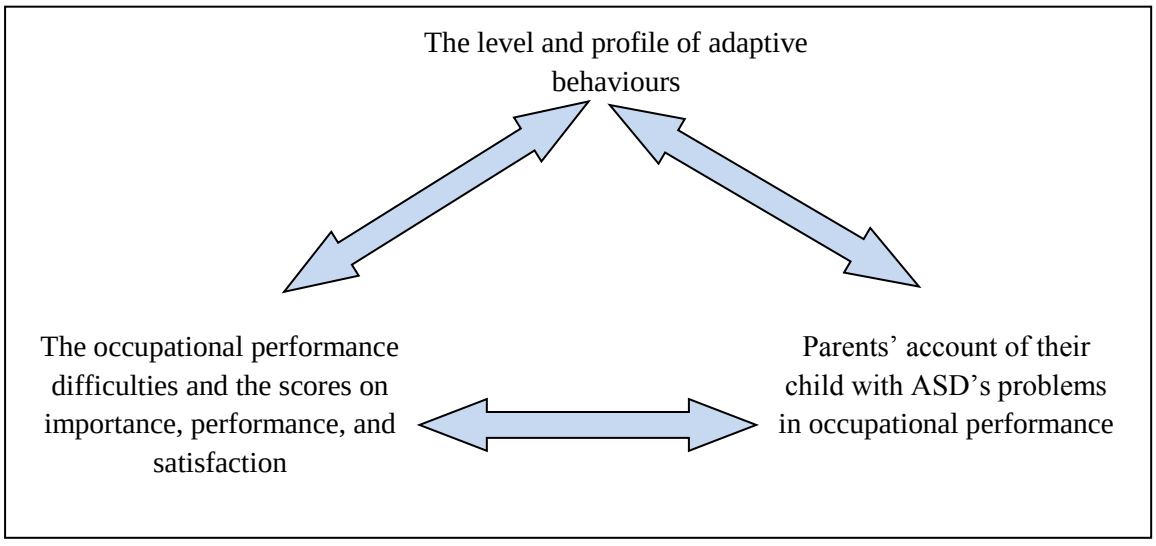

Figure 5.4. Triangulation process on the results obtained.

Stage 1 - Method of Data Analysis

Stage 1 served to answer the research questions asked in phase two of this study. The method of data analysis conducted to answer those research questions was explained in this stage.

Data analysis for research question # 1: **What is the level and profile of adaptive behaviour in children with ASD living in Peninsular Malaysia?**

To enable the interpretation of the results, raw scores obtained for each individual child in the Vineland-II were converted into derived scores. In order to do so, a computer programme, the Vineland-II ASSIST™ Scoring and Reporting System Version 1.1 (NCS PEARSON, Inc., 2007 – hereafter called the Vineland-II ASSIST™) software was used to score and generate results collected from the survey from parents for each child with ASD involved in this study.

Firstly, the raw scores collected for each sub-domain were entered and the Vineland-II ASSIST™ software produced results in term of (a) sub-domains v-scale scores, (b) domains standard scores, (c) confidence interval (set at 90%), (d) percentile ranks, (e) adaptive levels, (f) age equivalent, and (g) stanine.

Secondly, in order to produce the levels and profiles of adaptive behaviour skills, two attained scores were used in the analysis of (a) the derived scores attained for the domains and sub-domains and (b) the age equivalent score. In this study, the age equivalent scores were also used to produce the levels and profiles of adaptive behaviour skills; according to Carter et al. (1998), this is considered the most appropriate measure of developmental level. The individual results obtained on the domains' standard scores, sub-domains' v-scale scores and age equivalent scores were then entered into the PASW Statistics Version 18.0 for Windows (formerly SPSS-The Statistical Package for the Social Sciences – hereafter called SPSS) – to produce the group scores. The age equivalent score produced by the Vineland-II ASSIST™ software was in year:month format, and this age

format was converted into age in months format when entered into the SPSS. The domains' standard scores, sub-domains' v-scale scores and age-equivalent scores describe the relative level of adaptive behaviour skills on those areas compared with others of the same age in the standardisation sample of the Vineland-II. In the Vineland-II, the standard score has a mean of 100 and a standard deviation of 15. The v-scale score has a higher mean value of 15 and a standard deviation of 3. This higher value of the mean in the Vineland-II enables a better differentiation at low levels of performance, especially when it is used with very low functioning children with ASD (Sparrow et al., 2005a).

Using the SPSS, data were generated in terms of the mean scores, standard deviations, and minimum and maximum values of the domains' standard scores, sub-domains' v-scale scores and the age equivalents scores for all the children with ASD involved in this study as a larger group. These descriptive results are presented in the next chapter. In the Vineland-II, to allow easier interpretations and better understanding of the results by parents or caregivers, the mean scores obtained on the standard scores and v-scale scores, as compared to the mean scores of the standardisation sample were interpreted as:

1. *Low adaptive behaviour level* for the mean scores at and below 2 standard deviations below the standardisation mean
2. *Moderately low adaptive behaviour level* for the mean scores at 1 standard deviation below the standardisation mean
3. *Average adaptive behaviour level for the mean scores within the standardisation mean (scores between 85 to 115)*
4. *Moderately high adaptive behaviour level* for the mean scores at 1 standard deviation above the standardisation mean
5. *High adaptive behaviour level* for the mean scores at and above 2 standard deviations of the standardisation mean.

Data analysis for research question # 2: **What are the occupational performance difficulties that children with ASD living in Peninsular Malaysia display?**

At the end of the interview, parents were asked to list the five most important problems exhibited by their child with ASD and also to rank the problems listed in terms of their level of performance and satisfaction. The COPM provides data that are ranked and continuous (Novak, Cusick, & Lannin, 2009; Van Leit & Crowe, 2003) on the levels of importance, performance, and satisfaction that ranged between 1 – "not important at all/not able to do it /not satisfied at all" to 10 – "extremely important/able to do it extremely well/extremely satisfied", respectively. In order to get the total scores for each child, the scores obtained for the level of importance, performance and satisfaction were added together and divided by the number of occupational performance problems listed by parents. The total scores for the level of importance, performance, and satisfaction collected for each individual child were entered and analysed descriptively using SPSS in terms of their mean, standard deviations, and minimum and maximum values.

The next step involved grouping the five most important issues listed into categories (however, some parents listed less than five issues). In order to determine the suitable categories, all the problems listed by parents were read entirely to gain initial views and an understanding of the issues mentioned. Content analysis procedures as explained in Liamputtong's (2009) were adopted. The method of content analysis and procedures followed to determine the suitable categories are explained in detail later in this chapter under the heading of *'*Stage 2 – Data Analysis of Qualitative Data Obtained Using the Canadian Occupational Performance Measure Semi-Structured Interviews. The same content analysis procedure was followed in analysing the five most important problems listed by parents. Similar problems were grouped under the same category although they may have been reported in a different context.

For example, “unable to talk with friends during playing” and “cannot talk to tell his/her needs for toileting” were put under the category of “issues in communication”. Another example: “cannot do buttoning” and “cannot care for own safety” were grouped under the category of “issues in personal care activities”. Then, issues received for each category were counted and presented in terms of the number of problems listed and the number of the children with ASD reported to have that particular problems. One child with ASD may have more than one problems reported by parents in each category identified.

Seven categories of issues were developed from the content analysis of the problems mentioned by parents:

1. Issues in communication
2. Issues in personal care activities
3. Issues in socialisation
4. Issues in activities related to academic skills at school and/or at home
5. Challenging behaviours
6. Issues in play
7. Other occupational performance issues.

The total scores on the level of importance, performance and satisfaction for each identified category were computed into SPSS and the mean, standard deviations, minimum and maximum values for each category thus identified were presented as well.

Data analysis for research question # 3: **What is the relationship between the level of occupational performance in children with ASD and their parents' satisfaction level regarding that occupational performance.**

A Pearson product-moment correlation coefficient (*r*) (Pallant, 2011) was chosen to correlate total scores of the level of occupational performance ratings and the level of

satisfaction ratings obtained from administering the COPM outcome measure for all children (significance level of less than .05).

In order to determine the strength of the correlation obtained, guidelines by Cohen (1988, pp. 79-81) were used. According to Cohen (1988), the strength of the correlation is considered to be: small/weak (*r*=.10 to .29), medium (*r*=.30 to .49) and large/strong (*r*=.50 to 1.0).

Data analysis for research question # 4: **What is the relationship between the adaptive behaviour skills in children with ASD and their identified occupational performance difficulties, parents' satisfaction levels and priorities in occupational performance.**

In order to answer the question, the Spearman Rank Order Correlation (Pallant, 2011) was chosen to test the relationship between the result obtained from both the Vineland-II and the COPM scores. The nonparametric alternative test was chosen because, even though the scores on the level of adaptive behaviour skills obtained from the Vineland-II standard scores domains on the communication, daily living skills and socialisation were at the interval level of measurement, they were not normally distributed when statistically tested using Kolmogorov-Smirnov (K-S) Lilliefors (Pett, 1997). As well, they were assessed visually using histogram and box plot, which is a requirement of the parametric Pearson product-moment correlation (Pallant, 2011).

The data for levels of performance, parental satisfaction and importance were taken from the total scores of the respective ratings.

In conducting the Spearman Rank Order Correlation (Pallant, 2011), firstly, the standard scores obtained for each child with ASD in the three domains of communication, daily living skills and socialisation were combined (adaptive behaviour skills) and were divided by three (because only three domains were assessed in this study) to produce the total standard scores. These total standard scores were correlated with the total scores

obtained on the “level of performance”, the “level of satisfaction”, and the “level of importance” (significance level of less than .05).

Secondly, the correlations were made separately between the standard scores of each domain of communication, daily living skills, and socialisation, with the total scores obtained on the “level of performance”, the “level of satisfaction” and the “level of importance” (significance level of less than .05). This correlation process is simplified in Figure 5.5. The strength of the correlation obtained was determined, based on the guidelines by Cohen (1988, pp. 79-81), as mentioned earlier.

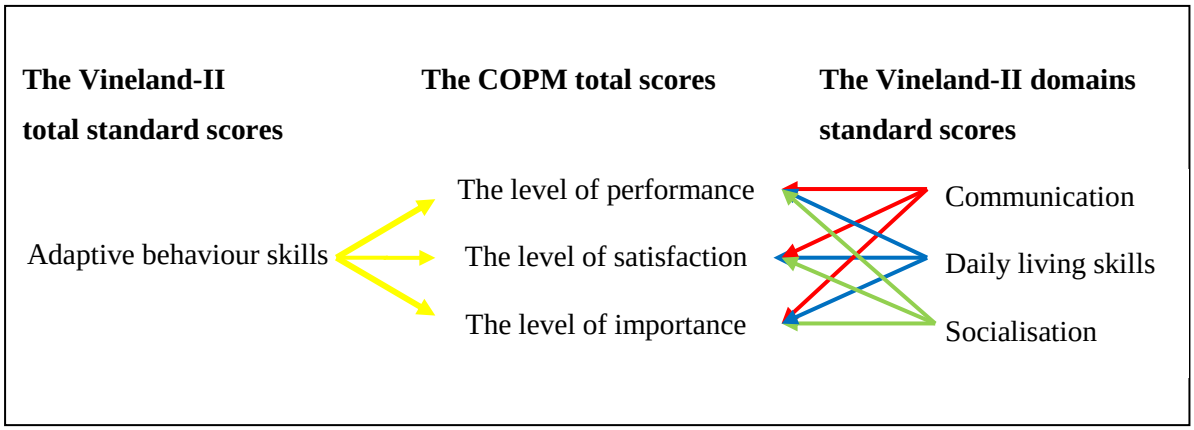

Figure 5.5. Correlations between the Vineland-II total mean standard scores, domains standard scores, and the COPM.

The method of data analysis performed in the Stage 2 is explained next.

Stage 2 – Data Analysis of Qualitative Data Obtained Using the Canadian Occupational Performance Measure Semi-Structured Interviews

All the audio-recorded interviews were transcribed verbatim. All the interview notes taken manually using pen and paper and interview transcripts regarding the aspects of personal care, play/school, and socialisation activities in children with ASD as viewed by their parents were then translated into English by the researcher for analysis. The information collected during the interviews was analysed to gain an understanding of their meaning (Rubin & Rubin, 2005). The content analysis method as outlined by

Liamputtong (2009), which involved breaking down the parents' answers into each phrase and then coding, was employed. The content analysis method is considered the most basic form of qualitative data analysis (Green & Thorogood, 2009; Liamputtong, 2009) and is the fastest growing analysis method adopted in many fields (Neuendorf, 2002).

Figure 5.6 is used to illustrate the process involved in the analysis of parents' answers gathered from the written notes of comments and audio-recorded interviews obtained during the COPM semi-structured interviews.

As illustrated in Figure 5.6, the analysis started with the process of reading and coding each individual parent's answers before the answers were grouped together. In performing the coding process, the steps and strategies as listed by Liamputtong (2009) (pp. 280-281) were followed and are summarised thus:

1. All the parents' answers were read to gain an overall understanding of the data collected
2. The parents' responses were re-read and initial codes were noted in the marginal notes columns. During the coding process, parents' wording was retained to maintain the essence of what the parents meant
3. The initial codes were reviewed and refined. Collapsing of the parents' answers and codes that refer to the same meaning were performed in the re-coding process
4. The categories and the sub-categories were grouped together.

In order to assist with the coding process, as suggested by Green and Thorogood (2009), all the parents' answers were arranged into a table format using the Word Processor program (Microsoft Office Word Professional XP version 2007). The table created consisted of seven columns (a) parents' codes, (b) parents' answers, (c) initial codes, (d) refined codes, (e) the categories and sub-categories, (f) remarks, and (g) can do lists.

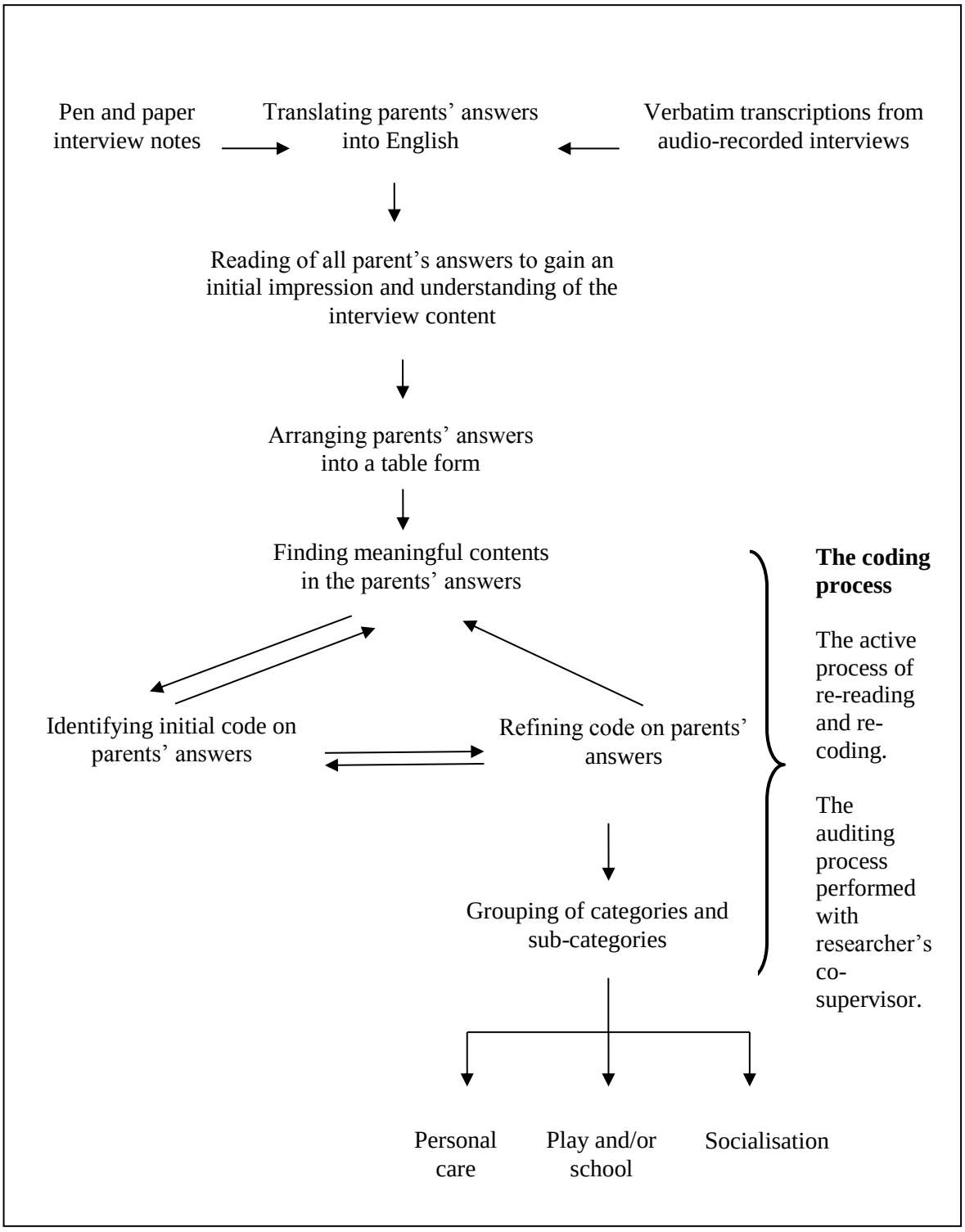

Figure 5.6. The process involved in the data analysis of the parents' accounts gathered from the written notes of comments and audio-recorded interviews.

Table 5.3 presents an example of the table created to assist the data analysis process. Three tables were created for each occupational performance domain and the parents' answers.

The numerical codes assigned for each parent were put in the first column named "parents' codes" and all the parents' answers to the questions were put in the second column. Where the parents were unable to provide an answer to a question, "No comment" was put in that column for that particular parent. In the "parents' answers" column, all the answers were arranged in a point-form format in which the answers were broken down to words or phrases for each point. During this coding process, care was taken to capture the essence of what the parents' meant in order to avoid misinterpretation during the coding process.

All the parents' answers were analysed according to their meaningful content and were assigned codes. In this study, focus of the analysis on the parents' answers was on the problems and/or activities that cannot be performed by the children with ASD as identified by their parents during the interviews. The first coding was done in the marginal notes during the process of reading of all the parents' answers in the written notes and transcripts that had been translated into English language which was then transferred to the table into the column named "initial codes", where the parents' answers were summarised (see Table 5.3, p. 129). This step of summarising the parents' answers in the initial coding process was performed for all the answers related to the problems given by the parents before the next step of refining the coding was performed in the column named "refined codes". In the process of refining the initial codes, the summaries of the parents' answers were re-read and, where necessary, re-coding was performed in the "refined codes" column. Where the summaries of the parents' answers referred to the same meaning, they were then collapsed to build the refined code. The process of collapsing parents' meaningful contents is shown with the symbol ' } ' (see example given in Table 5.3, p. 129).

Table 5.3

An example of the table created to organise the data analysis process

Parents' codes	**Question 1 - Area: Self-care** **Category: Personal care.** What are the personal care activities that you hope your child can do, needs to do or you expect that your child can do but he/she cannot, doesn't do or you aren't satisfied with how they do them? For example, the personal care activities can be in term of dressing, bathing, feeding, hygiene. **Parents' answers**	**Initial codes**	**Refined codes**	**Categories and Sub-categories**	**Remark**	**Can do lists**
101 (father)	- I hope that my son will know how to care for his own safety, not to do something dangerous, such as jumping from high places, simply crossing the road without looking to his left and right. - My son still cannot talk. - I hope that my son can talk, so that he can tell me what he wants.	- To know how to care for own safety. - Not to do something dangerous. - Cannot talk. - Cannot tell dad what he wants.	- Caring for own safety. - Cannot talk. - Cannot tell own needs.	- Personal care = Caring for own safety. - Communication = Cannot talk. - Communication = Cannot tell own needs.		
103 (mother)	- I hope he can dress by himself; he still cannot do buttoning; now he is using shoes with Velcro strap. - He has no problem with feeding; he can feed by himself without help. - He also has no problem with bathing. - He is able to go to toilet during the day to urinate or to do his big business. - In term of self-hygiene, such as washing hands, clean his face; he still needs help to do it properly.	- Cannot do buttoning. - Cannot wash hands and clean his face properly without help.	- Cannot do buttoning. - Need help with cleaning self.	- Personal care = Dressing. - Personal care = Cleaning oneself.		-Eating. -Bathing. -Toileting during the day. -Wearing shoes with Velcro strap.

More suitable codes or names were given to represent meaningful contents in the process of refining the codes. The process of refining the codes was done for all the parents' answers before the next step of categorising was performed. The categorising step involved the grouping of the "refined codes" given on the parents' answers into appropriate COPM categories of personal care, play and/or school and socialisation (see Figure 5.3, p. 117) and also the generated sub-categories. The ongoing process of re-reading and re-coding involved in assigning the codes and categories to the parents' answers enables the researcher to understand the data much more deeply (Liamputtong & Ezzy, 2005). The notes made on the "initial codes", "refined codes" and "categories and sub-categories" columns in the table not only enabled the process of refining the codes and categorising the parents' answers, but were also helpful in assisting the process of an "audit trail" with the researcher's co-supervisor in checking how and what codes and categories should be assigned to the answers (Liamputtong, 2009, p. 281).

Green and Thorogood (2009) also suggested this checking process in performing the coding process in qualitative data analysis. The purpose of performing the "audit trail" was to confirm the accuracy of the coding and the categorising process performed by the researcher on the parents' answers (Lincoln & Guba, 1985).

Agreement on the codes given and the grouping of the categories and sub-categories from the parents' answers was performed with the researcher's co-supervisor in the "audit trail" process mentioned earlier. Where concern arose on the codes and categories assigned, parents' answers were always referred to, in order to understand their meaningful contents, and codes and categories were then refined and agreed upon. Thus, the coding and categorising became an active process that went back and forth between the parents' answers, initial codes and the refined codes before the assignment of the categories and sub-categories was finalised.

The "remarks" column was used to put parents' opinions or thoughts expressed during the interview. The COPM was used to ask parents about the problem in

occupational performance faced by their children with ASD; however, instead of presenting with the problems asked, some parents indicated their child's abilities. Thus, the column "can do lists" were used to lists the activities that can be performed by the children with ASD, as indicated by the parents.

The results from the analysis of the parents' answers are presented in the next chapter where the categories and sub-categories are described and quoted excerpts from the parents are also included. The inclusion of the excerpts from the parents provides clear interpretations on the problems in occupational performance faced by the children with ASD (Mays & Pope, 2000). At the end of each quoted excerpt, the source of the quote is shown in bracketed information regarding the parents' code number (r000), relationships with the child – either mother (M) or father (F). Then followed the child's gender – either boy (B) or girl (G) and age in years:months (ym) format, and lastly the source of the quotes – either from the interview notes taken manually using pen and paper which is shown as PPN, or from the audio recorded notes which is shown as ARN - as an example: (r103,M,B4y10m,PPN).

Trustworthiness and Rigour of the Qualitative Component in this Research

In this research, care has been taken to ensure validity of the data, starting from the beginning of the data collection process where interviews were performed in a suitable vacant individual intervention and staff rest room where possible. Where such an opportunity to perform the interviews in those rooms could not be achieved, the interviews were then performed in the sitting area or in the intervention rooms in privacy where there were no other people around except the interviewed parents and their children. This ensured that the parents can share their information comfortably and have confidence that their information cannot be overheard by others.

Information collected from parents was carefully analysed in order to avoid incorrect interpretation during the data analysis process. The process of reading and re-

reading the parents' responses, careful initial coding and refined coding of those responses and the audit trail performed with the researcher's co-supervisor ensured that the parents' intentions were interpreted precisely. In addition, where concern arose regarding the coding given, the parents' responses were always referred to again to clear the matter up. By performing the translation process on the interview transcripts and interviews notes herself (which is explained in details later in this chapter), the researcher ensured that she captured the accurate meaning of the parents regarding their children with ASD's performance in daily living activities.

Working in Translation

As stated earlier, all the transcribed audio-recorded interviews and the interview notes were in the Malay language and these were then translated into English by the researcher for analysis. The researcher conducted the translation process herself, as, considering that she conducted the interviews, she could remember the non-verbal information expressed by parents during the interview process, adding to the validity of the data. In addition, the researcher is a native speaker of the Malay language – the language used in the interviews, and also a proficient speaker of the English language. Although the Malay language was used in the interview process, the multicultural society in Malaysia has some differences in the dialects of the Malay language spoken, so the decision to have the researcher conduct the translation process herself was considered sensible in this research. This is due to the researcher's ability to understand the majority of the Malay dialects used throughout peninsular Malaysia where the second phase of the research was conducted. The fact that the researcher herself was the one who performed all the interviews, and also came from the same cultural backgrounds as the parents involved in this research, gave added benefits to the translation process, in terms of conveying the correct meaning from Malay into English. The decision not to use a qualified translator services in conducting the translation work was to avoid a too formal

and literal translation that might weaken the richness and authenticity of the responses given by the parents (Hunt & Bhopal, 2004).

In order to avoid the situation of combining the roles of translator and active analyst, as described by Shklarov (2007), which might contaminate the translation process conducted by a bi-lingual researcher, the researcher refrained from making any data interpretations during the translation process and concentrated fully on the translation work instead. The data analysis was only conducted once all the interview notes and transcripts had been translated into English language completely.

In performing the translation, it was impossible to literally translate word-by-word from Malay into English as the sentence structure in the Malay language is not the same as in English. Hence, the emphasis was placed on gaining the accuracy of the concepts and the parents' intended meaning during the translation process.

Role Conflict during the Fieldwork – The Role of Researcher versus Occupational Therapist

During the data collection in the semi-structured interviews using the COPM, the researcher introduced herself in order to establish good rapport with the parents before the interview started. The researcher mentioned her qualification as an occupational therapist and her current use of postgraduate study leave to complete her doctoral candidature. From the researcher's experience and assessment in her fieldwork, parents tend to ask questions regarding the intervention for their child with ASD after the interview process. To be specific, the focus of questions asked by parents involved:

1. The typical child's developmental process
2. Advice on toilet training
3. Management of behavioural problems, including hyperactivity, temper tantrum, rigidity, and ritual repetitive behaviours

4. How to teach the child to communicate and/or to communicate effectively
5. How to encourage their child to play with peers.

These questions regarding intervention made the researcher reflect on the parents' concerns. It may be that they wanted information from this therapist in particular, or, what would be of greater concern, that they have not received information or intervention they required to address their child's occupational performance issues from their child's occupational therapy practitioner. In order to manage this role conflict, the researcher always discussed with the parents of the interventions that their children with ASD had been receiving and the researcher tried to explained the clinical reasoning behind the interventions provided to their children. This was to avoid giving conflicting advice or suggestions to the parents. Additionally, the researcher always gave some general and/or common suggestions to parents, such as in response to the questions about the typical child's developmental process and how to encourage play with peers. The parents were also asked about the strategies and/or measures taken to manage the problems themselves (especially at home) and the researcher evaluated the measures taken and discussed the benefits and/or how it could be improved further, rather than simply giving suggestions for solutions of their issues directly.

Summary

This chapter has explained the methods used to meet the aims and answer the research questions in phase two of the study conducted in Peninsular Malaysia. The respondents were parents of children with ASD whose perspectives on the adaptive skills, and occupational performance problems among their children with ASD were investigated, as well as the parents' priorities for the daily living abilities of their children. Two well-developed standardised assessment and outcome measures were administered to each

parent: (a) The Vineland-II (The Parent/Caregiver Rating Form – Second edition) (Sparrow et al., 2005b) and, (b) the COPM (Law et al., 2000, 2008), respectively. The tools were translated into the Malay language and reviewed by clinicians for use with the parents in Peninsular Malaysia. The translation of the tools used in the research involved a rigorous process of forward and backward translation procedures performed by qualified translators and native Malay language speakers to ensure content validity and accuracy.

The parents were recruited from two centres and ethical approval to recruit the respondents was granted from all of the organisations involved, both in Australia and Malaysia. The method of data analysis obtained from the Vineland-II and the COPM involved descriptive analysis and also, by conducting the parametric and nonparametric statistic test, an examination of the relationship between the data. The audio-recorded comments received from parents in the semi-structured interviews were transcribed verbatim. The verbatim transcriptions of the audio-recorded notes and pen and paper notes were then translated into English and were analysed using content analysis. Data from the Vineland-II and the COPM were analysed to answer the research questions asked in phase two of this research in terms of the levels and profile of adaptive behaviour skills and occupational performance issues exhibited by children with ASD in Peninsular Malaysia. The results are presented in Chapter VI.

CHAPTER VI

PHASE 2: RESULTS OF AN INVESTIGATION INTO DAILY LIVING SKILLS OF CHILDREN WITH AUTISTIC SPECTRUM DISORDER

The previous chapter detailed the methods employed in phase two of the research. In this chapter, the results are presented. Forty-five parents of 44 children with ASD consented to participate in this research (32 mothers, 11 fathers, and one unit of both parents together). All parents completed the Vineland-II survey and the COPM semi-structured interview. In completing the COPM semi-structured interviews, 33 interviews were in a form of written notes and 11 interviews were audio-recorded. Figure 6.1 presents the organisation of the result presentation in this chapter.

Introduction - Demographic Characteristics of the participants

Table 6.1 presents the demographic characteristics of the children with ASD involved in this research. The majority of the children with ASD were boys aged five years and below. The mean chronological age of the children with ASD involved in this study was five years and six months (66 months).

Table 6.1

Characteristics of the children with ASD

Characteristic	**N (%)**
Age (year)	
5 and below (pre-school aged group)	29 (65.9)
6 - 12 (school aged group)	15 (34.1)
Gender	
Boy	38 (86.4)
Girl	6 (13.6)

Whereas, the age range was three to 12 years (mean age = 5 years and 6 months, SD 2.17 years). This age range was further divided into two age groups of pre-school aged children (five years and below) and school-aged children (six to 12 years old).

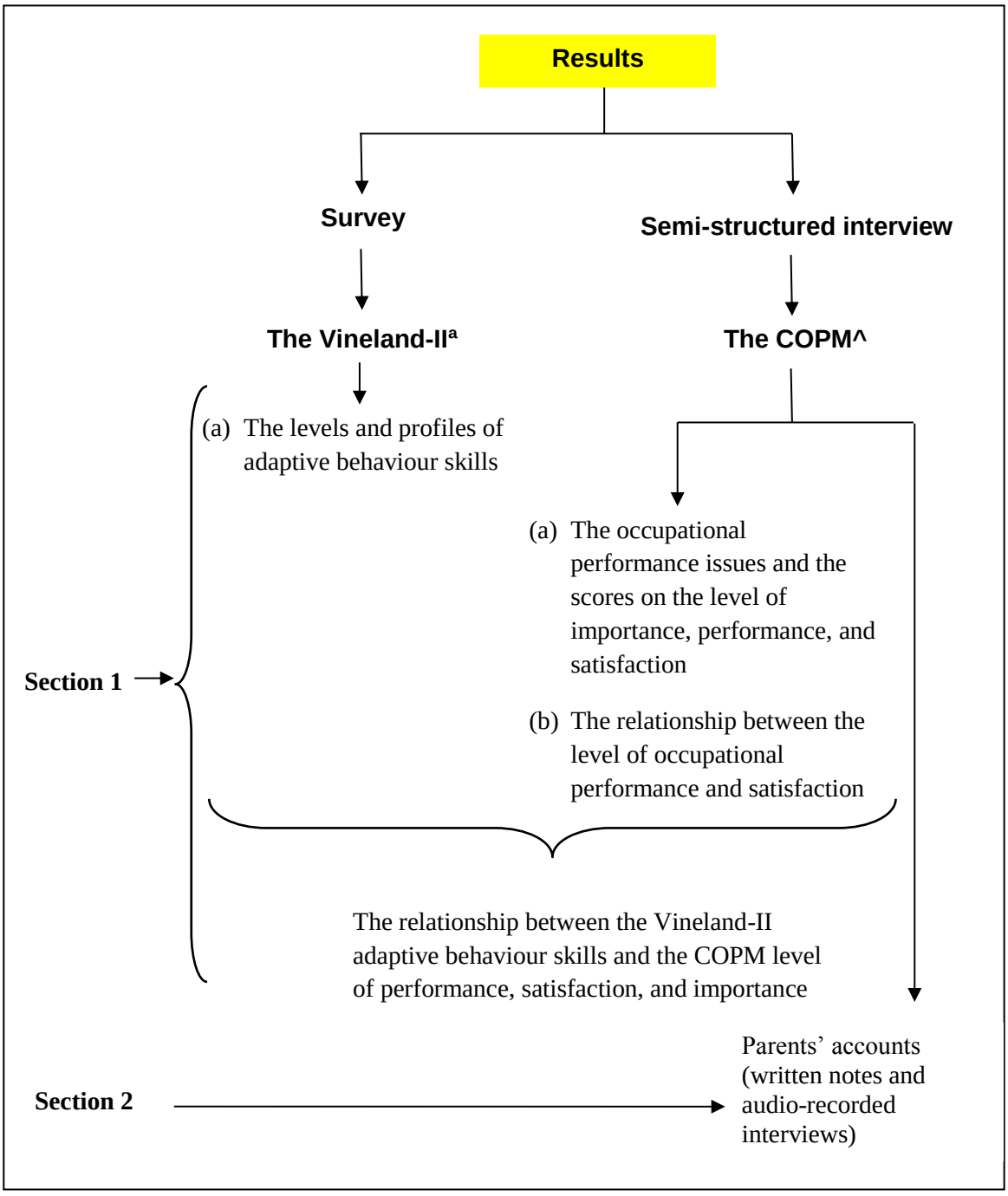

Figure 6.1. Overview of the result organisation.[6]

[6] *Note.* ª The Vineland Adaptive Behaviour Scales – Second Edition (Parent/Caregiver Rating Form) (The Vineland-II) (Sparrow et al., 2005b).
^ The Canadian Occupational Performance Measure (The COPM) (Law et al., 2000, 2008).

Section 1

The Levels and Profiles of Adaptive Behaviour Skills in Children with Autistic Spectrum Disorder in Peninsular Malaysia

Table 6.2 presents the mean scores, standard deviations, and minimum and maximum values obtained from the Vineland-II (domains' standard scores and sub-domains' v-scale scores) in the communication, daily living skills and socialisation scales. This summarises the answers to the first and second research questions asked in phase two of the research (the levels and profiles of adaptive behaviour skills in children with ASD), which is the method of data analysis has been explained in detail in Chapter V.

Table 6.2

Mean scores, standard deviations, and minimum and maximum values for the Vineland-II results on the communication, daily living skills and socialisation domains' standard scores and sub-domains' v-scale scores

The Vineland-II Standard Scores and V-Scale scores				
Domains and sub-domains	Mean	SD	Min.	Max.
Communication standard score*	**61.5**	**17.4**	**34**	**125**
Receptive VS^	8.6	3.8	2	19
Expressive VS^	6.8	3.0	2	19
Written VS^	10.5	3.5	4	20
Daily living skills standard score*	**71.3**	**14.7**	**35**	**105**
Personal VS^	9.8	3.3	1	17
Domestic VS^	11.7	2.6	4	18
Community VS^	9.4	3.0	3	15
Socialisation standard score*	**67.7**	**14.5**	**36**	**108**
Interpersonal relationships VS^	8.1	2.9	2	15
Play and leisure time VS^	9.0	3.3	2	22
Coping skills VS^	10.5	2.7	5	19

[7]

As can be seen from the results, the daily living skills domain was at 1-standard deviation below the mean, although only 1.3 over this, and the communication and socialisation domains were at 2-standard deviations below the mean of the standardisation

[7] *Note.* *The Vineland-II standard scores has a mean of 100 and standard deviation of 15. ^V-Scale scores. The Vineland-II V-scale scores have a mean of 15 and standard deviation of 3.

sample (mean=100, SD=15). Within the sub-domains, written, personal, domestic, community and coping skills were at 1-standard deviation below the mean, whereas, receptive, expressive, interpersonal relationships and play and leisure time skills were at 2-standard deviations below the mean of the standardisation sample (mean=15, SD=3). However, based on the mean age-equivalents scores, the socialisation domain was most impaired in the children with ASD in this research with total mean age equivalent reported at 25 months. Under each domain, the categories of expressive, community and interpersonal relationships were the sub-domains indicated as the most impaired with the mean age-equivalents indicated at 21, 32 and 18 months, respectively. Table 6.3 presents the detailed result for mean age-equivalent scores, standard deviations, and minimum and maximum age equivalent in months for the Vineland-II results on the communication, daily living skills and socialisation domains and sub-domains.

Table 6.3

Mean age-equivalent scores, standard deviations, and minimum and maximum age equivalent in months for the Vineland-II results on the communication, daily living skills and socialisation domains and sub-domains

The Vineland-II Age-Equivalents (Months)				
Domains and sub-domains	Mean	SD	Min.	Max.
Communication				
Receptive	29	37.0	1	216
Expressive	21	19.6	2	100
Written	42	21.0	22	93
Total mean communication age-equivalent	**31**			
Daily living skills				
Personal	40	25.0	6	138
Domestic	38	22.1	7	102
Community	32	18.9	1	72
Total mean daily living skills age-equivalent	**37**			
Socialisation				
Interpersonal relationships	18	19.2	1	94
Play and leisure time	26	21.1	1	114
Coping skills	32	24.5	1	114
Total mean socialisation age-equivalent	**25**			

Figures 6.2 and 6.3 illustrate the result for the profile of adaptive behaviour skills based on the mean scores of domains' standard scores and sub-domains' v-scale scores, respectively. Whereas, Figures 6.4 illustrates the profile based on the mean age-equivalents scores (in months) for the adaptive behaviour skills sub-domains.

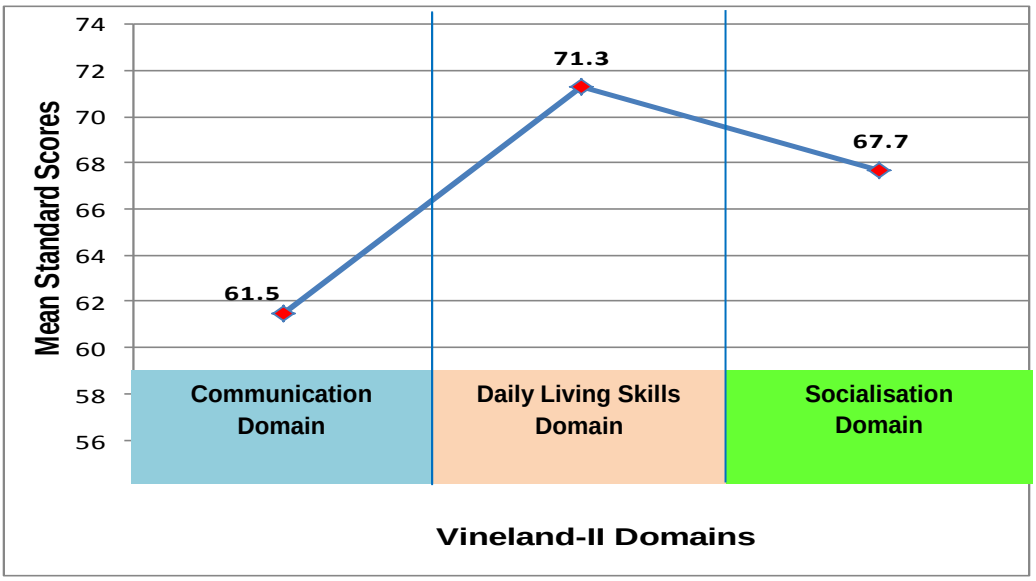

Figure 6.2. Profile of Vineland-II domains based on mean standard scores.

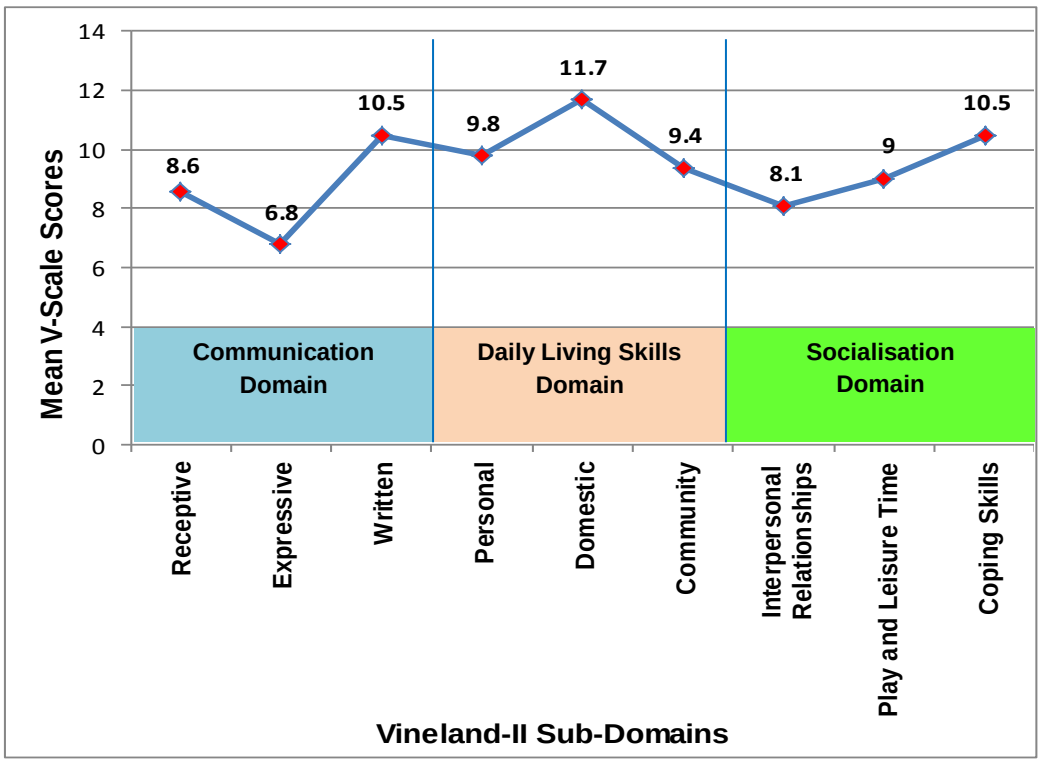

Figure 6.3. Profile of Vineland-II sub-domains based on mean v-scale scores.

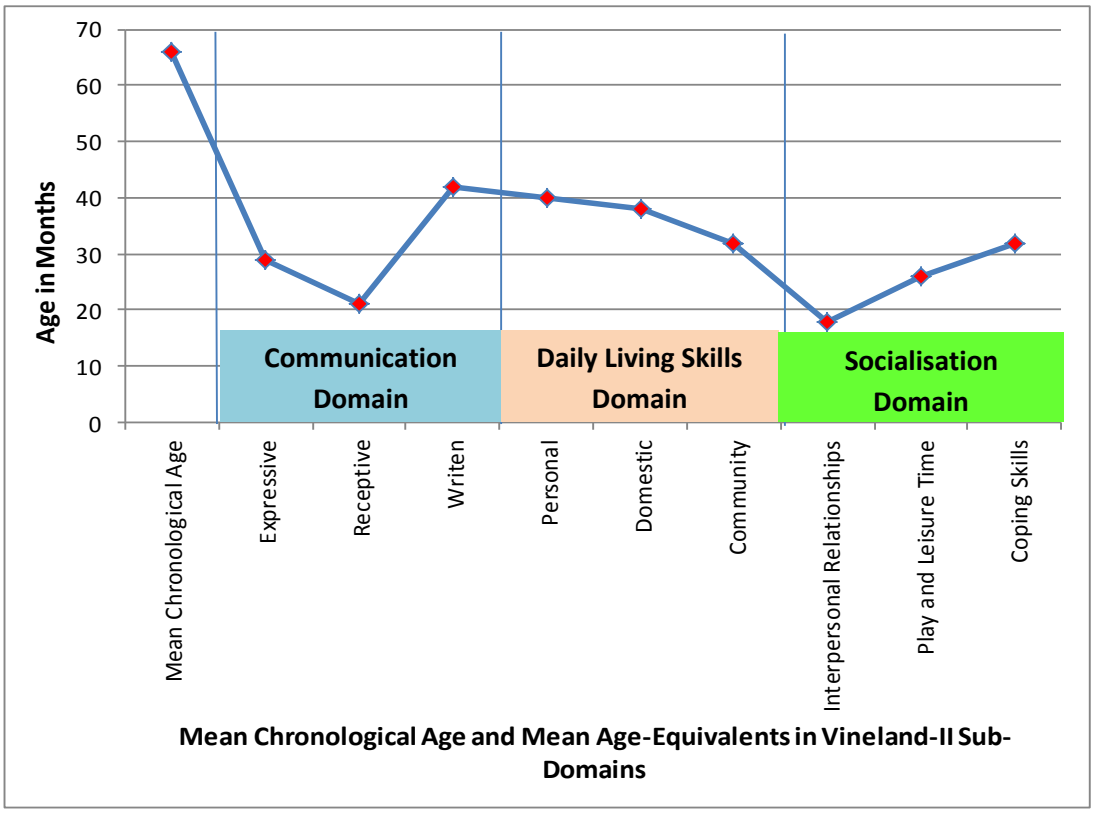

Figure 6.4. Profile of Vineland-II sub-domains of communication, daily living skills and socialisation domains based on mean age-equivalents compared to mean chronological age of the participants in months.

The Results from the Canadian Occupational Performance Measure in Children with Autistic Spectrum Disorder

A total of 140 activities were listed by parents as issues in the areas of occupational performance faced by their child with ASD. Table 6.4 presents the mean, standard deviations, and minimum and maximum values obtained from the COPM for the level of importance, performance, and satisfaction of all occupational performance issues reported by parents of children with ASD involved in this research, analysed as a group. All these 140 occupational performance issues listed by the parents were further grouped into seven identified categories. The analysis method of obtaining the categories was explained in detail in the previous chapter (Chapter V). Out of 44 children with ASD involved in this research, 31 (70.5%) had issues related to communication and 30 (68.2%) had issues related to personal care skills.

Table 6.4

Mean, standard deviations, and minimum and maximum values for the importance, performance and satisfaction scores on all 140 occupational performance issues listed in the COPM (N=44)

Level of	Mean	SD	Min.	Max.
Importance	9.18	1.380	5	10
Performance	3.35	1.877	1	8
Satisfaction	3.34	1.966	1	8

This was followed by issues related to socialisation (24 or 54.5%) and academic skills (22 or 50%). Furthermore, six (13.6%) children exhibited challenging behaviours and three (6.8%) children had issues with play. There were six further miscellaneous issues identified. Table 6.5 presents the mean, standard deviations, and minimum and maximum values obtained for each category of issues identified related to occupational performance issues in children with ASD.

The top four categories of issues experienced by the greatest numbers of children with ASD listed in the COPM are issues in:

1) Communication
2) Personal care activity
3) Socialisation
4) Activities related to academic skills at school and/or at home.

Appendix AC shows the detailed occupational performance problems for each of the top four identified categories.

Table 6.5

Mean, median, standard deviations, and minimum and maximum values for the importance, performance and satisfaction scores on each category of issues identified in the COPM

	Mean	SD	Min.	Max.
Categories				
Issues in communication (N*=31) (N=31)				
Importance	9.61	1.086	5	10
Performance	3.45	1.630	1	7
Satisfaction	3.71	1.987	1	7
Issues in personal care activities (N*=42) (N=30)				
Importance	8.93	1.568	5	10
Performance	3.55	2.074	1	8
Satisfaction	3.45	2.086	1	8
Issues in socialisation (N*=25) (N=24)				
Importance	9.28	1.208	6	10
Performance	2.92	1.605	1	6
Satisfaction	3.20	1.780	1	6
Issues in activities related to academic skills at school and/or at home (N*=27) (N=22)				
Importance	8.87	1.662	5	10
Performance	3.30	2.163	1	8
Satisfaction	3.11	2.025	1	7
Challenging behaviours (hyperactivity/severe tantrum/aggressive behaviours) (N*=6) (N=6)				
Importance	9.67	0.817	8	10
Performance	3.33	2.251	1	6
Satisfaction	3.33	1.966	1	6
Issues in play (N*=3) (N=3)				
Importance	8.33	0.577	8	9
Performance	3.00	1.000	2	4
Satisfaction	1.67	0.577	1	2
Other occupational performance issues (N*=6) (N=6)				
Importance	9.33	1.033	8	10
Performance	3.33	2.066	1	6
Satisfaction	2.67	2.251	1	6

[8]

[8] *Note.* N*= represent the number of issues, N= represent the number of children with ASD.

The Relationship between the Level of Occupational Performance in Children with Autistic Spectrum Disorder and their Parents' Satisfaction Level

To answer the third research question asked in phase two of the research, a statistical analysis was conducted to determine whether there is a relationship between the level of occupational performance in children with ASD and their parents' satisfaction level. The result on the Pearson product-moment correlation coefficient (*r*) (Pallant, 2011) shows a strong, positive correlation between the level of occupational performance and parents' satisfaction level at $r = .75$, n = 44, $p < .0005$, with high scores on the level of occupational performance in children with ASD associated with higher parents' satisfaction level.

The Relationship between the Adaptive Behaviour Skills and Identified Occupational Performance Issues, Parents' Satisfaction Levels and Parents' Priorities in Occupational Performance among their Children with Autistic Spectrum Disorder in Peninsular Malaysia

In answering the fourth research questions in phase two of the research, the Spearman Rank Order Correlation (Pallant, 2011) was chosen to test the relationship between the result obtained from both the Vineland-II and the COPM scores as explained in Chapter V. The Spearman Rank Order Correlation result shows a medium, statistically significant positive correlation between the adaptive behaviour skills and the COPM scores on the level of performance and satisfaction with high scores of the Vineland-II adaptive behaviour skills associated with higher level of performance and higher level of satisfaction. On the other hand, there is no statistically significant correlation between the adaptive behaviour skills and the COPM scores on the level of importance with weak correlation indicated.

In terms of the correlations between the standard scores of each domain of communication, daily living skills and socialisation and the total scores obtained on the

"level of performance", the "level of satisfaction" and the "level of importance", the Spearman Rank Order Correlation result shows a medium, statistically significant positive correlation between the communication, daily living skills and socialisation domains and the level of performance and satisfaction; there are high scores for the communication, daily living skills and socialisation domains associated with higher level of performance and higher level of satisfaction.

A statistically-significant positive correlation was also found between the socialisation domain and the level of importance with medium correlation indicated, with high scores for the socialisation domain associated with higher level of importance.

However, there is no statistically-significant correlation between the communication and daily living skills domains and the COPM scores on the level of importance with weak correlation indicated. Table 6.6 shows the detailed statistical result.

Table 6.6

Mean, median, standard deviations, and minimum and maximum values for the importance, performance and satisfaction

	Level of performance	Level of satisfaction	Level of importance
Adaptive behaviour skills	.457**	.434**	.297
Communication skills	.405**	.395**	.177
Daily living skills	.482**	.446**	.294
Socialisation skills	.435**	.362*	.327*

**Correlation is significant at the 0.01 level (2-tailed)
*Correlation is significant at the 0.05 level (2-tailed)

Section 2

The Results from Semi-Structured Interviews

From the analysis performed on the recorded interview transcripts and the COPM interview notes on the occupational performance issues faced by the children with ASD, eight sub-categories were identified in the personal care category, six sub-categories under the play and/or school category and four further sub-categories arose under the socialisation category. Figures 6.5, 6.6, and 6.7 illustrate the results and the number of responses received from parents for each category and sub-categories of occupational performance issues exhibited by the children with ASD. The concerns within each sub-category were identified and are presented together with some quoted excerpts from parents.

As can be seen from Figures 6.5, 6.6 and 6.7, the issues with communication appeared in all occupational performance categories; i.e., communication issues related to personal care activities, communication issues related to play and/or school activities and communication issues related to socialisation activities. Making and/or playing with friends was identified in two categories, i.e., making and/or playing with friends as associated with play and/or school activities and making and/or playing with friends as related to socialisation activities as well.

Occupational Performance Issues in Personal Care Activities

The question asked of the parents of children with ASD in the personal care activities was:

> What are the daily activities that you hope your child can do, need to do or expect that your child can do but he/she cannot, doesn't do or you aren't satisfied with how they do them? For example, the daily activities can be in term of dressing, bathing, feeding, hygiene.

Area	Category	Sub-categories	Number of response
Self-care	Occupational performance issues in personal care activities	Dressing	19 responses
		Toileting	15 responses
		Washing oneself	15 responses
		Eating	12 responses
		Caring for own safety	6 responses
		Communication	5 responses
		Not aware of other people's feelings	2 response
		Refusing changes in daily activities	1 response
Total responses received for occupational performance issues in personal care activities			**75 responses**

Figure 6.5. Illustration of the categories and sub-categories identified under the self-care area and the number of responses for each sub-category.

Area	Category	Sub-categories	Number of response
Productivity	Occupational performance issues in play and/or school activities	Performing work at school	14 responses
		Performing basic academic skills	15 responses
		Performing homework	8 responses
		Making and/or playing with friends	7 responses
		Communication	3 responses
		Performing gross and fine motor skill	3 responses
Total responses received for occupational performance issues in play and/or school activities			**50 responses**

Figure 6.6. Illustration of the categories and sub-categories identified under the productivity area and the number of responses for each sub-category.

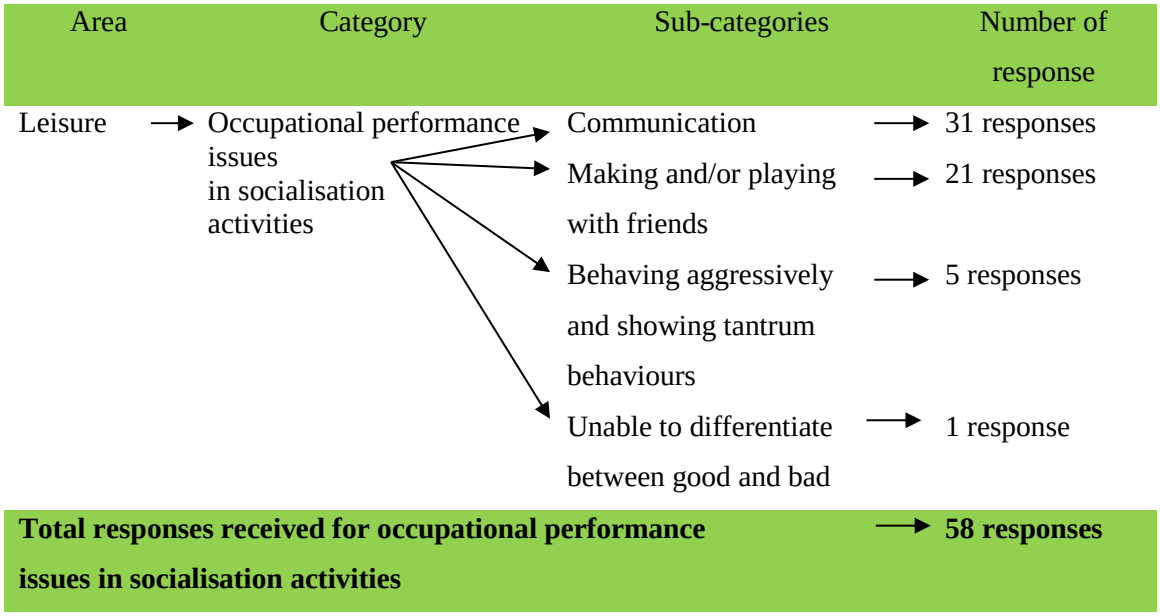

Figure 6.7. Illustration of the categories and sub-categories identified under the leisure area and the numbers of responses for each sub-category.

Initially, the sub-categories located in the interview data were those given as examples in the question asked to the parents: (a) dressing, (b) bathing, (c) feeding, and (d) hygiene.

A total of 75 responses were received from parents of children with ASD participating in this research and the number of responses and some quotes of issues in personal care activities expressed by parents are presented.

Difficulties in dressing. Difficulties in children dressing themselves received 19 responses, which makes it the highest number of issues expressed by parents under the category of personal care activities. The difficulties indicated in dressing vary. Some parents reported that their child with ASD performed the activity at a much lower stage than would be expected by his or her chronological age.

> I want him to be able to dress independently, [to] know how to manage his self-care activities (r142,M,B11y10m,ARN).

> … but we have to help him to put on his shirt. He can take his own shirt [from the cupboard], but he cannot put it on (r140,F,B3y4m,ARN).

Some parents indicated that their child still could not perform the dressing activity without help.

> What I can see is that he can put on his shirt but cannot do buttoning (r144,M,B6y9m,ARN).

And others expressed their hope that their child would learn these skills.

> I hope he can button his shirt and pants so that he can dress independently (r107,M,B4y,PPN).

However, some parents reported that, although their child could not perform the dressing activity fully alone, the child was able to help in the dressing process, as indicated by one parent:

> She can already put on her pants independently [pause] but she still cannot put on her shirt yet; once I put the shirt over her head, then she will raise her hands up (r137,M,G6y4m,ARN).

One parent specifically identified that her child does not like to be dressed up in new clothes, causing stress for the mother, as she explained:

> I also hope that her behaviour can be changed because she only likes old clothes and does not likes new clothes; she will try to take it off and will start to cry (r129,M,G4y4m,PPN).

Difficulties in toileting. Difficulties in toileting received 15 responses. Some parents reported that their child with ASD was incontinent, despite attempts at toilet training. This was very important to the parents of children who were not independent in toileting and caused them concern for the future.

> He is also still on diapers and he knows how to take it off himself [when the diaper is dirty]. So, I am also really hoping that he can do toileting independently (r123,F,B5y4m,PPN).

> ... I worried about her toileting [pause] she still cannot do toileting independently; she is still wearing Pampers [brand of diapers] (r137,M,G6y4m,ARN).

> … to do toileting independently [pause] I have tried [toilet training], but he still does not want to; he will still look for his Pampers [brand of diapers]. Actually he does not like to wear Pampers anymore; he seems uncomfortable [using diapers] (r139,M,B5y1m,ARN).

As can be seen from the code's excerpts above, the children were aged above 5 years and still incontinent. This can be difficult for their parents to manage, financially challenging, and hampers the child's school attendance. Inability to go to toilet at night was reported by one parent, who stated:

> It is also important that he can go to toilet at night (r108,F,B4y10m,PPN).

Another parent reported that her son's difficulties in toileting confused her, as he will not let her know that he wants to go to toilet earlier:

> I feel confused with my son's behaviour, because he will only show me that he has already urinated or has done his big business after he has done it [but not in the toilet], he will not tell me before that, but only after he has done it ,only then will he let me know, but it will be already too late (r115,M,B4y2m,PPN).

Difficulty in toileting and inability to be toilet trained also challenge parents' ability to cope as expressed by one parent:

> … [The problem is with] his toileting [pause] maybe because he is used to wearing Pampers [diapers]. So, in his mind, I think it is already set in his mind [to wear diapers]. I can't change it [not to wear diapers], I have already put the water hose in the bathroom [for him to use it to wash himself after toileting] and asked him to sit on the stool [potty], his teacher teaches him like that, but he still feels afraid. Until now he still refuses to use the toilet. Sometimes I get really stressed, I can't scold him, I can't do anything. If I scold him he will get scared of me; he might refuse it [to use the toilet] at all (r144,M,B6y9m,ARN).

The mother is probably justified in believing the child will resent being scolded and refuse to use the toilet. She is trying to be a good, caring mother but her son is now 6 and this is frustrating and troubling.

Difficulties in washing oneself. Fifteen responses were received regarding difficulties in washing oneself. The issues surrounding washing oneself ranges from the inability to clean certain body parts to taking a bath independently as demonstrated by quotes from some parents in the excerpts below. Some of the children were already 7 to 9

years old, but are still unable to manage their basic cleanliness needs such as washing hands and mouth and brushing teeth without assistance.

> I also hope he knows how to clean himself, such as, washing his dirty hand, cleaning his mouth after eating (r102,M,B7y,PPN).
>
> In terms of self-hygiene, such as, washing his hands, cleaning his face, he still needs help to do it properly (r103,M,B4y10m,PPN).
>
> He also has poor self-hygiene, he does not care to wash his hands when they are dirty or when his face is dirty or when he has a runny nose (r104,F,B3y3m,PPN).
>
> I want my daughter to be able to brush her teeth independently. She still cannot do that. I have to help her to brush her teeth every day. Sometimes, she refuses to brush her teeth and I have to force her [to brush her teeth] (r113,M,G9y4m,PPN).
>
> … [The problem is with] taking a bath. He cannot [take a bath by himself], he only plays with the water (r135,M,B4y11m,ARN).

Some parents reported that their child with ASD can take a bath independently; however, they are not satisfied with how well their child does it. Parents reported that their child could not clean themselves properly, such as using the soap to clean during bathing, which makes them feel dissatisfied with it:

> I have to bath him. Sometimes, he can also take a bath independently, but he does not soap himself (r142,M,B11y10m,ARN).
>
> He can take a bath, but he cannot clean himself because he does not use soap to clean himself. We still have to teach him to do that (r143,F,B7y11m,ARN).

The inability to clean oneself has also been associated with other health problems such as tooth decay as described by one parent:

> … firstly is brushing [his] teeth [pause] he still cannot do it independently. Maybe he does not like the texture of the toothbrush, so I bought him the soft plastic baby brush, but he still cannot do it himself and does not like it when I try to put it into his mouth. To me, brushing teeth is the most important because his teeth have started to decay [laugh], yes, so it is very important indeed (r134,M,B3y2m,ARN).

The mothers generally wanted their children to know how to care for their own hygiene and to keep themselves neat and tidy, especially if they were girls. This issue was

brought up by one mother who relates the issues of gender with the ability to clean oneself. She explained:

> I hope she knows how to take care of her self-hygiene, knows that she need to wash her hands when they are dirty, wash and dry her face when it is dirty, and blowing her nose, cleaning her face. To me it is important for her to be able to care for her self-hygiene independently, because she is a girl (r128,M,G6y4m,PPN).

Difficulties in eating. Difficulties in eating were reported by 12 respondents. One parent indicated:

> In terms of self-care activities, my only hope is that my son can eat independently, does not need any help. If he can do that, I can perform some other tasks; I do not need to wait with him and feed him (r114,M,B4y,PPN).

Managing the family daily routines and other house chores can be very busy and difficult tasks. Therefore, children were expected to be independent in caring for themselves in some basic occupational performance activities, such as eating independently which can reduce the parent's requirement to attend to their child with ASD needs and, in turn, give them extra time to attend to other house chores. However, some parents claimed that their child could eat independently, but it was messy when they ate on their own. This can end up with parents feeding their child in order to prevent them from having to clean up their child's mess after meal time, which in turn means that the child might not be able to learn to eat independently after all.

> I hope he can eat properly and not messy. [He is] not eating properly. [If he can eat without any mess] it will make our job easier; we won't have to clean it up (r140,F,B3y4m,ARN).

Picky or selective eaters were also present among children with ASD, as reported by their parents in this research. A few parents reported that their child refused to eat certain type of food and/or refused to hold their food:

> My daughter is too picky in her food selection. She will select what she wants to eat. She loves to eat cakes but will refuse to eat rice and noodles. However, she has no problem with drinks; she loves to drink all kind of drinks (r121,M,G6y4m,PPN).

> … however he can hold and eat finger foods, but he will refuse to hold and eat certain types of foods (r105,M,B3y5m,PPN).
>
> In term of eating, he is quite picky. He will refuse to eat certain food; he is so selective about food (r118,M,B4y10m,PPN).

The presence of picky or selective eating among children with ASD restricted family activities; for example, it probably can inhibit families from eating out at the restaurants or at the friend/family's house. One parent indicated that his son's difficulty in eating was related to the problem in motor control that makes it difficult for his son to coordinate hand-mouth movement:

> He still cannot feed properly; his hand movement is uncoordinated, and he cannot bring food to [his] mouth properly. [He] always spills [his] drinks and foods (r104,F,B3y3m,PPN).

Other than problems in motor control, difficulties in eating were also reported as due to the inability of the child to sit still until they had finished eating. One parent reported:

> I hope that my son can sit still during eating; it is difficult to feed him because he cannot sit still and always wants to leave the table (r126,M,B4y7m,PPN).

During the iterative analysis process, further sub-categories were identified from the data. These included the following sub-categories, and will be elucidated below. These were not necessarily high in number but were of high importance to those parents who discussed them.

1. Caring for own safety
2. Communication
3. Not aware of other people's feelings
4. Refusing changes in daily activities.

Difficulties in caring for own safety. Six responses were received regarding parents' concerns about the abilities of their child to care for his or her own safety, including safety at home and outside the home. Some parents claimed that their child with ASD could not recognise danger and did things that could be physically harmful to themselves:

> I hope that my son will know how to care for his own safety, not to do something dangerous, such as jumping from high places or simply crossing the road without looking to his left and right (r101,F,B5y2m,PPN).
>
> He does not care whether there is an uncovered surface drain ahead that he might fall in. He simply runs through it [laugh] (r139,M,B5y1m,ARN).

Some parents brought up the issues that their child's ability to care for his or her own safety was related to the inability of the child to follow instructions, especially when they are outside the house, which makes community participation an issue:

> … [He has] safety issues [pause]; he is okay around my house. The only problem is when we go outside; we have to always remind him. Sometimes he can follow my instruction, but most of the time he will simply run; he would not bother to listen (r141,M,B3y11m,ARN).
>
> I want him to be able to follow our instructions [pause], not to simply run here and there. This is the only problem now. When we go outside, go shopping, we really have to take care of him (r135,M,B4y11m,ARN).

The inability to recognise danger among children with ASD might result in parents restricting their children from socialising outside, as they needed to be observed for their safety most of the time. This intense attention needed to care for the child's safety might put parents under considerable stress that might also result in parents preferring to stay home with their child. This can also lead to the child, as well as the parents, becoming socially isolated.

Difficulties in communication. Inability or restrictions with communication were reported as associated with problems in personal care activities. From the excerpts below, it seemed that some parents were willing to do some personal care activities,

especially related to toileting for their child, as long as their child knew how to tell them their request:

> It will be also good if he can talk, so that he can let me know that he wants to go to the toilet; it will make my job much easier (r108,F,B3y8m,PPN).
>
> My son still cannot talk. I hope that my son can talk, so that he can tell me what he wants (r101,F,B5y2m,PPN).
>
> I really hope that he will be able to let me know that he wants to go to the toilet (r115,M,B4y2m,PPN).

One parent clearly indicated that her only priority was for her son to be able to talk since he could already perform most of the personal care activities independently. She explained:

> I want him to be able to talk, that is all [pause] yes, that is right [pause] because he can already perform most of the self-care activities independently, so, I really hope that he can talk now, hope he can tell me what he wants and what he does not like. … Yes, [pause] very important for him to be able to talk, because I feel pity for him [pause] sometimes he points to something that he wants but I cannot understand him, so, I feel pity for him [because he cannot talk] (r136,M,B4y1m,ARN).

Not aware of other people's feelings. Parents not only observed problems in performing daily activities, but also in the emotional aspect of their child with ASD. For example, one parent claimed that his child was not aware of other people's feelings:

> My son seems like he is not aware of other people feelings; he acted as if nothing happened even when he saw his little sibling [brother/sister] crying (r111,F,B3y5m,PPN).

One parent was concerned about this lack of awareness and the implications in the long term.

> I also hope that he knows the limits between males and females, so that he will change his clothes in the room and not to simply change his clothes anywhere (r122,M,B8y5m,PPN).

Clearly, the mother in this excerpt is concerned about her son's inability to be more sensitive regarding appropriateness, considering her son is already 8 years old.

Whereas, the emphasis on sameness in daily routine was an issue for one child as his mother explained:

> Another thing is, he will refuse to accept changes to his usual daily activities; everything must be the same every day, he will throw a tantrum if we change places (r118,M,B4y10m,PPN).

Emphasis on sameness among children with ASD can present great challenges for their parents and family, especially if the child also shows behavioural problems such as temper tantrums. This can affect family activities, as well as limiting the choices of family activities, in order to accommodate the child's condition.

Occupational Performance Difficulty in Play and/or School Activities

The question asked of the parents of children with ASD in the play and/or school activities were:

> What are the play and/or school activities that you hope your child can do, needs to do or expect that your child can do but he/she cannot, doesn't do or you aren't satisfied with how well they do them? For example, the play and/or school activities can be in terms of play skills, school skills, doing his/her homework.

Other than the sub-categories given as examples in the question asked of the parents that were identified - performing work at school, performing homework and making and/or playing with friends, there were a few further sub-categories identified from the data including:

1. Performing basic academic skills
2. Communication
3. Performing gross and fine motor skills.

Difficulties in play and/or school activities received a total of 50 replies from parents of children with ASD participating in this research. A total of six specific problems associated with play and/or school activities were identified, and the number of

responses and some quoted excerpts of issues expressed by some parents are presented below.

Difficulties in performing academic work at school. Difficulty in performing academic work at school was reported as a difficulty in play and/or school activities (14 responses). Most of the parents reported that their child with ASD could not sustain his or her concentration span at school, always wanted to leave the assigned chairs, and easily got distracted. Their teacher also complained to parent regarding this:

> He has low concentration span at school; he always leaves his chair and his work, giving up easily. I hope my son can have a better concentration span at school and can sit quietly to finish his work. His teacher is always complaining about this to me (r103,M,B4y10m,PPN).
>
> He also has a poor concentration span and can easily get distracted. It is really difficult to get him to sit and pay attention (r123,F,B5y4m,PPN).
>
> She also has a poor concentration span; she can only concentrate for a short period of time before leaving the activity to do something else (r129,M,G4y4m,PPN).

The inability to follow instructions and ignoring of instructions was also indicated as a problem in performing work at school by some parents:

> She refuses to do her work at school; she just ignores teachers' instructions even when her teachers force her to do [her task] (r113,M,G9y4m,PPN).
>
> I hope that my son can follow instructions (r123,F,B5y4m,PPN).

Some parents concluded that the difficulty in performing work at school exhibited by their child was associated with other behavioural aspect such as stubbornness and laziness, as described by two parents:

> She refuses to do her work at school; she just ignores teachers' instructions even when her teachers force her to do. She is quite stubborn. Sometimes I have to hold her hand to write and sit together with her (r113,M,G9y4m,PPN).
>
> He is not interested in reading and writing at school. He is lazy and not interested to do that (r119,F,B8y11m,PPN).

Difficulties with basic academic skills. Twelve responses were received regarding issues with basic academic skills in children with ASD. Among the concerns expressed by parents regarding this issue was the inability of their child to read, write, count, and recognise basic shapes. The problems was not only reported in pre-school age children (which is age appropriate), but in older children also.

> He is attending kindergarten three times a week. I hope he can perform his work at school, such as writing, spelling, and counting from 1 to 10 (r108,F,B3y8m,PPN).

> I just hope that my son can read, so that it will be easier for him at school (r125,M,B8y7m,PPN).

> My target for him in that aspect now is [pause] he can scribble only [pause] mostly he will scribble only, so, I tried to teach him about basic shapes such as drawing a circle, a rectangle; so far I can see that he can draw a circle shape when I ask him to do so, instead of just scribbling on the paper; however, it is still not a proper shape of a circle or rectangle, no, not yet (r134,M,B3y2m,ARN).

One parent related the importance of learning to write with building her child's ability to communicate with her by writing it down in order for her son to tell her what he wants. It can be said that some parents can accept the possibility that their child with ASD might not be able to communicate verbally; hence, they think of other possible ways for their child to communicate with them.

> The important thing to me is for him to be able to write [pause]. To me writing is important for him. He cannot talk, so, if he can write it down he can let me know what he wants (r142,M,B11y10m,ARN).

Difficulties in performing homework. Eight parents reported their child had difficulties in performing homework. Some of the issues regarding the difficulties in performing homework were associated with forgetfulness and laziness in children with ASD. Some parents specified that their child exhibited laziness in doing their homework, especially related to writing tasks.

> I hope he will do his homework, my son always forgets about his homework, sometimes he does not seem aware that he has homework to do (r102,M,B7y,PPN).

> She is quite lazy to write and also will get bored quite easily if I ask her to do her homework (r121,M,G6y4m,PPN).
>
> My son has problems in school skills such as writing and doing his homework; the only thing is that he is a bit lazy in completing his homework especially those tasks involving writing activities (r106,M,B5y9m,PPN).

The issue of hyperactivity was also associated with difficulty in performing homework among children with ASD. Some parents reported that their child could not sit still and some parent believed that the presence of hyperactivity in their child was the factor that inhibited the learning process:

> He cannot do his homework. He is too active and plays a lot; he cannot sit still and keep moving here and there, so it is difficult to teach him at home (r111,F,B3y5m,PPN).
>
> … his name [pause] he can write it if we spell it out for him. He can also write his sister's name [pause]; he is very hyper [pause], and that is the thing that hinders his learning (r135,M,B4y11m,ARN).

One parent believed that her child with ASD's difficulty in performing homework was related to the child's low self-confidence. The child always asked for help and could not decide on what should be done regarding her homework:

> She also has low self-confidence, always feeling unsure about something that she has to do and always asking for our help with her homework (r132,M,G10y,PPN).

Difficulties in making and/or playing with friends. Seven responses were received related to the difficulties in making and/or playing with friends. Some parents reported that their child with ASD did not like to play with other children and preferred to play alone:

> I hope that my son will be able to play with other children. My son does not want to play with other children at all or be with other children; he likes to play on his own (r101,F,B5y2m,PPN).

Some parents observed the presence of narrow choices in play activities, repetitive play behaviours and lack of purposeful play skills among their children with

ASD. Some parents commented that their child did not know how to play purposefully and some play with inappropriate household items.

> He really likes to play with a ball and coat hangers [pause]. To me it is not proper to play with coat hangers, it is not good [pause]. He will do like this, like this [to the coat hangers] [showing the actions of waving the coat hangers with her hand] (r142,M,B11y10m,ARN).

> … playing [pause] he [pause] instead of riding the bicycle, he will only play with the wheels ... turning the wheels [laugh]. So, he still does not know how to play with purpose, no, no purposeful play yet, not yet [laugh]; for example, instead of just playing with the toy cars' wheels, I hope he knows how to push the toy car like this [showing the action of pushing toy car on the table] [laugh]. He does not know how to play purposefully yet. Not yet (r134,M,B3y2m,ARN).

Inappropriate play behaviour with peers was a concern as expressed by one parent regarding his child with ASD:

> The only thing is that when playing with friends, with girl friends is a problem. He will disturb them. He will disturb them by pulling their hair, pulling their clothes. But he is not doing it to all his girl friends. He is not doing it to some of his girl friends. Not to all girls. He just does it to some of the girls that he does not like. He will pull their hair, pull their clothes, so, it makes them cry [pause] [He is playing] quite rough [pause] with girls. Rough. His teacher also complains about this (r143,F,B7y11m,ARN).

One parent commented that playing together with other children might enable her son with ASD to learn some skills from his peers, as she suggested:

> … [I want him to] play with other kids [long pause] because if he can play with other kids, maybe he can learn something from the other kids too [laugh] (r134,M,B3y2m,ARN).

However, one parent claimed that her child with ASD's difficulty in playing was that other children, even her own little sibling, did not want to play with the child:

> I think she can play together, but [pause], but, from what I can see, it looks like her little sibling just does not want to play with her [pause]. She wants to play with other kids; she did try to play together, but other kids do not like to play with her (r137,M,G6y4m,ARN).

The mother in this excerpt clearly observed that her child was rejected by peers and siblings, which in turn might limit the child's opportunity to socialise with others and narrow her chances to learn from others (Bellmore, 2011).

Difficulties in communication. Communication issues appeared in the majority of the children with ASD in this research. From the total of 44 children with ASD – 31 children were reported as having difficulty in communication. All 31 children were perceived by parents as having communication difficulties in socialisation activities, five children as having communication difficulties in the personal care activities and three children were perceived by their parents as having communication difficulties in the play/school activities (see Figures 7.5, 7.6 and 7.7). This means communication difficulties exist in all aspect of daily living activities. For example, two parents related their child's inability to talk to not having friends and also to being rejected by other children:

> He still cannot talk. I really hope he can talk, so that he can make some friends (r104,F,B3y3m,PPN).
>
> Other children also do not want to play with him because he cannot talk to them (r101,F,B5y2m,PPN).

Difficulties in fine and gross motor skills. Difficulty in fine motor skills was a concern for some parents:

> I think she still cannot hold a pencil properly to write (r129,M,G4y4m,PPN).
>
> … maybe for him to be able to use pencil for drawing or colouring…yes...[I want him to be able to] hold the pencils correctly (r138,M,B3y7m,ARN).

One child with ASD exhibited difficulty in gross motor skills. Although the child could walk, he could not run and jump properly:

> It will be good if his gross motor movement can be improved, such as running and jumping. He still cannot do them properly. However, he has no problem in walking (r127,F,B5y10m,PPN).

Occupational Performance Difficulties in Socialisation Activities

The question asked of the parents of children with ASD regarding socialisation was:

> What are the socialisation activities that you hope your child can do, needs to do or you expect that your child can do but he/she cannot do, doesn't do or you aren't satisfied with how well they do them? For example, the socialisation activities can be in term of visiting friends, making or answering phone calls, attending parties.

Difficulties in socialisation activities received a total of 58 responses from parents of children with ASD participating in this research. Four sub-categories were identified under socialisation activities consisting of:

1. Communication
2. Making and/or playing with friends
3. Behaving aggressively and showing tantrum behaviour
4. Inability to differentiate between good and bad.

The number of responses and some quoted excerpts of issues described by some parents are presented below.

Difficulties in communication. Although difficulty in communication was identified in all three occupational performance categories of personal care, play and/or school and socialisation activities, the highest number of responses received regarding difficulty in communication was in the category of socialisation activities. Difficulty in communication identified under the category of socialisation activities received 31 replies, which gives this sub-category the highest number of problems indicated under difficulty in socialisation (refer to Figure 7.7). The difficulty in communication was reported by some parents as an inability of their child to talk, or understand what is being said to the child. As well, the parent cannot understand what the child is saying to them:

> It would be really good if she could already talk. She still cannot talk, and cannot understand what we say to her (r121,M,G6y4m,PPN).

> She still cannot talk and sometimes she also cannot understand what I say. And when she says something, I cannot understand her either (r113,M,G9y4m,PPN).

Some parents realised that the difficulty in communication resulted in their child exhibiting challenging behaviours, such as crying, tantrums and violent behaviours. Some children with ASD push their parents to some location in order to indicate their intentions, as described here:

> He can only repeat what people say [to him]; he is still learning to talk. He can say 'papa' and 'mama'. I hope he can communicate better and can tell us what he wants. If he can talk, maybe this can reduce his violent behaviour, such as throwing things (r103,M,B4y10m,PPN).

> I hope he can talk so that he can tell me what he wants. It is easier for me if he can tell me what he wants. Sometimes he tries to tell me but I cannot understand it. He will randomly reach out his hand to something but when I give that thing to him, he throws it away and will start to cry and get angry (r107,M,B4y,PPN).

> My son still cannot talk. Sometimes, he will push me to some place and, when I cannot understand his intention, he will start crying and making noise (r112,F,B4y5m,PPN).

> In term of his socialization, I really hope that he can talk. It will be easier if he can talk so that he can tell me what he wants; maybe that will reduce his tantrum behaviours (r116,M,B7y11m,PPN).

One parent specifically wants his child to be able to communicate in order to let him know if the child is in pain or feeling uncomfortable rather than crying or showing tantrum behaviour as a way to tell him:

> To me, I hope he can let us know his feelings, such as letting us know that he is in pain or feeling uncomfortable. He will simply cry or throw a tantrum … yes, so that we know how to manage his problems [if he can let us know] (r139,F,B5y1m,ARN).

The inability to communicate was associated with the inability to make and play with friends, as some parents stated:

> I really hope that he can talk so that he can tell me what he wants. If he can talk, he might have some friends to play with (r109,F,B3y9m,PPN).

> To me, the most important thing is for him to be able to talk. Once he can already talk, he can play with his friends, he can go to school and also he can tell me what he wants (r117,M,B4y,PPN).

One parent mentioned that, not only her child, but his friends at school could not talk either, as he attended a special education facility.

> He just playing with them [other children] but does not talk. However, all the children there [in the special educational school] also cannot talk [laugh]. He does talk to his sister but I also do not understand what he says [laugh] (r135,M,B4y11m,ARN).

Difficulties in making and/or playing with friends. Twenty-one responses were received regarding the difficulty in making and/or playing with friends among children with ASD. Some of the parents emphasised a desire for their children with ASD to have friends and to be able to play with their friends:

> It is also important to get more friends and play with friends. He does not want to play with other children and also does not want to play with his own cousins (r107,M,B4y,PPN).

> In term of playing, I hope he can mix with other children and play together with them, so that he can have more friends (r105,M,B3y5m,PPN).

Having friends was also linked with having more activities to do both at home and at school for one child rather than watching television:

> I hope my son can mix and play better with his friends. This is important so that he can have more friends at school and at home. If he has more friends, he will have more activities to do other than watching television at home (r106,M,B5y9m,PPN).

Another parent claimed that her child's tantrum behaviours resulted in the child being unable to make friends because of his behaviour:

> He has problem with friendship because he is easily getting angry. If he doesn't get what he wants, he might get angry and throw a tantrum in front of his friends. That behaviour makes it difficult for him to get friends (r110,M,B4y5m,PPN).

Some parents reported that their child was having problems sharing toys and belongings with friends during play:

> He also has a problem in sharing his things. He refuses to share his toys at all. It is depending on his mood also. Sometimes he is willing to share his things; however, it is so seldom (r115,M,B4y2m,PPN).

> It is also important that he can talk and also can share his things with others, such as sharing his toys with others (r127,F,B5y10m,PPN).

While most of the parents in this research emphasised their child's need to play with peers, by contrast one parent said she does not allow her child to play with other children because he is too hyperactive and could not play nicely with his peers, as she explained:

> He likes to play with other children, but I do not allow him to. He is too hyperactive. He is lacking in understanding how to play nicely with them (r135,M,B4y11m,ARN).

Difficulty in making and/or playing with friends in one child was described by his parent as an inability to play with children/peers. The child was not having problems in playing with adults:

> He has no problem in socialising with adults, but he has problems with socialising with children [peers]…He is able to go and play with adults…[pause] He can communicate in his own way…He doesn't want to [play with other children] [pause;] he likes to keep to himself…so, that is part of his barrier (r141,M,B3y11m,ARN).

Behaving aggressively and showing tantrum behaviour. Five responses were identified in terms of behavioural issues under socialisation as some parents mentioned that their child behaved aggressively and showed tantrum behaviours, such as throwing and banging things:

> He shows really bad tantrum behaviour…yes…[He can throw a tantrum for] the whole day…yes...it was really bad. I hope his behaviour will change and he does not throwing such bad tantrums anymore… yes, it is important (r142,M,B11y10m,ARN).

> I really hope that his aggressive behaviours can be reduced. He likes throwing things and banging things (r101,F,B5y2m,PPN).

Inability to differentiate between good and bad. Another parent mentioned that she hoped her child could achieve full independence in managing his daily activities and would be able to differentiate between good and bad as he is already 10 years old now. The parent explained:

> I really hope that he can be as independent as he can be. He is already grown up. It is important that he can manage himself independently now. So far, he can eat and bath independently. But I really hope he knows how to differentiate things, such as between good and bad things (r120,M,B10y6m,PPN).

Summary

This chapter has presented the results of phase two of this research – parents' perspectives on the adaptive behaviour skills and occupational performance in children with ASD in Peninsular Malaysia, and their priorities in occupational performance for their child with ASD. Two tools were administered to collect data: (a) The Vineland-II (The Parent/Caregiver Rating Form) (Sparrow et al., 2005a), and (b) the COPM (Law et al., 2000, 2008). Results were analysed for 44 children with ASD obtained from 45 parents. The majority of the children with ASD in this research were boys aged five years and below (pre-school aged).

In terms of the domains of communication, daily living skills and socialisation, if measured based on the standard scores, the communication and socialisation domains in children with ASD in Peninsular Malaysia were most impaired with the level of adaptive behaviour skills reported at 2-standard deviation below the mean standardisation sample in the Vineland-II. The daily living skills domain was at 1-standard deviation below the mean standardisation sample in the Vineland-II. Whereas, within the sub-domains compared to the mean standardisation sample in the Vineland-II, (a) the written, personal, domestic, community and coping skills sub-domains were at 1-standard deviation below the mean, and (b) the receptive, expressive, interpersonal relationship and play and leisure

time skills sub-domains were reported at 2-standard deviation below the mean standardisation sample.

The mean age of the children with ASD involved in this research was 66 months. However, if measured based on the age-equivalent scores, the socialisation domain was most impaired among the children with ASD in this study with total mean age equivalent reported at only 25 months. Under each domain, the categories of expressive, community and interpersonal relationship were the sub-domains indicated as the most impaired with age equivalents indicated at 21, 32 and 18 months, respectively.

Parents listed a total of 140 occupational performance problems during the COPM semi-structured interviews, with problems in activities related to communication and caring for oneself reported as the problems experienced by the greatest numbers of children with ASD. Positive correlation was shown between performance and satisfaction among parents in this research regarding their child's ability. Seven categories of problems were identified when all the listed problems were grouped into categories.

Parents' accounts during the interviews were also presented in this chapter; content analysis conducted showed that parents brought up issues regarding the inability to communicate among their child with ASD in all three categories of occupational performance – personal care, play and/or school, and socialisation activities, whereas play and/or making friends appeared in two categories - play and/or school activities and also in socialisation activities as well.

CHAPTER VII

DISCUSSION AND CONCLUSION

The purpose of this chapter is to draw together the findings from both phases of the research, to reflect on the results in the context of the literature, and to recommend directions for future research and practice in the area of occupational therapy for people with ASD. Phase one of the research involved surveying occupational therapists who worked with children with ASD in Victoria (Australia) and Malaysia.

The aim of this phase was to compare practices between both countries. Therapists were asked questions regarding the frames of reference (FOR) and models of practice (MOP) they used to guide their practice, what aspects of adaptive behaviours were assessed, the assessments and/or outcome measures they used and interventions adopted.

The second phase of the research involved parents of children with ASD aged from three to 12 years in Peninsular Malaysia. Parents' opinions regarding their child's adaptive behaviour skills and occupational performance in everyday abilities were ascertained using a standardised assessment tool - the Vineland-II (Parent/Caregiver Rating Form) (Sparrow et al., 2005b) and an outcome measure - the COPM (Law et al., 2000, 2008), to identify the priorities for occupational therapy intervention for children with ASD in Peninsular Malaysia. This chapter discusses the findings of the study, its limitations and recommendations, as well as suggestions for further studies.

Characteristics of Children with Autistic Spectrum Disorder in the Context of the Services Provided by Occupational Therapy Practitioners

In this sample, the parents reported on children primarily under 5 years of age and there were more males than females. This is consistent with the reported characteristics of the population worldwide (Baird et al., 2006; CDC, 2014; Fombonne, 2003). This is the

age when ASD is commonly detected (CDC, 2014). Generally, parents become aware that their child has difficulties when they observe the difference between their child and typically developing siblings or peers (Twoy et al., 2007; Vaness et al., 2012). Developmental delay among children with ASD can usually be detected by the age of three (Gillberg et al., 1990; Howlin & Moorf, 1997; Ray-Subramanian et al., 2011), and early intervention is recommended for children with ASD to ensure better prognosis and to improve current and future occupational performance among those children (Baird et al., 2001; Dawson et al., 2010; Szatmari et al., 2003).

The age group seen most frequently both in Victoria and Malaysia involved children under five years old, consistent with our sample. The majority of the Malaysian and Victorian occupational therapy participants indicated that the most common age of children with ASD seen in their services was pre-school age - 69.2% in Malaysia and 69.7% in Victoria, respectively. However, there are contextual differences between the child health care systems in each country – Malaysian occupational therapy participants indicated that they seldom interviewed teachers or education staff. Whereas, the Victorian occupational therapy participants indicated that they often involved education staff. In Victoria, children start kindergarten at the age of three, and when they turn four, they can access kindergarten for 15 hours per week (State Government Victoria Australia, 2013). Another difference is that in Victoria, the policy is to include children with disability in mainstream schools, with the age for starting school being the year in which the child is five on or before the 1st of April. In Malaysia, however, it is not compulsory for children under five years to attend kindergarten. In addition, it was legislated in 2003 that the compulsory age for entering formal education in Malaysia, would be six (Kementerian Pendidikan Malaysia, 2002). This means that children in Malaysia enter formal kindergarten at the age of six and start their primary school years at the age of seven. This may be the reason why occupational therapy participants in Malaysia reported less contact with teachers/education staff in their practices. In Malaysia, children of less than six or

seven years of age do not have access to formal education, yet they comprise the principal group that occupational therapists see. In addition, the Malaysian Government has enacted the Persons with Disabilities Act (PWD), which means all children must be equally accepted into the school system (Malaysian Psychiatric Association, 2010). Nevertheless, some teachers still feel apprehensive about receiving children with ASD into their classrooms due to a lack of understanding of (a) the characteristics of children with ASD, and (b) the importance of inclusive education for these children (Mohamad Razali, Toran, Kamaralzaman, Mohamad Salleh, & Mohd Yasin, 2013).

In a study conducted in Queensland, Australia by Ashburner et al. (2010, unpublished report), 60.0% of the occupational therapy participants sampled reported that working in the ASD area was more challenging than other areas of occupational therapy practice - with 55.0% of them reporting that the complexity of the disorder was the most challenging aspect of working with people with ASD. This is consistent with the results of our research, where both Malaysian and Victorian participants reported that they find it more challenging to provide services to children with ASD, mainly due to the complexity of the disorders. It is unclear why this issue remains; however, it could be due to the limited research available on the effective interventions for this population that can be used by occupational therapists to guide their practices.

Family-Centred Practice

Including family members, such as parents, in the interventions of children with ASD has been found to benefit both the children with ASD and also their families (Burrell & Borrego, 2012; Miller-Kuhaneck & Britner, 2010). In this current study, the occupational therapist participants in both countries stated that they always worked with parents of children with ASD in their services. This is consistent with the findings from Ashburner et al. (2010, unpublished report), that collaboration with parents and/or caregivers was strongly recommended by the occupational therapy participants in their

study. Although the occupational therapy participants in this research, including those in Malaysia, strongly indicated that they were involving parents in their services for children with ASD, it is important to compare this with the Malaysian parents' concerns about the adaptive skills and occupational performance issues for their children in phase two of this research. Even though the Malaysian therapists stated that they were collaborating closely with parents in their services, issues regarding the child's daily activities such as personal care activities and communication skills were nevertheless not the focus of the interventions. This can be corroborated by the results which show that the occupational therapists were focusing more on providing sensory-based intervention rather than addressing the occupational performance difficulties faced by the children.

Input from families should be maximised by occupational therapy practitioners to ensure that the services and supports that are really needed by the families as the main caregivers of children with ASD are delivered (Amar, 2008; Bowker et al., 2011; Dunst et al., 2010; Hanna & Rodger, 2002; Miller-Kuhaneck & Britner, 2010). However, these results need to be interpreted with caution, because they were not from matched pairs of occupational therapist and parent/carer, and the parents interviewed were only from Malaysia, not Australia. None the less, it does point to some inconsistencies between occupational therapists' views of themselves as family friendly and considerate of the priorities of the families.

The results also point to important areas of occupational performance that are not being addressed. Having explored what the occupational therapy practitioners are doing, their priorities for intervention, training and their background models to guide their practice, it was evident that both Malaysian and Australian occupational therapy practitioners use similar approaches to children with ASD and their families, despite differences in cultural, ethnic, educational and healthcare systems. This has demonstrated an important need for focus on the cultural validity of interventions provided; occupational

therapists in Malaysia should develop their own practices in addressing the unique challenges faced by children with ASD and their family in Malaysia.

The guiding models and frames of reference tend to be towards sensory-based approaches. The emphasis on providing sensory-based approaches in the occupational therapy services by the occupational therapy participants can be seen in all areas of practice that they reflected on - their interventions, assessments, assessment tools, models and frames of reference. Additionally, their professional development needs in terms of the training that they had attended, and wanted to attend, were also heavily focused on sensory-based approaches/training.

What is most concerning regarding the data from the therapists is that only two of the parents put sensory-based issues as their priorities for management. In contrast, all therapists felt sensory issues were important. This is important for two reasons: children and adults with ASD do exhibit sensory difficulties as part of their condition (DSM-V, 2013a), but there is limited evidence that any kind of direct intervention has an effect on changing these underlying hyper- or hypo-sensitivities (e.g. sensitivity to touch or auditory stimulation) (American Academy of Pediatrics, 2012). The occupational therapy practitioners, however, could provide a solution based on the modifications and/or adaptations to the environment and/or on the tasks given in order to accommodate sensory challenges, among these children in performing their daily living activities. What has been shown to be effective with these sensitivities is the management of the environment (Koegel et al., 2012), or the use of cognitive strategies with higher functioning individuals (Rodger & Brandenburg, 2009). Yet sensory management appears to be the first port of call for occupational therapists working with children with ASD (Arbesman & Lieberman, 2010; Case-Smith & Arbesman, 2008; Watling et al., 1999a). In addition, parents identified priority areas that required management by either intervening in the environment, changing the way activities were performed, or using specific skills related to hygiene, priorities that bore no relation to the priorities being set by therapists.

Considering the multiple and often unique challenges exhibited by children with ASD, the use of observation in multiple environments can provide useful information about their needs for planning and providing occupational therapy services for this group (Rodger et al., 2010), particularly as most of the issues stated by the parents occurred in home or school environments (Case-Smith & Arbesman, 2008; Zachor & Curatolo, 2013). Therefore, considering that the method of assessment in multiple environments was not administered or administered less by occupational therapists (as only 36.0% and 10.0% of the Malaysian occupational therapy participants reported that they "often" and "always" performed assessment in multiple environment in their assessments, respectively), it is of concern in respect to the services received by the Malaysian children with ASD and their families. In Victoria, the majority of the occupational therapist participants indicated that they "often" and "always" performed observation in multiple environments in their services for children with ASD (68.2%).

After a study of the occupational therapy practitioners and their services across two nations, phase two of the research was restricted to parents of children with ASD in Peninsular Malaysia. As discussed previously in Chapter I, Malaysia is still a developing country that has high human development need, so, in theory, should be able to develop its own skills in providing best healthcare services and in improving its people's well-being. Autistic spectrum disorder is complex, and parents are vulnerable and susceptible to theories and therapies that have not been researched and may be harmful (Amar, 2008; Bowker et al., 2011; Dolah et al., 2012; Prior et al., 2011). In Malaysia, foreign-based therapists are opening treatment centres for children with ASD (Amar, 2008). These centres apply the services that they give to children and families in their country of origin without modification to the Malaysian population. This is neither cost effective for the families or Malaysia, nor is it culturally appropriate. Thus, it is essential that Malaysian occupational therapists identify best practice, and then see whether this best practice is culturally appropriate in the Malaysian context (Amar, 2008; Arbesman & Lieberman,

2010; Bowker et al., 2011; Wilder et al., 2004), as it may not be optimal in the Malaysian context.

This is the first time a study of this kind has been performed with this population in Malaysia, and, in the light of the above, it was important to identify the priorities and goals of the parents and children where possible. However, given the results of the research, the similarity in work practices of the occupational therapy practitioners studied from both countries, and the mismatch between the priorities of the parents and the interventions that they are being offered in Malaysia, it is important that the second phase of this research is repeated with parents of children with ASD attending occupational therapy services in Australia. It is particularly important to identify whether the interventions given by Australian occupational therapy practitioners are in tune with the goals of the parents and children with ASD, so, that results for Australia and Malaysia can be compared.

Age of the Children on whom Services were Concentrated

Occupational therapy participants in both Victoria and Malaysia indicated that they saw pre-school children more frequently than any other group, and this was confirmed by parental participants in phase two of the research. Nevertheless, the dominance of the pre-school group and the absence of older children in this research raises concern. McConachie and Robinson (2006) reported that as the children with ASD grow older, their contact with related services reduces. However, as children with ASD grow older the difference in skills between them and their peers increases (Duncan & Bishop, 2013). This makes the occupational performance issues that they face more pronounced (Duncan & Bishop, 2013; Kanne et al., 2011).

It is of concern that occupational therapists tend to only work with younger children. Transition to school is vitally important; however, enabling transitions, environmental modifications and access to productive and leisure occupations, as heavily

emphasised in the CMOP-E model (Polatajko, Townsend & Craik, 2007), should be occurring throughout school, secondary school and entry into adulthood. This does not appear to be happening and the occupational roles and performance of older children with ASD are not being addressed in either context, especially those of the participants involved in the study.

A large number of occupational therapist survey participants in Malaysia (39.2%) and Victoria (60.9%) indicated that they had never addressed the adaptive behaviour skills in the area of productive occupations (work or vocational skills) in their services provided to children and adolescents with ASD. This is of major concern, as it appears that this area is highly important for children and their families, but is neglected by occupational therapy practitioners. These findings raise questions regarding the skills of occupational therapy practitioners in the area of ASD. It maybe that occupational therapy practitioners are not well equipped – either in terms of facilities, suitable settings, knowledge and expertise to provide services to adolescents with ASD who need work- or vocational skills-related assessments and interventions in Malaysia, and Australia as well.

Work and/or vocational skills-related assessments and interventions are one of the occupational performance aspects that can be provided by occupational therapy practitioners to their clients (DeLany, Ellexson, & Larson, 2011; Liu, Hollis, Warren, & Williamson, 2007). However, if occupational therapy practitioners are unable to provide this, there is a gap in occupational therapy service delivery in Malaysia in that aspect, which needs further attention by the profession. Again, this pattern was seen in occupational therapist participants in Victoria, and requires further exploration.

As children with ASD grow older, their challenges in daily living occupations may become of greater concern, and impede their ability to participate in the community, as well as increase the amount of support required (Duncan & Bishop, 2013; Gabriels et al., 2007; Kanne et al., 2011; Szatmari et al., 2003). Nevertheless, it appears that they may not have access to these services from occupational therapy practitioners.

The ability to communicate effectively with others, manage daily living needs independently, and be actively involved in community living are among the important skills needed by adolescents with ASD as a preparation for them to enter adult life, including accessing productive occupations (Duncan & Bishop, 2013; Gupta & Singhal, 2009). Hence, occupational therapy practitioners should play an active role in helping those children and adolescents acquire the necessary skills in this vital transitional stage right from the beginning, but there is limited evidence that this is a service priority by the participants involved in this study.

The Difficulties in Occupational Performance among Children with Autistic Spectrum Disorder in Peninsular Malaysia

In this research, occupational performance was measured using the Vineland-II survey (Parent/Caregiver Rating Form) (Sparrow et al., 2005b) and the Canadian Occupational Performance Measure (COPM) (Law et al., 2000, 2008). This part of the discussion will examine findings concerning difficulties in occupational performance among children with ASD in Peninsular Malaysia from the Vineland-II, followed by the findings from the COPM.

Difficulties in occupational performance: The Vineland Adaptive Behaviours Scales-Second Edition (Vineland-II)

The Vineland-II was used as it is the gold standard for measuring adaptive behaviour skills of children with ASD (Kanne et al., 2011; Scattone et al., 2011; Sparrow et al., 2005a). The results of the Vineland-II with this sample indicated that in the domains studied - communication, daily living skills and socialisation skills, the children performed these skills with greater difficulty than typically-developing children, which is consistent with previous investigations in this area (Duncan & Bishop, 2013; Lord & Schopler, 1989a; Perry et al., 2009; Rodrigue et al., 1991; Stone et al., 1999).

Firstly, there was a difference between the published norms and the sample studied. If measured with the mean standard scores (SS), the children with ASD involved in this research presented with a profile of adaptive behaviour skills in which the communication skills domain was the most affected (mean SS= 61.5), followed by the socialisation domain (mean SS= 67.7) and with the daily living skills domain as the least affected (mean SS= 71.3). This means that, compared to the normed population samples, children with ASD in Peninsular Malaysia in this research were at 1-standard deviation below the mean in their daily living skills domain, and the communication and socialisation domains were at 2-standard deviations below the mean of the normed sample. From the results obtained, it can simply be defined that the level of adaptive behaviour skills among the children with ASD in Peninsular Malaysia involved in this research were at "low adaptive behaviour level" for the daily living skills domain, whereas the communication and socialisation were at the "moderately low adaptive behaviour level". This finding was similar to the recent study by Ray-Subramanian et al. (2011) on the profile of adaptive behaviour skills if measured using mean standard scores, in which the authors concluded that the delay in adaptive behaviour skills could be seen in children with ASD as early as under three years of age.

If measured based on the age-equivalent scores, children with ASD in Peninsular Malaysia in this research present with significant impairment in socialisation skills as the most affected domain, followed by relatively impaired communication skills and impaired daily living skills. This is consistent with other studies performed in US and UK using age-equivalent scores as their performance measures (Carter et al., 1998; Charman et al., 2004; Perry et al., 2009), which also found that the socialisation domain was most affected based on the mean age-equivalent scores.

The results on the mean standard scores and age-equivalent scores on the Vineland-II demonstrate that children in Peninsular Malaysia involved in this research

present with similar adaptive behaviour skills as the children with ASD studied in other regions.

The daily living skills of the Malaysian children in this study were less impaired than either socialisation or communication skills, but that does not necessarily indicate that this is an area of strength in this population. The sample of participants in this research reflect a younger age group – typically pre-school, where impairments in adaptive skills are less apparent, and less disabling than for older children, adolescents and adults. With older participants, it is likely that the adaptive behaviour skills would fall at 2-standard deviation below the mean. This is an area for further investigation.

The Vineland-II was able to identify difficulties in certain areas/domains of adaptive behaviours experienced by the sample of Malaysian children, but it does not give information about how to help parents in managing the daily needs of their children with ASD. Many of the parents are acutely aware of these differences, and the most impaired skills are not necessarily those which are the parents' highest priority.

Difficulties in occupational performance: The Canadian Occupational Performance Measure (COPM)

Parents identified four priority categories related to their child's difficulty in occupational performance (a) problems in communication, (b) problems in socialisation, (c) problems in activities related to caring for oneself, and (d) problems with activities related to academic skills at school and/or at home. The lack of identification of activities related to academic skills at school and/or at home by the Vineland-II assessment indicates the limitation of relying on only one impairment-based assessment such as the Vineland-II – where adaptive skills (that is caring for oneself) are 1-standard deviation below the norm, compared to communication and socialisation skills. This is because the Vineland-II only identifies the area/domain of difficulties but not the specific skills deficits in that identified area/domain, whereas, with the COPM assessment of semi-structured

interviews, parents prioritised all four areas and the parents' satisfaction in those related activities was also low (Table 6.5, p. 143).

Sensory skills were not identified as priorities by parents, yet this was the chief service offered by the occupational therapy practitioners both in Malaysia and in Victoria, as indicated by their survey responses – to questions on models and frames of reference used, assessments and interventions provided and their goals in providing therapy. A major concern exists as to whether the parents and children are able to have their needs met by occupational therapy services, or could it be that therapists are reporting the problems in self-care activities problems in sensory processing difficulties instead. Meeting parents' needs can be considered vital; there are strong, positive correlations between the level of occupational performance abilities among the children with ASD and their parents' level of satisfaction. This indicates that the higher the occupational performance abilities among the children with ASD, the higher their parents' satisfaction level, which makes it essential for occupational therapy practitioners to address matters that are priorities of the child and their family.

Occupational Therapy Practitioners and Their Services

In this research, it was found that there are contradictions between parents' priorities and what they actually received from the occupational therapy services. This, again, might help explain why the majority age group of children with ASD served by occupational therapy participants both in Malaysia and Victoria was below five. Possibly, some parents and children with ASD, who attend occupational therapy services, may discontinue or default their therapy appointments due to perceptions that they are not having their children's most pressing problems addressed, not having their priorities met when managing their children with ASD's daily activities, or, even worse, might be receiving therapy that is superficial, not family-centred and irrelevant to the problems of the children. There is evidence to suggest that, when parents are not satisfied with the

occupational therapy services that they received for their children with ASD, they will stop attending the services at some point and look for other alternatives (Diamantis, 2010).

Furthermore, these may add to the reasons why school-age children and teenagers with ASD are not adequately served by occupational therapy services; the intervention that they received as young children does not give their families confidence that their needs will be met in the future, or exhibits a lack of understanding of what occupational therapy should focus on. Occupational therapy with children and families with ASD should focus on meeting and addressing the occupational performance needs of the children and families, and this is clearly not occurring.

On the other hand, the lower number of teenagers and adolescents with ASD obtaining occupational therapy services could also stem from the sources of funding being concentrated more on early child development; hence, more services and experts are easily available for younger age group compared to adolescents group. This makes services for younger aged children with ASD more easily obtainable and the occupational therapists are more skilled and experienced in servicing these younger children.

Parents' priorities for encouraging socialisation for their children is supported by other research, in particular the findings from the study conducted by Dawson et al. (2004) which found that pre-school aged children with ASD performed significantly worse in aspects of socialisation skills, such as in social orienting, joint attention, and attention to another's distress, as opposed to children with developmental delay and typical development. When tested, children with ASD often failed to respond to social stimuli, such as facial expressions, humming, calling the child's name, snapping fingers and patting hands on thighs (Dawson et al., 2004; Paul, Chawarska, Cicchetti, & Volkmar, 2008).

Parents' emphasis on activities related to communication with their child with ASD, highlighted in the Vineland-II results, was also reflected in their personal accounts from the COPM semi-structured interviews. Difficulties in communication appeared in all

occupational performance categories asked about during the interviews (Figures 6.5, 6.6 and 6.7). Parents reported problems in communication in the aspects of personal care, play and/or school, as well as problems related with communication in the aspect of socialisation activities. From parents' accounts during the interviews, it can be concluded that the communication problems involved both verbal and non-verbal abilities, ranging from the children with ASDs' inability to indicate their wishes, to not understanding when people communicate with them and not having sufficient communication ability to create successful social relationships. The ability to communicate among the children with ASD appears to be the key in managing their daily occupations (Clark, Miller-Kuhaneck, & Watling, 2004; Hébert et al., 2012; Szatmari et al., 2003).

Some parents also concluded that the inability of their child with ASD to communicate leads the child to social isolation and to being rejected by peers (Chapter VI). Hence, it can be assumed that parents in this research are seeing the ability of their child with ASD to communicate as the essential element in building positive social relationship and achieving a decent quality of live, both for the children with ASD and also for the parents as well (Aldred et al., 2004; Hébert et al., 2012). Furthermore, research indicates that the inability of children with ASD to develop communication skills is one of the early markers observed by parents and which concerned them regarding their child's developmental stage as early as 12 months of age (Hébert et al., 2012; Veness et al., 2012). Paul et al. (2004) also found in their study that communication abilities was the most impaired aspect in children with ASD, with expressive language abilities and elaborate language usage poor among those children.

The majority of occupational therapy participants in Malaysia and Victoria used sensory-based approaches in theoretical models utilised, assessments administered and interventions provided, consistent with previous finding in the US (Watling et al., 1999a) and Queensland, Australia (Ashburner et al., 2010, unpublished report). However, only two issues reported as important by parents can be assumed to be associated with sensory

difficulties in this research: "does not like new clothes" and "selective eaters" (Chapter VI). Furthermore, these sensory issues occurred for only three children from the sample of 44 participants. It can be observed through parents' accounts in the qualitative data collected in the interviews that some parents did state issues that can be associated with sensory difficulties around personal care activities, such as "does not like the texture of the toothbrush" and "refuses to hold and eat certain types of foods" (Chapter VI, p. 151 and 153, respectively). However, none of the parents who mentioned these problems during the interviews listed them as most important to them, when asked to list the five most important occupational performance problems at the end of the interview session.

As only 7% of children in this study can be assumed to experience sensory issues (based from their parents' feedback) and this was not indicated as high priority by parents, this raises serious questions and concerns about why Malaysian occupational therapy participants indicated that the management of issues related to sensory processing difficulties was one of their main common short-term intervention goals when providing services for children with ASD. The concern is whether occupational therapy practitioners may have been focusing too much on providing sensory-based approaches in their services instead of looking at improving the matters that are more important to parents, such as providing services in daily living activities and/or modification to the environment that will enable the child to participate in society, school, and life (American Academy of Pediatrics, 2012; Arbesman & Lieberman, 2010).

The focus on addressing sensory processing issues in occupational therapy intervention goals was also reported by the respondents in the study conducted by Ashburner et al. (2010, unpublished report) with 77.0% of the respondents in Queensland, Australia indicating this. In fact, the emphasis on administering assessments and providing interventions around sensory-based approaches by occupational therapy practitioners were reported in a study by Watling et al. (1999a) conducted more than a decade ago in the US. Looking at these trends, services provided by occupational therapy

practitioners to children with ASD should be carefully planned and tailored to precisely match those that are identified as the most important to the child and their parents and/or caregivers in order to be client- and family-centred (Arbesman & Lieberman, 2010; Diamantis, 2010; Ling-Yi, 2010; Rodger et al., 2010). In this current research, parents emphasised the importance of their child with ASD achieving abilities in communicating, activities related to socialising, caring for oneself and academic skills, as opposed to managing sensory processing difficulties - the service largely provided by the occupational therapy participants involved in this research. Clearly, parents of children with ASD in this research highlight the importance of increasing occupational performance in order to increase the quality of life for their children in daily occupation (including academic aspects) and socialisation.

Consistent with the focus given to the theoretical models utilised, assessments administered and interventions provided to children with ASD that are highly based on sensory integration and/or processing approaches, again the greatest number of the occupational therapy participants, both in Malaysia and Victoria, similarly indicated, when asked about their professional development needs, that they have attended and wanted to attend courses related to sensory-based approaches (i.e.: 25.8% and 42.3% of the occupational therapy respondents in Victoria and Malaysia, respectively). This differs greatly from the number of occupational therapy respondents who indicated that they would like to attend courses or trainings related to activities of daily living or self-care skills with only rather small numbers of occupational therapy respondents indicating this (i.e.: 4.5% and 1.9% of occupational therapy respondents in Victoria and Malaysia, respectively). However, judging from the parents' priorities in terms of the problems faced by their child with ASD, it can be said that the occupational therapy practitioners should focus their research, interventions, and their related training needs on the aspects related to occupation-based, rather than sensory aspects, of care (Diamantis, 2010; Rodger et al., 2010; Ling-Yi, 2010). As the focus for occupational therapy practitioners should be on

occupational performance, perhaps more focus on this would be appropriate in their interventions provided for children with ASD and their family. Although decreased independence in the aspect of activities of daily living is believed to be associated with the sensori-motor difficulties among children with ASD (Jasmin et al., 2009), there should also be some balance in the services provided in those two areas. Therefore, emphasis on sensory-based interventions should be approached with caution by the occupational therapists involved. Above all, occupational therapy practitioners should focus their intervention and training lens on advancing their skills and knowledge in providing useful strategies for children with ASD and their families in order to increase independence and improvement in performance and satisfaction in daily occupation (Ling-Yi, 2010). For example, enabling access to suitable meaningful activities, in order to gain shared interests and roles to improve communication and socialisation, as well as improving performance in their self-care activities skills - the things that were far more important according to the parents in this research. Additionally, better occupational performance among children with ASD can also be achieved if occupational therapists applied their knowledge in sensory-based interventions to achieve daily living skills through environmental adaptation and/or modification, and also by changing the characteristics of the tasks to better meet the individual needs of the children with ASD.

It is interesting to note that what is expressed as the most common problems in children with ASD are also those most identified as parental priorities on the COPM. The areas identified include communication, being able to care for oneself and relationships/socialisation, which are the categories measured in the Vineland-II. However, whilst the Vineland-II was able to identify that there were issues in those areas, the COPM was able to elucidate what the problem was related to the child's ability to do activities, and thus provide a basis for intervention. For example, one parent emphasised that he wanted his son to be able to let him know when the child was in pain or feeling uncomfortable, rather than just simply crying or tantrumming as the only method to

communicate pain (Chapter VI, pp. 163-164). In order to capture the details and individualised needs of these children, the use of qualitative information should accompany any impairment-based test. The COPM was found to be a useful tool to achieve this. Furthermore, the parents of the child with ASD are the experts in their child's needs, and are the ones required to manage and accommodate their child's access to everyday occupations (Carothers & Taylor, 2004, Joosten & Safe, 2014). Occupational therapy practitioners should closely collaborate with parents in the assessment and intervention process for children with ASD (Amar, 2008; Douglas & Taylor, 2004; Ling-Yi, 2010).

Family-centred practice recognises that parents have to consider the needs of the child with ASD in the context of their whole family, as well as their economic and cultural background. Ensuring that intervention is evidence based as well as meaningful is part of family-centred practice, as is not interfering with family function or having parents allocate certain amount of their time every day to focus on performing certain interventions such as those that are sensory-based. Such requirements may interrupt other necessary occupations as well as upset the routines of other family members, which may lead parents to abandon the services, or worse, practices may interfere with family functioning (Phelps et al., 2009). Hence, meaningful family-centred interventions should be provided with the focus on enabling the parents and other family members to easily manage and synchronise the needs of the children with ASD within family daily living routines, specifically, and also into community life generally (Fernell, Eriksson, & Gillberg, 2013; Joosten & Safe, 2014; Zachor & Curatolo, 2013).

Occupational therapy practitioners must equip themselves with detailed knowledge about ASD (James, Pizur-Barnekow, & Schefkind, 2014), in order for them to fully understand the child's difficulties in occupational performance. In this way, occupational therapists can improve their ability to enhance family functioning as well as that of the child with ASD (Karst & Van Hecke, 2012; Ling-Yi, 2010). For example, they

might help parents to understand their child's behaviours, and help educational staff understand why children behave the way they do, without putting a sensory overlay on top of this.

Research Limitations and Recommendations

The prime limitations in this research was getting participants representative of occupational therapy practitioners in Malaysia, especially from East Malaysia, involved in phase one of the research. Due to the poor response rate obtained from the respondents in Malaysia, especially from East Malaysia, with data derived from only nine occupational therapists, other strategies will have to be considered to engage more participants in future research. Although occupational therapists in Malaysia are from the same country, the fact that they are working in different regions and have their own challenges to contend with, is worth exploring further. If the MOTA database was completed in terms of the members' names, current addresses, and areas of specialty, a questionnaire could be mailed to that target group; this could increase the response rate. The results obtained from this survey of Malaysian occupational therapists working with children with ASD could be used to increase MOTA's ability to organise research activities in order to develop the profession further, organise much needed courses or professional development for its members and also to plan future strategies to build clear directions for the profession in Malaysia.

The difficulties in getting more participant numbers in Malaysia might partly be due to the inadequate database of the MOTA, which has incomplete information, such as incomplete names and addresses of its members. Some occupational therapy practitioners in Malaysia are not registered as MOTA members, which might also influence the chances of getting more potential participants through the association database. Since the membership in MOTA is open to all occupational therapists working either in public or in private practices in Malaysia, a database that contains complete and current information about its members would be a valuable resource. An accurate and up-to-date database

would be useful in terms of the development and understanding of the workforce and service needs, as well as a useful resource for assisting with research regarding the future directions of this profession in Malaysia. For future study, it is suggested that occupational therapy practitioners registered and working under the Ministry of Health, Malaysia (MOH) and also in other government agencies, such as under the Ministry of Women, Family, and Community Development, should be recruited.

Due to the nature of the mail survey adopted in the data collection in phase one of this research, some participants may have different interpretations of the questions asked; however, efforts were made to minimise this during the questionnaire development, validation and testing process, as well as in designing the questionnaire to include both closed- and open-ended questions to give the participants the opportunity to express their own opinions about the questions asked. For any future study, in addition to collecting data regarding the occupational therapy services with children with ASD via a mail survey, conducting face-to-face interviews with practitioners would be a beneficial strategy to capture the accurate meaning of the participants' opinions and clarify any ambiguity in their understanding of the questions asked. Owing to the nature of this study, it was not possible to conduct face-to-face interviews with occupational therapy practitioners, due to time and resources constraints.

The inability to match the occupational therapy participants to their clients of children with ASD is another limitation of the study. Matching of pairs of therapists and clients could yield more accurate information regarding the services offered and the client's expectations or priorities. In future, a study could be done on the pairs of therapists and clients to focus on the services offered in order to ascertain the strength of the client- and family-centred approaches being practiced by the occupational therapy practitioners. However, an effort was made in this study to ensure that the parents of children with ASD interviewed were also those who were receiving occupational therapy

services in the two centres in Peninsular Malaysia where the Malaysian occupational therapists were surveyed in phase one (i.e.: The UKMMC and NASOM).

In this research, the survey of the parents of children with ASD was only performed in Peninsular Malaysia due to some constraints as explained in pages 111-112. It would be beneficial if the second phase of the research could have also been conducted in East Malaysia and Victoria as well. The perspective of parents of children with ASD from Victoria could be compared to those of Malaysian parents to see whether there are similarities or differences in terms of their priorities regarding their children with ASD's occupational therapy services, given the potential differences in culture, socioeconomic factors and healthcare services available.

Another limitation of this research concerns the age of the children involved in the study as the majority of them were preschool-age children. It would be beneficial if a similar study could be done with teenagers and/or adolescent with ASD when their challenges in performing daily occupations could be much greater. It would be beneficial to explore this as the information gained could be used to prepare occupational therapy practitioners to provide interventions most needed by the adolescent with ASD population, considering their needs for successful transition to adult life. In addition, efforts should be made to include more participants from private practices and non-government organisations (NGOs) that offer services to this population, regardless of whether they are offering occupational therapy services in their centres. This might be achieved by including or recruiting participants from companies or NGOs providing services for children and adolescents with ASD registered under the Ministry of Women, Family, and Community Development, Malaysia (especially under its Social Welfare Department and Social Institute of Malaysia Division).

Implications for Occupational Therapy Education, Practice, and Professional Development

It is of great concern that practitioners did not refer to literature on which to base their interventions. In both contexts, practitioners preferred to acquire knowledge and skills by attending face-to-face training (such as attending workshops, short courses and conferences) (Table 4.8, p. 101). Regarding the method of acquiring knowledge and skills, it was concerning to see that literature reviews are among the methods least preferred by the participants, both in Victoria and Malaysia. It is concerning that some practitioners are not using evidence to guide their practice, which can also be because there are limited literatures available to base their practices on or could also be because of the difficulties gaining access to the literatures. Providing well-researched occupational therapy interventions for children with ASD is vital. It can only be presumed that the method of literature reviews is not highly preferred by the respondents in this research because:

1. They are not well equipped with the knowledge and skills to perform the search and also to analyse the research strengths and weaknesses (Arbesman & Lieberman, 2010)
2. They do not have the facilities needed, such as computer and/or internet connection to perform the web-based search and/or the access to the databases necessary to perform the literature search (Leong, Carter, & Stephenson, 2013; Arbesman & Lieberman, 2010)
3. They do not have time to perform the literature review process. If this is the case, it is the responsibility of practitioners to make sure that they are able to manage their time wisely and provide themselves with a suitable time allocation for their professional development needs to ensure that they keep up-to-date with the current evidence in practices for children with ASD.

Some studies suggest that the ability to acquire language skills among children with ASD is a strong indicator of the achievement of independence in daily living skills (Kanne et al., 2011). As discussed previously, some parents in this research emphasised the importance of their child with ASD being able to communicate in order to let them know their needs and feelings; hence, this finding can be useful to occupational therapy practitioners in planning their interventions with a focus on increasing the ability of children with ASD to appropriately interact and communicate their needs in daily occupations. Therefore, close collaboration with other health care professionals, especially with speech therapists, to achieve the communication skills required for children with ASD to successfully engage in daily occupations is strongly recommended.

Based on the results obtained in this research, it is suggested that the standardised assessment tool to assess the child with ASD's level of adaptive behaviour skills - the Vineland-II (Sparrow et al., 2005b) - provides useful information of overall skills or abilities of the children. However, in order to identify individual intervention needs for developing occupational performance skills, important to the occupational therapy practitioners in the process of intervention planning, the semi-structured interview of the COPM (Law et al., 2000, 2008) should be used. This would be in addition to other assessments indicated by the COPM or other tools to assess the daily occupation abilities among those children. The COPM should be used by practitioners prior to using other tools such as a sensory processing assessment - for example the Sensory Profile (Dunn, 1999) - so that they can ensure that they are meeting the needs of the parent and child. If sensory processing is a difficulty for the child and impacting on occupational performance, then best practice in this area should be applied. However, at present, it appears that this is the priority of therapists rather than of parents. Information gained from the two tools used in this present study (the COPM and the Vineland-II) can be used to plan individualised interventions for the children with ASD and their families. Furthermore, both tools also provide valuable methods for reassessment, because the performance of the

children with ASD can be reassessed using the same tools in order to measures their achievement.

As the majority of the information collected in this research involves children with ASD aged below five years (as collected in phase one and two of the research), we do not have a picture of occupational therapy practices with children of school age or adolescence. However, this older age group of children with ASD also needs considerable attention regarding their abilities in managing their daily occupational performances, which could be more challenging as they grow older, in order to ensure their smooth transitions into adult life. Furthermore, as the children with ASD become older, the expectation that they will become more independent in managing their daily occupation activities also grows higher (Duncan & Bishop, 2013). Adolescents with ASD should be able to acquire skills in managing their involvement in community activities, vocational skills, productive work and preparation for other life roles. To date, there is no strong evidence that sensory-based interventions will enable the child to do this at a later age or stage (Prior et al., 2011).

In ensuring quality service provision for clients, the occupational therapy profession should establish suitable mechanisms for monitoring and measuring clients' satisfaction in their occupational therapy services. One possible way to achieve this is by conducting surveys with both clients and practitioners to understand their priorities and challenges in receiving and providing occupational therapy services. This kind of survey should be done regularly to keep up-to-date with the constantly changing and advancing information regarding the diagnosis of ASD, treatment options, government legislation and support service availability. Information gained from such surveys could be used by the profession to prepare the content in the occupational therapy curriculum and also to allow regular professional training offered to occupational therapy practitioners to be more goal-directed, based on best evidence, and, as well, family-centred. The profession should also prepare therapists to be more actively involved in delivering their services in the

community and school setting as well. Environmental modifications should be performed by the therapists in order to help children with ASD function effectively in their daily occupations and also to ensure that skills are generalised across activities and environments (Kinnealey et al., 2012).. Using the child's immediate environment as the intervention setting can be more client-centred and, at the same time, cost effective.

Suggestions for Future Research

There are a number of research questions arising from this work. Firstly, with regard to the training needs of occupational therapy practitioners, it was concerning that only a small number of occupational therapy participants in both countries indicated that they would like to attend courses or training related to occupation-based approaches (such as activities of daily living or self-care skills) and the majority wanted to attend courses related to sensory-based approaches. This may be because practitioners feel that they are already equipped with knowledge required to provide occupation-based approaches. Or, that therapists are struggling with understanding the diagnosis of ASD. In which case, another possible reason is that the practitioners misunderstand the hyper/hypo sensitivity that is part of the diagnosis of ASD. The rationale then becomes one where managing sensory processing difficulties may enhance the child's occupational performance. However, at present, there is no evidence for this, and thus further research to determine the evidence for or against this rationale must be performed.

Further studies focusing on specific intervention strategies adopted by occupational therapy practitioners in providing services to children with ASD, and understanding their clinical reasoning is essential (Polatajko & Cantin, 2010). It was concerning that very few occupation-based assessments and interventions were undertaken by the occupational therapy participants with their clients of children with ASD and their families, as opposed to the sensory-based assessments and interventions administered (Diamantis, 2010; Rodger et al., 2010).

In relation to intervention by sensory-based approaches, which was preferred by the greatest number of occupational therapy respondents in both Victoria and Malaysia, future research to investigate the extent and effectiveness or non-effectiveness of this approach is warranted. Such research, conducted both by questionnaire survey and face-to-face interview with occupational therapy practitioners might provide an understanding of how and why they utilise the sensory-based approaches in their occupational therapy intervention for children with ASD. Useful questions would be: (a) are they using the sensory-based approaches entirely in their intervention (b) are they just using them partially and in combination with other occupation-based approaches, and (c) what intervention goals are they trying to achieve with the administration of the sensory-based approaches and what is the rationale?

The findings from the study lead to an urgent need for further investigation in a number of areas. Firstly, the profession should explore appointment attendance problems and the reasons for continuation/discontinuation of services. If parents are discontinuing services because they are not getting their needs met, this must be explored. Furthermore, an exploration of parents' perceptions of the services that they are currently receiving is urgently warranted. Mismatches between the occupational therapy services provided and the parents' priorities may explain why both the Malaysian and Victorian occupational therapists' participants in phase one of the research, stated that "challenges from parents/caregivers" was one of the top issues and also "challenges when working with children with ASD". Further research needs to be carried out to identify and understand the reasons for these responses from the occupational therapist participants. Some parents may have challenged the rationale for the interventions provided, or expressed dissatisfaction about not getting the service that they really wanted and hoped or needed to get from their therapists. These challenges faced by the occupational therapist participants could also stem from their limited skills and knowledge in managing the complex disabilities shown by the children with ASD in order to address the matters of most

concerned to their parents. If that is the case, clearly, the education and trainings of the occupational therapists working with children, as well as adolescents with ASD, need to be enhanced and funding in the service provisions for adolescents with ASD needs to be strengthened (James, Pizur-Barnekow, & Schefkind, 2014; Leong, Carter, & Stephenson, 2013).

The majority of the information regarding the occupational performance abilities among children with ASD was gained from pre-school aged children, and the majority of participants also served this client's age group. Hence, this raises concerns and questions about where children between five and 18, and especially adolescents, are receiving assistance, and who, or which professional bodies, provide the needed assessments and interventions they receiving, if any. Further exploration of this issue is important to ensure that older children and adolescents with ASD are receiving appropriate interventions in preparing them for smooth transition into adult life (Duncan & Bishop, 2013).

In addition, face-to-face interviews with the parents of children with ASD in phase two of the research could not be conducted in the East Malaysia region due to language, time and financial constraints. It would be interesting and valuable to explore and understand the challenges faced by parents or caregivers of children with ASD in that region in future research, in order to understand whether there are differences in their challenges and the supports they need in that particular region. On top of that, the inclusion of an interviewer who is competent in the local languages and dialects used by most of the peoples in that region would be useful in order to catch their exact perceptions during the interviews.

One further area of research would include investigating the perspectives and expectations of parents and/or caregivers of children with ASD regarding occupational therapy. Listening to the needs and perspectives of parents could be used by the practitioners and the profession to improve and deliver services that are really needed, and expected by their clients.

A further area of research involves outcome measurement. The COPM semi-structured interview was very useful in providing information on the level of importance, performance and satisfaction as perceived by parents who participated in this research, regarding the progress of their children with ASD after receiving occupational therapy services. This would be useful to measure change, but also to ensure that the services are matching the priorities of the parents and child.

Finally, it would be useful for phase two of the research to be repeated with parents of Australian children with ASD, and possibly matching their answers with those of the occupational therapists. The similarity in approaches used by occupational therapists in the two countries in this study was unexpected, so it is important to look at whether or not the parental expectations, and mismatched goals, were similar between the two countries also. The results in the Malaysian population indicate that it is important to explore this in the Australian context. Finally, studies that address the occupational performance issues and needs of children and young people with ASD at primary school, school transition, secondary school and transition into adult life is fundamentally important. These would be beneficial in both Malaysia and Australia.

Conclusions

There are great similarities in the occupational therapy practices for young children with ASD between Malaysia and Victoria. It can be concluded that the service provisions by occupational therapy practitioners in Malaysia and Victoria are similar, with the major emphasis on providing assessments and interventions, as well as in their requirement of courses and training in professional development, based on sensory-based approaches, despite differences in cultural, educational and healthcare systems.

Generally, the findings from this research focussed on the occupational therapy services provided for pre-school children with ASD aged between three and five years. Pre-school aged children with ASD comprised the largest group serviced by occupational

therapy practitioners both in Malaysia and Victoria. This raises concern regarding the type of service and service provider needed for school-aged children and adolescents with ASD, as life roles, adaptive behaviour and vocational skills are clearly important goals for occupational therapy practitioners in preparing children for these transitions in their lives.

Mismatches were shown between occupational therapy services provided and the parents' needs and priorities. Hence, it can be concluded that there is little harmonisation between what parents are expecting and what they are receiving from the occupational therapy services provided for their children with ASD. It was found that occupational therapy participants in this research were focusing more on providing their assessments and interventions according to sensory-based approaches, and saw their professional development needs in these terms, rather than related to daily living skills interventions, which parents indicated as priority concerns. The complexity of the ASD symptomatology can most likely confuse both parents and therapists; however, it can also be concluded that it is vital for the occupational therapy practitioners to consider parents' or families' priorities and concerns in establishing the goals and objectives of children with ASD in their intervention planning process, in accordance with family- and client-centred practices.

Use of the Vineland-II (Parent/caregiver rating form) (Sparrow et al., 2005b) is able to indicate the overall limitation in the domains of communication, daily living skills and socialisation. However, use of the COPM semi-structured interview was able to provide more details about the individualised occupational performance problems in the children with ASD. The COPM is an important tool for occupational therapy practitioners to use in planning interventions for children with ASD. It can be concluded that the use of the standardised tool of the Vineland-II (parent/caregiver rating form) (Sparrow et al., 2005b) accompanied by the COPM (Law et al., 2000, 2008) semi-structured interview outcome measure is suitable for children with ASD and their families in Malaysia. The Vineland-II (parent/caregiver rating form) (Sparrow et al., 2005b) can be used as a

screening tool for occupational therapy practitioners to gain some basic information about the child's abilities and disabilities, whereas, through the use of the COPM (Law et al., 2000, 2008) semi-structured interview, occupational therapy practitioners can explore details of aspects of daily living skills that need attention and are given greatest priority by parents. Hence, information obtained from those tools can be used to plan for individualised occupational therapy intervention.

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APPENDIX 2

ONE ARTICLE RELATED TO THE THESIS PUBLISHED IN THE AUSTRALIAN OCCUPATIONAL THERAPY JOURNAL

Australian Occupational Therapy Journal

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Research Article

Evidence-based practice in occupational therapy services for children with autism spectrum disorders in Victoria, Australia

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***Background*:** *The current practice of occupational therapy services provided for children with autism spectrum disorders in Victoria, Australia was investigated – specifically, practice in terms of the theories, assessments and intervention strategies utilised. Identification of professional development needs was also explored. The purpose was to identify how occupational therapy practice may have changed over the last decade and to explore what additional developments are required in the field.*

***Method*:** *A self-administered survey was mailed to 322 registered members of Occupational Therapy Australia Limited, Victoria Branch.*

***Results*:** *A valid response rate of 20.5% was obtained. The majority of the participants worked in private practice, and had between one and five years of work experience. Theories, assessments and interventions that are associated with or based on, sensory integration and/or processing approaches are highly utilised by the participants in their service delivery with children with autism spectrum disorders. Participants indicated that they felt they needed training and courses around sensory integration.*

***Conclusions*:** *We concluded that there were few changes in occupational therapy practice related to the selection of theoretical models, assessments and interventions by the participants in this study over the last decade. It is essential for occupational therapists not to neglect the goals of providing occupation-based interventions to children with autism spectrum disorders by focusing only on sensory-based approaches. An urgent need for occupation-based approaches to working with children with autism spectrum disorders and their families is required.*

KEY WORDS *interventions, professional development, theory.*

Introduction

Globally, the incidence of children diagnosed with autism spectrum disorders (ASD) has increased substantially over recent years (Baron-Cohen *et al.*, 2009). Children diagnosed with ASD are often reported to show difficulties in their day-to-day performance in self-care, school and play skills (Bailey, Hatton, Mesibov, Ament & Skinner, 2000). Deficits in occupational performance components and capacities may limit the ability of such children to interact effectively with their surroundings and the people around them. The consequence of this may be a potential increase in social isolation (Bailey *et al.*, 2000; Spreckley & Boyd, 2009). Occupational therapy is one of the most common services received by children with ASD (McLennan, Huculak & Sheehan, 2008).

Watling, Deitz, Kanny and McLaughlin (1999a) published one of the first reported studies on occupational therapy services specifically for children with ASD. The authors reported that the most frequently used frames of reference by occupational therapists were the sensory integration, developmental and behavioural models. The most common assessment tools included informal Sensory Processing History, Sensory Profile, Ayres' Clinical Observations, Self-care Checklist and Peabody Developmental Motor Scales. The most common interventions used by the participants included sensory processing, play and behavioural management.

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Accepted for publication 15 April 2012.

Ashburner, Ziviani and Rodger (2010, unpublished report) conducted a survey regarding occupational therapy services for children and adults with ASD in Queensland, Australia. They found that most participants give more attention in managing sensory issues in the area of assessment, intervention, knowledge and training needed. The preferred method of professional development by therapists was attending workshops, with most participants reporting that they had attended formal training in sensory approaches compared to other training areas. Families/carers were highly involved in the assessment and goal planning process of the intervention for people with ASD; thus, most of the participants implemented family centred/client-centred practice in their occupational therapy service for people with ASD. The majority of the participants asserted that working in the autism field was very challenging. Many indicated that they were only 'somewhat confident', or 'neither confident nor under-confident or fluctuating confidence' in working in the field of ASD.

The interventions provided for children with ASD are controversial in terms of their effectiveness and evidence, such as Sensory Integration (Heflin & Simpson, 1998; Hyatt, Stephenson & Carter, 2009). A systematic review by Case-Smith and Arbesman (2008) on occupational therapy interventions used for children with ASD, illustrate six emergent categories of intervention. The most commonly used intervention by occupational therapists was sensory integration and sensory-based interventions. Rodger, Brown and Brown (2005) surveyed paediatric occupational therapists in Australia and found that children with developmental delays (including children with ASD) were among the diagnostic groups served most frequently by the participants. They further found that theories and intervention approaches associated with sensory integration were the most often utilised for children with developmental delays. The assessments that were most frequently used with these children were Test of Visual-Motor Integration, Sensory Profile (SP), Bruininks Osteretsky Test of Motor Proficiency (BOTMP), Handwriting Speed Test (HST), Motor-Free Visual Perception Test (MVPT) and Peabody Developmental Motor Scales (PDMS).

The current practice of occupational therapy services provided for children with ASD in Victoria, Australia was investigated in this study – specifically, practice in terms of the theories, assessments and intervention strategies used. The professional development needs identified by participating occupational therapists were also investigated.

Methods

Survey development, expert review, revisions and testing

A questionnaire titled *'Current Practice of Occupational Therapy for Children with Autism: A National Survey of Practitioners©'* was developed by Watling, Deitz, Kanny and McLaughlin (1999b) in their survey of practitioners in the USA. With the permission of the first author, we updated this tool. The survey was modified by reviewing relevant occupational therapy textbooks and literature (Case-Smith, 2005; Case-Smith & Arbesman, 2008; Kramer & Hinojosa, 2010; Miller-Kuhaneck, 2004; Mulligan, 2003; Watling *et al*., 1999a) and additional information added using – *'The Paediatric Occupational Therapy Practitioner Survey©'* developed by Brown and Rodger (2001).

Once the tool had been updated, it was sent to 12 experts in the occupational therapy and autism fields to ensure its face and content validity. The questionnaire was modified according to the feedback received from the experts. The final version of the questionnaire titled *'Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders'* consisted of six sections; Section A: Frame of reference and models of practice, Section B: Assessments/outcome measures, Section C: Intervention, Section D: Adaptive behaviours, Section E: Professional development needs, and Section F: Demographic information (The questionnaire can be obtained from the first author).

In this study, the participants' occupational therapy practice was explored to determine which frames of references (FOR), models of practice (MOP) and interventions or programmes were utilised, age groups of children with ASD served most frequently, and areas of adaptive behaviours addressed. The participants also answered questions regarding the assessment and outcome measures utilised, standardised assessments performed, short-term occupational therapy intervention goals, and collaboration with other people or professionals were also included.

Participants and sample size

The participants in this survey were occupational therapists who were members of Occupational Therapy Australia Limited, Victoria Branch (OTAL, Vic.). All participants must have worked or must be currently working, with children with ASD in occupational therapy services in Victoria. The association was consulted for their help in identifying potential participants for the survey; and 323 occupational therapists were identified. One potential participant was excluded from the study as the participant did not work in Victoria. Hence, surveys were mailed to 322 participants.

Procedures

Ethical approval was obtained from the Monash University Human Research Ethic Committee (MUHREC), Australia. A self-administered survey was mailed to OTAL, Vic. members who had identified themselves as working in paediatric occupational therapy practice, together with the introductory letter, explanatory statement and a stamped self-addressed envelope. Reminders were also sent out at 2 and 4 weeks to ensure higher response rates (Salant & Dillman, 1994). Return

of the surveys by the participants was considered as their consent to take part in the study.

Data entry and analysis

Data were entered into the PASW Statistics Version 18.0 for Windows (formerly SPSS-The Statistical Package for the Social Sciences) and descriptive analyses were performed. Answers given to open-ended questions were summarised and categorised (Liamputtong, 2009).

Results

Response rates

Of the 322 surveys mailed to occupational therapists registered through OTAL, Vic., 118 participants returned their surveys (a response rate of 36.6%). Of the 118 responses, 52 participants were excluded because they indicated that they have never worked with children with ASD. Data from 66 participants were analysed, producing a valid response rate of 20.5%, a satisfactory level (Weisberg, Krosnick & Bowen, 1996). If we withdraw the 52 negative responses from the total, the response rate rises to 24.4%, which would be even more satisfactory.

Characteristics of the Participants

The participants' level of academic qualifications, place of work, years of work experience as an occupational therapist, and years of work experience with children with ASD is presented in Table 1. The greatest number of the participants worked in private practice (25.8%). Many also reported that they worked in more than one setting (17.0%). The greatest number of the participants had graduated within the past 5 years (28.8%). Almost half of the participants (45.4%) had between 1 and 5 years experience of working with children with ASD.

TABLE 1: *Participants' demographics and employment characteristics*

Participants' academic levels	
Highest academic qualification	Frequency (%)
Diploma/certification in occupational therapy	1 (1.5)
Bachelors degree in occupational therapy	50 (75.8)
Graduate-entry masters degree in occupational therapy	6 (9.1)
Coursework/research masters	7 (10.6)
Research doctorate in occupational therapy	1 (1.5)
Other	1 (1.5)
Total	66 (100.0)
Participants' practice settings	
Setting of current practice	Frequency (%)
Hospital	2 (3.0)
School	11 (17.0)
Community-based care	11 (17.0)
Early intervention services	14 (21.2)
Private practice	17 (25.8)
More than one setting	11 (17.0)
Total	66 (100.0)
Participants' working experience	
Years of practising as an occupational therapist	Frequency (%)
Less than 1 year	1 (1.5)
1–5 years	19 (28.8)
6–10 years	14 (21.1)
11–15 years	10 (15.2)
16–20 years	9 (13.6)
More than 21 years	13 (19.7)
Total	66 (100.0)
Years of working with children with ASD	Frequency (%)
Less than 1 year	7 (10.6)
1–5 years	30 (45.4)
6–10 years	14 (21.2)
11–15 years	7 (10.6)
16–20 years	4 (6.1)
More than 21 years	4 (6.1)
Total	66 (100.0)

Occupational therapy practice

Frames of reference and models of practice

Results show that the majority of the participants used frames of reference (87.9%) and models of practice (87.9%) to guide their work with children with ASD (Table 2). The most commonly used FOR was sensory integration (72.7%). The coping FOR was the least commonly used (4.5%). Meanwhile, the Canadian Model of Occupational Performance and Engagement (CMOP-E) was the MOP used by the greatest number of the participants (43.9%).

Interventions

Six interventions emerged as being 'often' and 'always' utilised by more than 50% of the participants. These interventions or programmes were: (i) early intervention programmes (65.5%); (ii) sensory diet (Kimball, 1999) (62.5%); (iii) environmental modifications (57.8%); (iv) sensory integration training (Kimball, 1999) (56.4%); (v) play therapy (55.2%); and (vi) sensorimotor stimulation (Huebner & Lane, 2001) (52.5%). Two programmes – the Social Communication, Emotional Regulation and Transactional

TABLE 2: *Frame of reference and model of practice utilised by the participants*

Frame of reference (FOR)	
Type of FOR	Frequency (%*) (n = 66)
Coping (Williamson & Szczepanski, 1999)	3 (4.5)
Acquisional (Royeen & Duncan, 1999)	9 (13.6)
Psychosocial (Olson, 1999)	18 (27.3)
Occupational (Primeau & Ferguson, 1999)	13 (19.7)
Sensory Integration (Kimball, 1999)	48 (72.7)
Other FOR	14 (21.2)
Model of practice (MOP)	
Type of MOP	Frequency (%*) (n = 66)
Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007)	29 (43.9)
Cognitive Orientation to daily Occupational Performance (CO-OP) (Polatajko & Mandich, 2004)	16 (24.2)
Ecology of Human Performance Model (Dunn, Brown & McGuigan, 1994)	6 (9.1)
Model of Human Occupation (MOHO) (Kielhofner, 2008; Kielhofner & Burke, 1980)	20 (30.3)
Person-Environment-Occupation (PEO) (Law *et al.*, 1996)	23 (34.8)
Other MOP	16 (24.2)

*Percentages do not total 100% because participants can indicate more than one FOR and MOP.

Support (SCERTS) model (Prizant, Wetherby, Rubin, Laurent & Rydell, 2006) and Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) (Mesibov, Shea & Schopler, 2004), were very infrequently used (89.5% and 86.4% respectively).

Age group of children with ASD served most frequently

In children with ASD, age group below 5 years (preschool) was reported as the age group being served most frequently by the participants (69.7%) followed by the age group 6–18 years (40.9%). Meanwhile, 10.6% participants indicated that they served both age groups equally.

Adaptive behaviours

A high percentage of participants rated that they often addressed self care activities (58.5%), social skills (47.7%), school- readiness skills (50.8%) and play/leisure participation (46.2%) in their services. In the category, 'sometimes' addressed, participants reported the categories of home living (38.5%), communication skills (34.9%) and self-determination (35.4%). Community use, health and safety education and work/vocational skills were rated as 'seldom' or 'never' addressed.

Methods of assessments and outcome measures

More than 77 per cent (77.3%) of the participants indicated that they always performed interviews with parents or careers in their assessments and 4.5% indicated that they never used standardised assessments in their services for children with ASD. Four additional categories were identified using open-ended questions: (i) assessment based on previous case notes; (ii) reports from integration aides; (iii) questionnaires to parents and teachers; and (iv) informal assessment of family capacity to engage in treatment and to develop family centred self-management strategies and task analysis.

Use of standardised assessments

A high number of participants (90.0%) reported that they used sensory processing or sensory integration assessments, with the Sensory Profile (Dunn, 1999)/Sensory Profile School Companion (Dunn, 2006) being the tool used most frequently (80.3%). Whereas, only 15.2% of the participants reported that they administered psychosocial or social interaction skill and diagnostic assessments. Table 3 presents the detailed results.

Participants were asked to describe how they administered the non-standardised assessments. Replies indicated: (i) using interviews or observations (24 replies); (ii) assessments created by the workplace or developed by the therapist (18 replies); and (iii) using items from the standardised assessments informally to guide the assessment process (five replies).

Short-term occupational therapy intervention goals

The most common short-term occupational therapy intervention goals listed were: (i) managing issues related to sensory difficulties (26 replies); (ii) improving attention and concentration skills (19 replies); (iii) improving self-care skills (16 replies); (iv) improving communication and social skills (15 replies); and (v) improving physical functions (e.g. motor skills, strength) (15 replies).

Collaboration with other people or professionals

Participants rated the frequency of working with other people or professionals. More than 74 per cent (74.2%) reported that they always worked with parents/caregivers, 42.2% reported that they always worked with teachers/education staff, 47.0% reported that they often worked with speech therapists/speech pathologists. Meanwhile, psychologists received an equal higher per-

TABLE 3: *Frequencies and percentages on the use of standardised assessments and the tools utilised for each area of assessment*

Standardised assessments and the tools used (n = 66)	Frequency (%)
Using developmental screenings and evaluations	34 (51.5)
The Beery-Buktenica Developmental Test of Visual-Motor Integration (BEERY VMI) (Beery,1997)	6 (9.1)
The Hawaii Early Learning Profile (HELP) (Vort Corporation, 2004)	5 (7.6)
The Peabody Developmental Motor Scales (PDMS) (Folio & Fewell, 1983)/(PDMS-2) (Folio & Fewell, 2000)	4 (6.1)
Using functional or adaptive skill assessments	29 (43.9)
The Adaptive Behavior Assessment System-11 (ABAS-II) (Harrison & Oakland, 2003)	4 (6.1)
The Child Initiated Pretend Play Assessment (ChIPPA) (Stagnitti, 2007)	3 (4.5)
The Peabody Developmental Motor Scales (PDMS) (Folio & Fewell, 1983)/(PDMS-2) (Folio & Fewell, 2000)	3 (4.5)
The Sensory Profile (Dunn, 1999)	3 (4.5)
The Miller Function and Participation Scales (M-FUN) (Miller, 2006)	3 (4.5)
Using activities of daily living skill assessments	17 (25.8)
The Canadian Occupational Performance Measure (COPM) (Law *et al*., 1994)	3 (4.5)
The Pediatric Evaluation of Disability Inventory (PEDI) (Haley, Coster, Ludlow, Haltiwanger & Andrellos, 1992)	2 (3.0)
Using school-related skill assessments	33 (50.0)
The School Function Assessment (SFA) (Coster, Deeney, Haltiwanger and Haley (1998)	8 (12.1)
The Beery-Buktenica Developmental Test of Visual-Motor Integration (BEERY VMI) (Beery,1997)	4 (6.1)
The Miller Function and Participation Scales (M-FUN) (Miller, 2006)	4 (6.1)
The Sensory Profile (Dunn, 1999)/Sensory Profile School Companion (Dunn, 2006)	4 (6.1)
Using play and leisure participation assessments	21 (31.8)
The Child Initiated Imaginative Play Assessment (ChIPPA) (Stagnitti, 2007)	5 (7.6)
The Functional Emotional Assessment Scales (FEAS) (Greenspan, 1992)	2 (3.0)
Using gross or fine motor skill assessments	52 (78.8)
The Bruininks-Oseretsky Test of Motor Proficiency (BOT) (Bruininks, 1978)/(BOT-2) (Bruininks & Bruininks, 2005)	16 (24.2)
The Peabody Developmental Motor Scales (PDMS) (Folio & Fewell, 1983)/(PDMS-2) (Folio & Fewell, 2000)	14 (21.2)
The Beery-Buktenica Developmental Test of Visual-Motor Integration (BEERY VMI) (Beery, 1997)	12 (18.2)
Using sensory processing or sensory integration assessments	60 (90.0)
The Sensory Profile (Dunn, 1999)/Sensory Profile School Companion (Dunn, 2006)	53 (80.3)
The Sensory Processing Measure (SPM) (Parham, Ecker, Miller-Kuhaneck, Henry & Glennon, 2007)	5 (7.6)
The Sensory Integration and Praxis Test (SIPT) (Ayres, 1989)	3 (4.5)
Using psychosocial or social interaction skill assessments	10 (15.2)
The Functional Emotional Assessment Scale (FEAS) (Greenspan, 1992)	3 (4.5)
The Assessment of Motor and Process Skills (AMPS) (Fisher, 2003)	1 (1.5)
Pragmatic Observation Checklist (Johnston, Weinrich & Glaser, 1991)	1 (1.5)
Using environmental assessments	13 (19.7)
The School Version of the Assessment of Motor and Process Skills (SCHOOL AMPS) (Fisher, Bryze, Hume & Griswold, 2005)	1 (1.5)
Home safety checklist (The Royal Children's Hospital, Melbourne, 2008)	1 (1.5)
Using diagnostic assessments	10 (15.2)
The Childhood Autism Rating Scale (CARS) (Schopler, Reichler & Renner, 1988)	3 (4.5)
Psychoeducational Profile-Third Edition (PEP-3) (Schopler, Lansing, Reichler & Marcus, 2005)	2 (3.0)

centage of responses on both 'sometimes' and 'often' (32.3%).

Perceived level of confidence

Participants were asked to indicate their perceived level of confidence when working with children with ASD. Nearly half (48.4%) of the participants rated their level of confidence as 'high' or 'very high', 45.3% rated their level of confidence as 'moderate' and 6.3% rated their level of confidence as 'low'.

Professional development

The participants' professional development needs were presented under the headings of the training/certifica-

tion/continuing education courses attended and would like to attend, and the preferred methods of obtaining knowledge and skills.

Training/certification/continuing education courses attended

The participants listed the courses they had attended on the following topics related to occupational therapy services for children with ASD: (i) sensory-based interventions (32 replies); (ii) social skills (15 replies); (iii) training on assessments tools (13 replies); (iv) courses/seminars on gaining knowledge about ASD (nine replies); and (v) play skills (seven replies).

Training/certification/continuing education courses participants would like to attend

The participants listed the courses that they would like to attend that related to their occupational therapy services for children with ASD, and there were 50 replies. The five top courses that they would like to attend were: (i) sensory-based interventions (17 replies); (ii) social skills (13 replies); (iii) training on assessments tools (five replies); (iv) courses/seminars on gaining knowledge about ASD (five replies); and (v) interventions on activities of daily living/self-care skills (three replies).

Preferred methods in obtaining knowledge and skills

Participants' preferences in the method of obtaining knowledge and skills showed that more than 60% of the participants indicated that they have 'high preferences' and 'preferred the most' for:

i. Hands-on mentoring by expert/experienced therapists (51.6% high preferences and 28.1% preferred the most)
ii. Multidisciplinary workshop with discussion and problem solving (54.7% high preferences and 6.3% preferred the most)
iii. Short courses of specialist certification on a certain technique/programme (43.1% high preferences and 26.2% preferred the most)

The least popular method of obtaining knowledge and skills was online courses (26.6%). The detailed results are presented in Table 4.

The participants listed two other methods of obtaining knowledge and skills as follows: (i) video conferences that might benefit occupational therapists that are located in remote areas; and (ii) distance education learning.

Discussion

Occupational therapy practice

The results of the FOR and interventions or programmes highly utilised by the participants in this study match the findings from other studies such as Ashburner *et al.* (2010, unpublished report), Case-Smith and Arbesman (2008) and Rodger *et al.* (2005), in which the authors found that theories and intervention approaches associated with or based on, sensory integration were utilised most often by occupational therapists for children with ASD. It is interesting that this is consistent with the Watling *et al.* (1999a) survey, which

TABLE 4: *Results on preferred method in obtaining knowledge and skills*

Preferences on methods of obtaining knowledge and skills.

Methods of obtaining knowledge and skills	*n**	Not preferred (%)	Low preferences (%)	Moderate (%)	High preferences (%)	Preferred the most (%)
Hands-on mentoring by expert/experience therapists	64	1.6	1.6	17.2	51.6	28.1
Case presentation of intervention and technique	64	1.6	14.1	45.3	35.9	3.1
Multidisciplinary workshop with discussion and problem solving	64	0.0	7.8	31.3	54.7	6.3
Short courses of specialise certification on certain technique/programme	65	4.6	4.6	21.5	43.1	26.2
Online courses	64	26.6	23.4	21.9	20.3	7.8
Conferences or seminars	66	4.5	16.7	31.8	37.9	9.1
Literature reviews	64	17.2	25.0	37.5	20.3	0.0
Advanced post-professional academic degrees	63	22.2	25.4	25.4	22.2	4.8

*n**, represents number of participants providing rating. In a five-point Likert scale ranging from 1 (very low/not preferred), 2 (low/low preferences), 3 (moderate), 4 (high/high preferences) and 5 (very high/preferred the most).

found that almost 82% of the participants from their study reported as always using sensory integration as their theoretical model in their services for children with ASD. Sensory integration and other interventions based on sensory integration approaches were among the interventions or programmes reported as being highly utilised by the participants in this study. On the other hand, the results show that almost half of the participants in this study indicated that they often performed environmental modifications in their intervention for children with ASD. It is possible that some aspects of 'changing the environment' related to changes to the sensory environment. As this was not clear from these results, this aspect warrants additional exploration in future studies.

Environmental modifications have been identified as the interventions that are most likely to enable children with ASD to achieve success in their daily activities, and to enable families to successfully manage the children's daily needs (Cale, Carr, Blakeley-Smith & Owen-DeSchryver, 2009). Cale *et al.* (2009) found that environmental modifications effectively reduced behavioural problems and increase completion of activities and daily routines in the children with ASD. Other than sensory-based interventions and environmental modifications, early intervention programmes and play therapy also were reported as being utilised by more than 50% of the participants in this study. This might be related to the age of the children with ASD served by most of them (below 5 years).

With respect to the area of adaptive behaviours in daily living activities, emphasis was given to the areas of self-care activities, school-readiness skills, social skills and play/leisure participation, as almost half of the participants indicated that they often addressed these areas of adaptive behaviours in their services. These are the common problem areas in adaptive behaviours that were challenges to children with ASD and their families (e.g. Jasmin, Couture, McKinley & Reid, 2009), and which should be the focus of intervention by occupational therapy (Rodger, Ashburner, Cartmill & Bourke-Taylor, 2010).

Interviews with parents/carers of children with ASD were reported by the majority of the participants as always being performed in their occupational therapy services for children with ASD, which is consistent with the findings from Ashburner *et al.* (2010). This reflected that the participants in this study are involving families in their practice. It is important to take into account the family's needs and challenges in planning interventions, as some studies show that higher levels of stress are present in parenting children with ASD as compared to children with other conditions (e.g. Gray, 2002; Wolf, Noh, Fisman & Speechley, 1989). Input from families should be maximised by occupational therapists to ensure that the services and supports that are really needed by the children with ASD and their families are delivered.

As can be seen from the results in Table 5, the use of standardised assessments is consistent with the results on the participants' use of FOR and interventions or programmes, with sensory-based assessments being the most frequently used standardised assessments. Ninety per cent of the participants indicated that they use sensory processing or sensory integration assessments in their services for children with ASD, with the Sensory Profile (Dunn, 1999) and/or Sensory Profile School Companion (Dunn, 2006) being the tool of choice. The gross and fine motor skills assessments were the second most frequently used assessment, with the Bruininks-Oseretsky Test of Motor Proficiency (BOT/BOT-2) (Bruininks, 1978;/Bruininks & Bruininks, 2005) being the tool of choice. This could be because most children with ASD, as reported in the literature (Adamson, O'Hare & Graham, 2006; Baranek, 2002; Dawson & Watling, 2000; Jasmin *et al.*, 2009) exhibit sensory processing difficulties and motor skill difficulties. Sensori-motor difficulties that present among children with ASD have also been reported as associated with decreased independence in performing daily living skills (Jasmin *et al.*, 2009). When asked to list the most common short-term occupational therapy intervention goals for children with ASD, the participants listed managing issues related to sensory difficulties most frequently, along with improving cognitive functions and motor skill abilities. This suggests that occupational therapists may use their knowledge and expertise in managing issues related to sensori-motor difficulties as a way of achieving occupation-based goals, rather than focusing solely on sensory-based intervention. The aim of occupational therapy is to improve performance and participation in occupation among children with ASD; however, as reported by participants in this study, goals tend to focus on improvement in sensory processing rather than occupational performance. Although there is scope for using sensory components in an occupation focused goal, it appears that improving sensory function tends to be the goal identified. Given the paucity of research regarding the effectiveness of the sensory processing intervention in improving occupation in daily activities among children with ASD, it may be time to review the evidence for both sensory processing and occupation-based approaches among occupational therapy practitioners with this population.

Involvement of parents/carers in developing suitable intervention goals for their children with ASD was important to participants, and considered necessary to gain their full participation and co-operation in the intervention process. Collaboration with other professionals was also highly rated as either 'often' or 'always' by the participants in this study. This result is consistent with the finding from the Watling *et al.* (1999a) survey that occupational therapists regularly collaborate with other professionals during both the evaluation and intervention process. This high collabo-

ration with parents/carers and other professionals in delivering services for children with ASD shows the need for soft-skills abilities, such as effective communication skills, among occupational therapists to ensure successful collaborations (Watling *et al*., 1999a). Occupational therapists should also be prepared with knowledge about other professionals' roles and the services that they offer. This can ensure smooth collaboration to ensure effectiveness on cost, time and energy in the service delivery, as role duplication and task redundancies can be avoided.

Professional development

In this study, similarities can be seen in the results concerning completed attendance at courses related to occupational therapy services for children with ASD and courses that participants indicated they would like to attend. Courses associated with, or based on, the sensory integration approach was reported as both 'most attended' and 'would like to be attended' by the participants. These results, again consistent with the results for theories, interventions or programmes and standardised assessments utilised by the participants in this study, highly emphasise the utilisation of sensory-based intervention for children with ASD. The indication that participants want to attend courses related to, or based on, sensory integration interventions more than any other possible course may reflect that many of the participants in this study indicated that they wanted to understand more about managing issues related to sensory difficulties as exhibited by children with ASD. It is of potential concern that the majority of interventions are sensory-based, and thus, the occupational needs of the children and their families in addition to sensorimotor resources may not be addressed.

When asked about the methods of obtaining knowledge and skills, hands-on and face-to-face training were the methods preferred by most of the participants in this study. The participants indicated that online courses were their least preferred method. However, some participants also suggested video conferencing and distance learning. The profession should therefore consider these methods, as they may be beneficial to those who are located in remote areas and may be cost effective. Vismara, Young, Stahmer, Griffith and Rogers (2009) found distance learning through telehealth to be equally as effective as face-to-face training when teaching therapists to implement an early intervention approach for children with ASD. Distance learning may therefore overcome the location and financial barriers of occupational therapists, enabling them to keep up-to-date in their services for children with ASD and their families.

Study limitations and future research

Due to the nature of this study, a higher response rates would have been desirable, although was not possible. Even so, a 20.4% valid response rate for a mail survey can be considered as satisfactory, according to Weisberg *et al*. (1996). Due to the nature of the mail survey adopted in this study, some participants may have different interpretations on the questions asked. Future research should be undertaken with a larger survey involving occupational therapists from other states for better understanding of the services provided for children with ASD and their families in Australia.

Findings from this study demonstrate that additional research should be undertaken to find the most effective interventions that are highly supported by evidence in managing issues relating to children with ASD, in particular those related to sensory difficulties, as this is the most common focus in service delivery. Future research should also be carried out to understand the main focuses of the families in managing the daily needs of their children with ASD. This information can be used as a guideline in delivering occupational therapy services to children with ASD and their families so as to fulfil what is really needed by them.

Conclusion

Results from this study illustrate that theories, assessments and interventions that are associated with or based on, sensory integration and/or processing approaches are highly utilised by the participants in their occupational therapy services for children with ASD despite demands made on the occupational therapists to provide intervention that is highly supported by evidence of its effectiveness (Rodger *et al*., 2010). As compared to the findings from Watling *et al*. (1999a), this is disappointing as it illustrates that there have been few changes in evidence-based practice related to the selection of theoretical model, assessments and interventions by the participants in this study in the last decade. Managing issues related to sensory difficulties exhibited by children with ASD were the main focus among the participants in this study; hence, the majority of them indicated that they would like to attend training or courses that related to or based on, sensory integration approaches. It is of potential concern that the majority of interventions are sensory-based, and that the occupational needs of the children and their families are less likely to be the focus on interventions (Rodger *et al*., 2010). Hence, an urgent need for occupation-based approaches to working with children with ASD and their families is required.

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APPENDIX 3

ONE ARTICLE RELATED TO THE THESIS ACCEPTED FOR PUBLICATION IN THE BRITISH JOURNAL OF OCCUPATIONAL THERAPY

British Journal of Occupational Therapy

Malaysian Occupational Therapists' Practices with Children and Adolescents with Autism Spectrum Disorders

Journal:	*British Journal of Occupational Therapy*
Manuscript ID:	126-Jul-2013-RP.R2
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Key Areas:	Paediatrics < Clinical, Professional Development, Assessment < Clinical
Keywords:	Theory, Interventions, Professional development

Abstract:

Introduction: Occupational therapy is one of the health care professions that provide assessments and interventions for children and adolescents with ASD. However, to date, there is no information available regarding occupational therapy practices in Malaysia for this population. The purpose of this study is to describe the occupational therapy services for children and adolescents with ASD in Malaysia, including the perceived training needs of practitioners.
Method: We surveyed the registered members of The Malaysian Occupational Therapy Association (MOTA) using a mailed questionnaire.
Findings: A response rate of 15.5% was obtained. The majority of the responses were from those working in hospital settings who had less than five years experience working as occupational therapists with children and adolescents with ASD. The theories, assessments, interventions, and training related to respondents' practice mainly revolved around sensory-based approaches. Encouragingly, more than seventy percent of the respondents claimed that they performed assessments of daily living activities in their service. Client-centred practice was further feature of occupational therapist respondents involved in this study.
Conclusion: Future study is needed, especially to engage more respondents in order to produce more generalizable results and to explore in-depth of the aspect of continuing educations needed by occupational therapists in Malaysia.

Malaysian Occupational Therapists' Practices with Children and Adolescents with Autism Spectrum Disorders

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Introduction

The recently published Diagnostic and Statistical Manual of Mental Disorders – 5th Edition (DSM-V), American Psychiatric Association (APA, 2013) specified two major characteristics of impairment in Autism Spectrum Disorder (ASD):

1) Deficits in social interaction and social communication,
2) Restricted, repetitive patterns of behaviour, interests, or activities.

The DSM-V recognises that the four previously separate disorders under the Diagnostic and Statistical Manual of Mental Disorders-IV-text revision (DSM-IV-TR) classification (APA, 2000), that is: (a) autistic disorder, (b) Asperger's disorder, (c) childhood disintegrative disorder and (d) pervasive developmental disorders not otherwise specified, are actually a single condition with different level of symptom severity in those two core deficits mention earlier. In this study, the ASD criteria as stated under the DSM-IV-TR (APA, 2000) were used because the DSM-V (APA, 2013) was only published after the research data had been collected. Internationally, it has been reported that the prevalence of this condition is increasing (Baron-Cohen et al., 2009; MacDermott, Williams, Ridley, Glasson, & Wray, 2006), with boys diagnosed more frequently than girls at a ratio of 4:1 (Fombonne, 2003).

This article reports the results of a survey of the practice of occupational therapists in Malaysia with children and adolescents with ASD. The prevalence of ASD in Malaysia is estimated at 1.6 per 1,000 (Mohd Kassim, Othman, Lai, & Mat Yusoff, 2009). Malaysia is divided into two regions separated by the South China Sea; Peninsular Malaysia to the west and East Malaysia on the Island of Borneo. National management and administrative tasks (including matters regarding children with special needs), are governed federally from central Peninsular Malaysia. Occupational therapy services in Malaysia have been available for over 50 years. Though first introduced by Barbara Tyldesley, member of the British Association of Occupational Therapists (BAOT) in 1958,

information about occupational therapy practices with children and adolescents with ASD in Malaysia is still limited.

Globally, occupational therapy practitioners form one of the professional groups involved in providing services to children and adolescent with ASD (Provost, Heimerl, & Lopez, 2007) and begun to do so in Malaysia as well (Amar, 2008). However, we have very little evidence to guide best practice approaches with this group (Jasmin et al., 2009; Wallen & Imms, 2006). Concern has also been expressed that the interventions we do use have not been well documented for evidence-based practice, and that we risk losing our occupational focus if we do not mindfully attend to it, in addition to other approaches (Rodger, Ashburner, Cartmill, & Bourke-Taylor, 2010). Hence, the main aim of occupational therapy - to provide occupation-based intervention - should always be the focus of every clinician dealing with children with ASD (Arbesman & Lieberman, 2010; Rodger, Ashburner, Cartmill, & Bourke-Taylor, 2010; Wagenfeld & Kaldenberg, 2005).

The majority of the occupational therapy services for children and adolescents with ASD in Malaysia are provided in the hospital/clinic-based setting (Muthuraman Sellathurai Pathar, President of Malaysian Occupational Therapy Association, personal communication, 2011). A minimum of a diploma/certificate in occupational therapy is required to practice in Malaysia. The training of local occupational therapists at certification level in Malaysia was started over 30 years ago under the Ministry of Health, Malaysia (MOH) with the primary objective being to fulfil requirements of government hospitals and clinics. However, over the past 15 years, training of occupational therapists at diploma and degree levels has increased, with courses offered by the Ministry of Higher Education (MOHE) and other private educational providers (Mohd Suleiman Murad, Occupational Therapy Lecturer, personal communication, 2012). Occupational therapy practitioners in Malaysia are reported to be receiving an increasing number of referrals for children and adolescents with ASD for assessments and interventions (Rohana Mukahar, Head of

Occupational Therapy Department, Universiti Kebangsaan Malaysia Medical Centre, personal communication, 2009).

To date, there is no information available regarding the theories, assessments and interventions utilised or further education needs of Malaysian occupational therapists working with children and adolescents with ASD. Database searches including CINAHL Plus, Medline, ProQuest, PsycINFO and ERIC on the keywords of *occupational therapy* and *Malaysia* and *service/practice* and *autism/autistic* returned no results for literature published between 1992 and 2012. Hence, the aim of this study is to describe the occupational therapy practices in Malaysia provided to children and adolescents with ASD aged between three and eighteen years, in terms of theories, assessment, intervention and professional development needs. Occupational therapists working throughout Malaysia were surveyed in this study. Thus, this is the first published study reporting on the occupational therapy services for children with ASD in Malaysia.

Literature review

Occupational therapy is one of the most common services received by children with ASD and their families (McLennan, Huculak, & Sheehan, 2008). In the U.K., the prevalence of ASD was reported at 1% in a total population of school-aged children between 5-9 years (Baron-Cohen et al., 2009). In the U.S., the overall estimated prevalence of ASD was reported at one in 50 children – a significant increase from that previously reported (Blumberg, et al., 2013). Occupational therapy within the U.S., for example, provides various interventions including early intervention programs, social skills training and educational intervention programs (Case-Smith & Arbesman, 2008). Although much is now known about the characteristics of children who have ASD, the underlying occupational performance issues and effective interventions for children with ASD remain poorly understood (Wallen & Imms, 2006). Furthermore, explicit information regarding the interventions and services received by children with ASD and their families is limited (McLennan et al., 2008). It

was reported that children with ASD experienced difficulties in personal care activities (Allik, Larsson, & Smedje, 2006; Cermak, Curtin, & Bandini, 2010; Flynn & Healy, 2012; Twachtman-Reilly, Amaral, & Zebrowski, 2008), poor engagement in school or classroom activities and with peers (Falkmer, Granlund, Nilholm, & Falkmer, 2012), as well as motor difficulties that can cause occupational performance problems for those children (Green et al., 2009; Liu, 2013; Rinehart & McGinley, 2010; Shetreat-Klein, Shinnar, & Rapin, 2012).

To date, there have been three studies reporting on occupational therapy services provided specifically - for children and adults with ASD: Watling, Deitz, Kanny, and McLaughlin (1999a) performed a study in the U.S., Ashburner, Ziviani, and Rodger (2010, unpublished report) in Queensland, Australia and Kadar, McDonald, and Lentin (2012) in Victoria, Australia. Despite a gap of a decade, there are strong similarities in the findings of those studies. They relate to the emphasis given by the occupational therapist participants in managing issues and providing interventions related to sensory processing difficulties exhibited by people with ASD, as well as the need for knowledge related to sensory-based approaches in the area of assessment, intervention, and training in their service for this population. Despite the therapists' emphasis on working with sensory processing difficulties in these reports of their practice, there is currently little evidence of the effectiveness of the sensory-based interventions or approaches for children and adolescents with ASD (Hyatt, Stephenson, & Carter, 2009).

It is also important for occupational therapists to consider the use of other related approaches and/or useful strategies in their interventions for children and adolescents with ASD (Arbesman & Lieberman, 2010). Increasingly, studies that investigate improvement of occupational performance of children and adolescents with ASD are being performed (Rodger & Brandenburg, 2009), such as the Cognitive Orientation for Daily Occupational Performance (CO-OP). CO-OP is a task-orientated problem-solving approach that utilises cognitive skills to improve occupational performance (Rodger, 2004). Other than that, the use of physical strategies which are more

occupation- and activity-focused, such as leisure and recreation activities, in interventions among children and adolescent with ASD has also been observed (O'Brien, 2010).

Methods

Design

A self-administered questionnaire was mailed to occupational therapists in Malaysia. The questionnaire used in this study was adapted from a questionnaire titled *'Current Practice of Occupational Therapy for Children with Autism: A National Survey of Practitioners©'* developed by (Watling, Deitz, Kanny, & McLaughlin, 1999b) for their survey of occupational therapists in the USA. This questionnaire was selected as the basis for the questionnaire used in this study. Considerable modification was required, as the original questionnaire was (a) designed for therapists based in the USA, and (b) designed and carried out prior to 1999 (Watling, 2009, personal communication). Permission to do so was granted by the first author. The questionnaire was modified to include more current information related to occupational therapy and ASD by reviewing relevant occupational therapy textbooks and literature (Case-Smith, 2005; Case-Smith & Arbesman, 2008; Kramer & Hinojosa, 2010; Miller-Kuhaneck, 2004; Mulligan, 2003; Watling et al., 1999a) and was also based on a questionnaire titled – '*The Paediatric Occupational Therapy Practitioner Survey©*' (Brown & Rodger, 2001, unpublished tool) (permission to modify the questionnaire was granted by the author). The modified questionnaire includes more current assessment tools and interventions provided to children with ASD compared to the original questionnaires. To ensure its face and content validity, the questionnaire was sent to 12 experts in the occupational therapy and/or ASD field internationally (including experts from U.S.A., Australia, Malaysia and Taiwan).

The purpose of sending the initial questionnaire to the experts was to ensure that the design of the questionnaire works in practice, and also to identify and amend problematic questions and refine

the questionnaire, as well as to identify problems relating to the content, wording, layout, length, and instructions in the questionnaire. The questionnaire was further tested by six Malaysian occupational therapists who had experience working with children with ASD, to ensure that the English language used in the survey was applicable to Malaysian occupational therapists. None of the six tested therapists suggested that the questionnaire should either be in Malay language or bi-language (i.e.: English and Malay languages) because English is used in most of the teaching delivery and training activities of the occupational therapists in Malaysia. The feedback received was used to produce the final version of the questionnaire titled *'Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders'* used in this study (The questionnaire can be obtained from the corresponding author).

The final questionnaire was divided into six sections:

- Section A: the frame(s) of reference and model(s) of practice utilised with children with ASD.
- Section B: the assessments or outcome measures administered to children with ASD.
- Section C: the interventions utilised in occupational therapy services for children with ASD.
- Section D: the areas of adaptive behaviours addressed in occupational therapy services for children with ASD.
- Section E: the issues on professional development needs among occupational therapists.
- Section F: the respondents' demographic information including personal and professional information.

The developed questionnaire was also used to collect data from occupational therapists in Victoria, Australia and these results have been reported in the Australian Occupational Therapy Journal, volume 59, issue 4 (Kadar et al., 2012).

Respondents

The respondents in this survey were Malaysian qualified non-international occupational therapists who were members of the Malaysian Occupational Therapy Association (MOTA). To be included in the study, the respondents must work or have worked with children and adolescents with ASD in occupational therapy services either in Peninsular or East Malaysia. The association was consulted for their help in identifying potential respondents for the survey.

The first author was given access to the MOTA members' information database to locate addresses for mailing out the survey. However, out of 459 ordinary members listed (December, 2009), only 362 members had their full names and addresses recorded in the database. The remaining 97 members had incomplete names or addresses. It was not known whether the complete details of members were current. There was also no indication on the database of the members' service areas or specialties (such as whether they are working in the paediatrics area or in any other specialised areas) to enable the researchers to select and mail the surveys only to those in the target group for the purpose of this study; hence, the survey was mailed to the 362 Malaysian occupational therapists whose full names and addresses were on the MOTA database.

Procedures

Ethical approval was granted by The Monash Human Research Ethical Committee (MUHREC) and The Research Promotion and Co-Ordination Committee, Economic Planning Unit (EPU), Prime Minister's Department, Malaysia. The self-administered survey was mailed to members on the MOTA database, together with an introductory letter, explanatory statement and a stamped, self-addressed envelope. In order to encourage the response rate, reminders were sent out at two and four weeks (Salant & Dilman, 1994). Return of the anonymous surveys by the respondents was considered as their consent to take part in the study. To ensure the privacy and confidentiality of the

respondents, no identifying information was kept or recorded by the researchers. No incentive was provided for participating in the survey.

Data analysis

Numerical data were entered into the SPSS Version 18.0 and analysed to generate descriptive statistics such as frequencies and percentages. The answers given to open-ended questions were categorised following the content analysis process described by Liamputtong (2009, p. 281). Firstly, all responses to open-ended questions were read entirely for each question to gain an understanding of their meaning. Codes were then assigned to all answers for each question by the first author. These codes were then grouped together into categories and the replies for each code and category were then counted (Liamputtong, 2009). However, to prevent bias, an audit trail was performed by the third author to ensure the coding and categorising was accurate. Where discrepancies arose, the respondents' responses to the open-ended questions were always referred to in order to ascertain the correct coding and categorising.

Results

Response rates

Seventy-eight respondents returned their survey during the 3-month data collection period. However, 26 were excluded, because they indicated that they had never worked with children with ASD. These 26 negative responses were excluded from the survey sample total of 362, making the valid response rate 15.5% for a total of 52 respondents. According to Weisberg et al. (1996), the response rate for postal surveys tends to fall between 10% and 50%. The response rate for this study is at the lower end of this range. Due to the limitations of the MOTA database, we cannot be sure if

this is a valid response rate representative of Malaysian occupational therapists who have worked with children and adolescents with ASD.

Characteristics of the Participants

Results show that 82.7% of the respondents were from Peninsular Malaysia and 17.3% were from East Malaysia. In terms of the respondents' academic qualifications, 71.0% held diploma/certificates in occupational therapy and all of them are qualified general occupational therapy practitioners, as none reported that they had received any certification or specialised training in certain areas, such as certification in sensory integration. The majority of the respondents worked in hospital settings (82.7%). 57.7% of the respondents reported having one to five years working experience as occupational therapists. Table 1 detailed the participants' characteristics.

Table 1: The details result on the participants' working experiences as occupational therapists and working with children with ASD and their academic qualification

Participants' working experiences	Frequency	Percentage
Years of practicing as an occupational therapist		
Less than 1 year	6	11.5
1-5 years	30	57.7
6-10 years	9	17.3
11-15 years	6	11.5
16-20 years	1	2.0
Total	**52**	**100.0**
Years of working with children with ASD		
Less than 1 year	31	59.6
1-5 years	18	34.6
6-10 years	3	5.8
Total	**52**	**100.0**
Highest academic qualification		
Diploma/certification in occupational therapy	37	71.0
Bachelors degree in occupational therapy	14	27.0
Coursework/research masters	1	2.0
Total	**52**	**100.0**

Occupational Therapy Practice

Frames of reference and models of practice

Results showed that 98.1% of the respondents indicated that they used Frames of Reference (FOR) and 92.3% Models of Practice (MOP), to guide their service delivery with children and adolescents with ASD. The most common FORs in use were the Sensory Integration FOR (Kimball, 1999) (92.3%), and Psychosocial FOR (Olson, 1999) (63.5%). In terms of models of practice, the Model of Human Occupation (MOHO) (Kielhofner, 2008; Kielhofner & Burke, 1980) was used by the majority of the respondents (73.1%).

Interventions

The six interventions/programs indicated as being "often" and "always" used were: (1) Play therapy (86.6%), (2) Sensory Integration Training (79.2%), (3) Sensorimotor Stimulation (78.8%), (4) Pre-school Training (77.0%), (5) Early Intervention (65.4%), and (6) Snoezelen therapy (60.8%).

Age group of children with ASD served most frequently

69.2% of the respondents reported that they mainly see children with ASD aged below 5 years (pre-school) and 36.5% for those aged between 6 and 18 years, with 9.6% of the respondents seeing both age groups.

Methods of assessment and outcome measures

The following methods of assessments were reported by the majority of the respondents as "often" and "always" utilized: performing interviews with parents/caregivers (90% of the respondents), utilizing informal assessment/screening tools (70.8%), utilizing standardized assessment/screening tools (56.3%) and observation in multiple environments (46%). Two methods of assessment were

reported by the majority of the respondents as "seldom" and "sometimes" used; namely, interviews with teachers/education staff (70%) and interviews with other health professionals (67.3%). Four types of standardized assessments were administered by the majority of the respondents. These assessments and the tools frequently used were (1) developmental screenings and evaluations (76.9%) (Denver Developmental Screening Test), (2) activities of daily living skill assessments (76.9%) (Modified Barthel Index of Activities of Daily Living), (3) gross or fine motor skill assessments (69.2%) (Denver Developmental Screening Test), and (4) sensory processing or sensory integration assessments (67.3%) (Sensory Profile/Sensory Profile School Companion).

Short term occupational therapy intervention goals

The answers to the open-ended question where the respondents were asked about their top five most common short-term occupational therapy intervention goals when working with children and adolescents with ASD, showed that the top five most common short-term goals were: (1) improving attention and concentration skills (26 responses), (2) improving communication and social skills (26 responses), (3) managing issues related to sensory difficulties (18 responses), (4) improving self-care skills (16 responses), and (5) improving physical functions (e.g., motor skills; muscle strength) (15 responses).

Collaboration with other people or professionals and the level of confidence

All respondents had collaborated with parents/caregivers in their provision of services for children and adolescents with ASD. The majority of the respondents (67.3%) reported that they "always" worked with parents/caregivers, 51% reported they "sometimes" worked with teachers/education staff, and 38% reported they worked with speech therapists/speech pathologists. Furthermore, the majority of the respondents felt "moderately" confident when working with children and

adolescents with ASD (59.6%), 38.3% felt "high" or "very high" confidence, and 2.1% felt "low" confidence.

Professional development

Training/certification/continuing education courses either attended or listed as desirable to attend

The three most frequently attended courses for professional development related to the provision of services for children and adolescents with ASD were:

1) sensory-based interventions/trainings (12 responses)

2) knowledge/understanding about ASD (nine responses), and

3) behavioural skills training (four responses).

The three most frequently stated courses that the respondents would like to attend were:

1) sensory-based interventions/training (22 responses)

2) behavioural skills training (15 responses), and

3) social skills training (eight responses).

Preferred methods for obtaining knowledge and skills

Table 2 lists the respondents' preferred methods for obtaining knowledge and skills. Hands-on mentoring by expert/experience therapists and attending short courses of specialised certification on certain techniques/programmes were two methods most preferred by Malaysian occupational therapists in obtaining knowledge and skills; these were reported by 43.1% and 33.3% of the respondents, respectively. Only 4% of the respondents gave top preference to the method of literature reviews to obtain knowledge and skills.

Table 2: Results on preferred method in obtaining knowledge and skills

Preferences on methods of obtaining knowledge and skills.						
Methods of obtaining knowledge and skills	n†	Not preferred (%)	Low preferences (%)	Moderate preferences (%)	High preferences (%)	Preferred the most (%)
Hands-on mentoring by expert/experience therapists	51	0.0	3.9	21.6	31.4	43.1
Case presentation of intervention and technique	51	0.0	3.9	31.4	49.0	15.7
Multidisciplinary workshop with discussion and problem solving	51	2.0	0.0	21.6	49.0	27.5
Short courses of specialise certification on certain technique/programme	51	2.0	3.9	29.4	31.4	33.3
Online courses	49	10.2	30.6	44.9	8.2	6.1
Conferences or seminars	50	6.0	6.0	30.0	50.0	8.0
Literature reviews	50	10.0	20.0	38.0	28.0	4.0
Advanced post-professional academic degrees	47	14.9	14.9	27.7	23.4	19.1

n† Represents number of participants providing rating. In a five-point Lickert scale ranging from 1 (not preferred), 2 (low preferences), 3 (moderate), 4 (high preferences) and 5 (preferred the most)

Discussion

Descriptions of the occupational therapy practices in Malaysia with children and adolescent with ASD

The fact that the majority of the respondents in this study worked in hospital-based settings is consistent with the statement made by Muthuraman Sellathurai Pathar, the President of the Malaysian Occupational Therapy Association (personal communication, 2011). The data gathered in this study were largely from respondents who have worked as occupational therapists and with children and adolescents with ASD for less than 5 years. Most respondents were from Peninsular Malaysia; thus, generalization of the results obtained in this study to the practices of all Malaysia occupational therapists working with children and adolescents with ASD is limited.

Clearly, further study is needed in order to get a more representative description of the occupational therapy practices in Malaysia with children and adolescents with ASD. Similar to the findings from Watling et al. (1999a), Ashburner et al. (2010, unpublished report) and Kadar et al. (2012),

respondents from Malaysia also reported the use of theories, assessments and interventions associated with sensory-based approaches for children and adolescents with ASD. These are evident in the high reported use of the sensory integration FOR (Kimball, 1999) to guide their practice and also in the choice of the sensory integration training (Kimball, 1999) and sensorimotor stimulation (Huebner & Lane, 2001) in their interventions. However, this is quite concerning as, while none of the respondents in this study reported that they have received specialised training or are certified in sensory integration, some of them are using sensory integration intervention approaches in their services for children and adolescents with ASD. Unlike users of sensory-based stimulation, therapists who want to provide sensory integration therapy should undergo extensive training and be certified in that therapy.

It is interesting to note that, besides assessments and intervention based on sensory integration and sensory-based stimulations, majority of respondents also indicated performing activities of daily living skills assessments, developmental screenings and evaluations and gross or fine motor skills assessments. This is an encouraging result to see, especially the fact that 76.9% of the respondents stated that they performed activities of daily living skills assessments in their practices with children and adolescent with ASD. According to Green et al. (2009), motor impairments are found to be common in children with ASD which might explain why the majority of the respondents reported performing gross or fine motor skill assessments in their services for children with ASD in Malaysia.

Occupational therapists' perspectives on occupations-based practice can be varied (Estes & Pierce, 2012; Müllersdorf & Ivarsson, 2011); however, interventions based on daily occupation in order to achieve independence, such as self-care activities, should be the main focus in occupational therapy services with this population (Arbesman & Lieberman, 2010; Diamantis, 2010; Rodger et al., 2010). According to Drysdale, Casey, and Porter-Armstrong (2008), training on daily activities such as shopping and telephone tasks in community-based training for children with intellectual

disability might be more effective compared to classroom-based training. Studies show that children with ASD experience difficulties managing their daily occupation regardless of their level of cognitive function; for example, children with high functioning autism (Perry, Flanagan, Geier, & Freeman, 2009; Schatz & Hamdan-Allen, 1995). Moreover, the gap between the ability to function independently in daily living skills has been reported to widen as the children with ASD grow older (Kanne et al., 2011). In order to enhance occupational performance in children with ASD, no single approach or therapy might be effective to achieve this. Best practices may be the combination of those interventions that use or modulate sensory experiences among those children, which may be achieved through play to enhance their skills in daily living activities.

It is important for occupational therapy practitioners to implement evidence-based intervention in their service with children with ASD, as reports show that parents are highly likely to abandon interventions which were either ineffective or poorly based on evidence (Bowker, D'Angelo, Hicks, & Well, 2011). In a setting such as Malaysia, where resources for interventions are much less available than in more developed countries, this becomes even more essential. Lyons, Casey, Brown, Tseng, and McDonald (2010) suggested that additional education in conducting research activities might be beneficial to occupational therapist practitioners in order to improve their abilities in guiding their practices based on strong evidence. However, the very low preference for acquiring knowledge and skills via reviewing literatures indicated by the respondents in this study is quite concerning. This decision could be due to heavy workloads faced by occupational therapy practitioners that make it difficult for them to implement evidence-based practices, as reported by occupational therapists from across seven acute National Health Services (NHS) in UK (Humphris, Littlejohns, Victor, O'halloran & Peacock, 2000). This highlights the area that needs to be strengthened in the education of occupational therapists, at least during the student period (Arbesman & Lieberman, 2010).

It can be seen from the results of this study that a high percentage of the respondents worked closely with parents/caregivers of children with ASD. A study by Boyd, McDonough, Rupp, Khan, & Bodfish (2011) showed that parents' involvement in the intervention of children with ASD managed to significantly reduce repetitive behaviours among such children; other encouraging results were also achieved.

Regarding professional development needs, the majority of the respondents in this study indicated that they had either attended or needed to attend courses related to sensory-based approaches to improve their knowledge and skills in their service with children with ASD. This emphasis on attending and desire to attend courses related to sensory integration therapy and sensory-based approaches needs to be explored further to ascertain the reasons the respondents feel that they are lacking in this area of intervention compared to some other areas, such as the occupation-based intervention in daily living; hence, why they need to know more about sensory integration therapy and sensory-based intervention. It is also essential for occupational therapists to clearly explain to the parents about the limited evidence available on the effectiveness of the use of sensory integration therapy (American Academic of Pediatrics, 2012; Arbesman & Lieberman, 2010).

Study limitations and future research

A major limitation of this study is the size and representativeness of the sample with the majority of the responses from respondents in Peninsular Malaysia. For future research, the response rate obtained could be improved if the membership' database kept by MOTA were updated and completed in terms of its members' full name, their current addresses and also their specialty areas (if any). A database that contains complete and current information about its members would be an important source of information for further development and understanding of workforce and service needs, as well as a useful resource for assisting with research regarding the future and directions of this profession in Malaysia. Future research to explore how the practitioners

incorporate sensory integration therapy and sensory-based approaches in order to improve occupational performance, as well as other intervention approaches, into their occupational therapy services for children and adolescents with ASD would be very worthwhile.

Conclusion

This is the first published study reporting on the occupational therapy practices in Malaysia with children and adolescents with ASD. Regardless of differences in cultural, educational and health care systems, results from this study illustrate similarities in occupational therapy practices with children with ASD in Malaysia to those in other international studies (Watling et al., 1999a; Ashburner, Ziviani, and Rodger, 2010, unpublished report; Kadar et al., 2012). The majority of the respondents in this study reported using theories, assessments and interventions that are associated with, or based on, sensory integration and/or processing approaches in their practices with children and adolescents with ASD. However, it was also encouraging to see that the majority of the respondents reported that they performed activities of daily living assessments in their service, which reflected that this area of daily occupation was not being overlooked by them. The element of client-centred practice was also highly implemented by occupational therapist respondents involved in this study, as they reported that they sought to involve parents/caregivers of children and adolescents with ASD in their service deliveries.

Acknowledgements

We would like to extend our gratitude to the occupational therapists in Malaysia who were willing to spend their valuable time in completing the questionnaire. We would also like to thank Malaysia Occupational Therapy Association (MOTA) for its help in assisting with the addresses for mailing out the survey to its members. Furthermore, we would like to acknowledge Dr. Jill Ashburner for sharing her information on a survey of current practices, training and professional development

needs of occupational therapists who provide services to people with Autism Spectrum Disorders (Ashburner, Ziviani, and Rodger, 2010, unpublished report) freely and for her generous help.

Conflict of interest: None declared.

Key Findings

- Occupational therapy practices in Malaysia for children and adolescent with ASD highly utilised sensory integration therapy and sensory-based approaches in their theories, assessments and interventions.
- An encouraging percentage of participants performed the interventions of daily living skills in their service for children with ASD.

What the study has added

This is the first published study to describe the practices of occupational therapy with children with ASD in Malaysia. Future study involving more representative samples from both Peninsular and East Malaysia will assist in defining the practices clearly.

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APPENDIX A

INTERVENTIONS FOR CHILDREN AND ADOLESCENTS WITH ASD

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)

Study	Aims of study	Study design	Participants	Results	Study level
Baranek, G. T. (2002).	1. Summarise the empirical literature with respect to sensory and motor development/ abnormalities in children with autism, 2. Evaluate the scientific basis of sensory and motor interventions used with children with autism, and describe implications of these findings for education and further research.	Systematic review focused on past 10 years studies.	Systematic review.	Although some studies show positive results in the used of sensory and motor interventions for children with autism, the evidence remains weak owing to some limitations in the study design.	Level I
Escalona, A., Field, T., Singer-Strunck, R., Cullen, C., & Hartshorn, K. (2001).	To determine the effectiveness of massage therapy in increasing sleeping pattern in children with ASD.	Randomised Controlled Trial into massage therapy group and reading group as control.	20 children with ASD (12 boys and 8 girls), ages 3 to 6 years.	Results show that the children in the massage group exhibited less stereotypic behaviour, more on-task and social relatedness behaviour during play observations at school, and experienced fewer sleep problems at home.	Level I

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Field, T., Lasko, D., Mundy, P., Henteleff, T., Kabat, S., Talpins, S., et al. (1997).	To investigate the effects of touch therapy on three problems commonly associated with autism including inattentiveness (off-task behavior), touch aversion, and withdrawal.	Randomised Controlled Trial to touch therapy group and touch control group.	22 children with ASD (12 boys) who had attended a special preschool half days for 2 years participated in the study.	Aversion to touch decreased in both group, off-task behaviour also decreased in both groups, and orienting to irrelevant sounds also reported to decrease in both groups, but significantly more in the touch therapy group.	Level I
Bettison, S. (1996).	To investigate the effects of auditory training on children with autism using modulated music.	Randomised controlled trial to experimental group receiving modulated music and control group receiving unmodulated music.	80 children, 3-17 years of age.	Significant improvements in both groups in: - behavior and severity of autism, - improvement in abnormal responses to sound and other sensory abnormalities, - Verbal and performance IQ increased significantly.	Level I
Edelson, S.M., Arin, D., Bauman, M., Lucas, S.E., Rudy, J.H., Sholar, M., et al. (1999).	To evaluate the effectiveness of auditory integration training (AIT).	RCT, double-blind study. Experimental group receiving auditory process music and control group receiving auditory unprocessed music.	19 children and adults with ASD (9 in experimental group and 10 in control group.	- significant reduction in behavioural problems, - reduced sound sensitivity, - improved hearing and comprehension, and - increase eye-contact.	Level I

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Edelson, S.M., Arin, D., Bauman, M., Lucas, S.E., Rudy, J.H., Sholar, M., et al. (1999).	To evaluate the effectiveness of auditory integration training (AIT).	Randomised controlled trial, double-blind study. Experimental group receiving auditory process music and control group receiving auditory unprocessed music.	19 children and adults with ASD (9 in experimental group and 10 in control group.	Results show: - significant reduction in behavioural problems in experimental group, - reduced sound sensitivity, - improved hearing and comprehension, and - increased eye-contact.	Level I
Mudford, O.C., Cross, B.A., Breen, S., Reeves, D., Gould, J., et al. (2000).	To evaluate the effectiveness of auditory integration training (AIT).	Crossover experimental design.	16 children with ASD.	Results show decreased hyperactivity and problem behaviours, however, no individual child was identified as benefiting clinically or educationally from the intervention.	Level I
Field, T., Field, T., Sanders, C., & Nadel, J. (2001).	To determine whether multiple sessions of an adult imitating the behavior of children with autism might increase their social initiations and responsiveness.	Randomised controlled trial.	20 non-verbal children with ASD (10 girls, 10 boys) ranging in age from 4 to 6 years.	Results show that adults' imitations behaviours might be potentially useful in increasing social initiations and responsiveness in children with ASD.	Level I

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Sinha, Y., Silove, N., Wheeler, D., & Williams, K. (2004).	To determine the effectiveness of auditory integration training (AIT) or other methods of sound therapy in individuals with ASD.	Systematic review.	Systematic review.	Results on the effectiveness of AIT were inconclusive and more research is needed to inform parents', carers' and practitioners' decision making about the effectiveness of AIT for individuals with ASD.	Level I
Hwang, B., & Hughes, C. (2000).	To investigate the effects of social interactive interventions.	Systematic review.	Systematic review on 16 empirical studies.	Results show that increases were found for social and affective behaviours, nonverbal and verbal communication, eye contact, joint attention, and imitative play. Limited generalization or maintenance of target behaviours was also reported.	Level I
Legoff, D.B. (2004).	To investigate the effectiveness of using LEGO in improving social competence in children with ASD.	Nonrandomised clinical trial.	47 children, with five groups of seven and two groups of six. 34 males and 13 females, ages between 6 and 16 years.	Improvement in motivation to initiate social contact with peers and ability to sustain interactions with peers, and overcoming autistic symptoms of aloofness and rigidity. No evidence of gains during the waiting list period and no gender differences were found on outcome, age of clients was not correlated with outcome.	Level II

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Legoff, D.B., & Sherman, M. (2006).	To investigate the effectiveness of using LEGO in improving social competence in children with ASD and to investigate whether the benefits would be sustained over a longer period and would generalize to a broader range of skills and social development.	Nonrandomised clinical trial.	60 children with ASD, mean age of 9.3 years in LEGO group, and 57 children with ASD mean age of 10.1 years in comparison group.	Children with ASD in the LEGO group showed significant improvement in social skills as compared to the control group.	Level II
Schleien, S.J., Mustonen, T., & Rynders, J.E. (1995).	To evaluate the effects of inclusive art activities, activities designed to encourage cooperation and positive interactions, on the frequency of social interactions between participants with and without autism.	A multiple baseline design across groups.	15 students with autism and 53 nondisabled students. Children with autism ranged from 4 to 11 years.	Results support the use of inclusive art classes as a medium for promoting social interactions directed toward children with autism by their nondisabled peers.	Level III
Greenspan, S.L., Wieder, S. (1997).	To investigate the patterns in symptoms, processing difficulties, early development and response to intervention in children with ASD.	Before-after, one group study design.	200 children with ASD (age range between 22 months to 4 years at initial evaluation).	With appropriate intervention programme, children with ASD were reported as capable of developing empathy, affective reciprocity, creative thinking, and healthy peer relationship.	Level III

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Mahoney, G., & Perales, F. (2005).	To compares the effects of relationship-focused early intervention on children who were classified as having either pervasive developmental disorders (PDDs) or developmental disabilities (DDs)	Before and after comparisons.	20 children with PDDs and 30 children with DDs.	Both groups of children made significant improvements in their cognitive, communication, and socioemotional functioning. However, children with PDDs made greater improvements on the developmental measures than children with DDs.	Level III
Panerai, S., Ferrante, L., & Zingale, M. (2002).	To compare the effectiveness of two educational treatments, the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) programme and the integration programme for individuals with disabilities.	Nonrandomised clinical trial.	8 children with ASD in each group - the TEACCH program and an integration programme. All participants were boys and matched in gender and severity, mean age 9 years.	Children with ASD in the experimental group show significant improvement as compared to the children in a comparison group.	Level II

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Ozonoff, S., & Cathcart, K. (1998).	To investigate the effectiveness of a TEACCH-based home program intervention for young children with autism.	Nonrandomised clinical trial.	11 children with ASD in the treatment group and 11 children with ASD in control group.	Results show that children in the treatment group improved significantly more than those in the control group on the skills of: - imitation, - fine motor, - gross motor, and - nonverbal conceptual skills.	Level II
Rogers, S.J., Herbison, J.M., Lewis, H.C., Pantone, J., & Rels, K. (1986).	To investigate the program model for young children with autism, PDD, or severe emotional handicaps and to investigate the developmental changes which the children in the program demonstrated after at least six months of enrolment.	Before and after, descriptive study.	26 children, ages between 2 to 6 years, who had infantile autism, pervasive developmental disorder, or severe emotional handicaps.	Results show that the children demonstrated positive changes in several targeted developmental areas including: - cognition/ perceptual - fine motor, - social/emotional,and - language skills.	Level III
Reynhout, G., & Carter, M. (2006).	To investigate the evidence on the effects of social stories.	Systematic review.	Systematic reviews on 16 studies (12 were single-subject design).	The combined effects on the effectiveness of social stories remain minimal.	

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Bauminger, N. (2002).	To investigate the effectiveness of a cognitive behavioral intervention for the facilitation of social-emotional understanding and social interaction.	Before and after design.	15 high-functioning children with ASD, aged between 8 to 17 years.	Results demonstrated progress in three areas of: - interpersonal problem solving, - affective knowledge, and - social interaction. Children were more likely to initiate positive social interaction with peers after treatment in term of: - improved eye contact and ability to share experiences with peers and - to show interest in peers.	Level III
Broderick, C., Caswell, R., Gregory, S., Marzolini, S., & Wilson, O. (2002).	To explore the possibilities for supporting adolescents with Asperger syndrome to join youth groups and clubs in the community.	Before and after design.	9 individuals in 2 groups, aged 12 to 15 years.	Participants reported to have increased self-esteem and confidence after receiving the programme.	Level III
Ozonoff, S., & Miller, J. (1995).	To investigate the effectiveness of a social skills training program for normal-IQ adolescents with autism.	Before and after design.	9 male adolescents. 5 in treatment group and 4 in control group.	Social skills training providing systematic instruction was able to improve performance on several false belief tasks.	Level III

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Howlin, P., & Yates, P. (1999).	To encourage greater independence in areas such as work and living arrangements.	Before and after design.	10 individuals (all male), average age of 28.4 years.	Results show improvement in appropriateness of communication, although total amount of speech did not change.	Level III
Diggle, T., McConachie, H.R., & Randle, V.R.L. (2003).	To determine the extent to which parent-mediated early intervention has been shown to be effective in children with ASD aged 1 year to 6 years 11 months.	Systematic review.	Systematic reviews on 2 studies.	Results show that parent-mediated intervention was more effective compared to community day care.	Level I
Sofronoff, K., Leslie, A., & Brown, W. (2004).	To increase parental competence in management of problem behaviours associated with Asperger syndrome.	Randomised controlled trial.	51 parents of children with Asperger syndrome aged between 6–12 years.	Parents reporting fewer and lower intensity of problem behaviours and increased social interactions.	Level I
Drew, A., Baird, G., Baron-Cohen, S., Cox, A., Slonims, V., Wheelwright, S., et al. (2002).	To investigate the effectiveness of parent training intervention for children with autism in improving joint attention skills and joint action routines.	Randomised controlled trial.	24 children with and randomized to the parent training group or to local services only.	Children with autism in the parent training group were reported to show improvement in their language abilities compared to children with autism in the local services group.	Level I

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Koegel, R.L., Bimbela, A., & Schreibman, L. (1996).	To assess collateral effects of two different parent training paradigms during unstructured dinnertime interactions in the family setting.	Nonrandomised controlled trial.	17 children with autism and their families.	Participants whose parents were taught to focus on motivating and responding to them were reported to show more positive parent-child interaction.	Level II
Sofronoff, K., & Farbotko, M. (2002).	To investigate the effectiveness of parent management training on self-efficacy in parents with children with Asperger syndrome.	Nonrandomised group comparison into 2 formats of intervention group and non-intervention group.	45 mothers and 44 fathers of children diagnosed with Asperger Syndrome whose children were aged between 6-12 years.	Results indicated that parents in both intervention groups reported fewer problem behaviours and increased self-efficacy in their children with Asperger syndrome.	Level II
Lovaas, O. (1987).	To investigate the effectiveness of the intensive behavioural treatment in children with ASD.	Nonrandomised clinical trial into experimental group receiving 40 hours per week of intensive discrete trial training and control group receiving 10 or fewer hours per week of discrete trial training.	19 pre-school age children with ASD into experimental group and 19 pre-school age children with ASD into control group.	9 children in the experimental group had been placed in regular education classroom and had IQs in the normal range as compared to only 1 child in the control group.	Level II

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
McEachie, J.J., Smith, T., & Lovaas, O. (1993).	To investigate the effectiveness of the intensive behavioural treatment in children with ASD. Follow-up study from Lovaas, O. (1987).	Nonrandomised clinical trial into experimental group receiving 40 hours per week of intensive discrete trial training and control group receiving 10 or fewer hours per week of discrete trial training.	19 children with ASD into experimental group and 19 children with ASD into control group. Mean age of participants were 11.5 years.	8 out of 9 children in the experimental group from the Lovaas (1987) study were reported to be indistinguishable from average children on their IQs and adaptive behaviours. Therefore, this result confirmed the original result of Lovaas (1987).	Level II
Sallows, G.O., & Graupner, T.D. (2005).	To investigate the effectiveness of the intensive behavioural treatment for children with ASD, both administered by professionals and by parents.	Randomised controlled trial into clinic-directed group or parent-directed group as control group.	24 children with ASD.	Children in both groups show improved cognitive, language, adaptive behaviours, social behaviours, and academic performance.	Level I
Smith, T., Groen, A., & Wynn, J.W. (2000).	To investigate the effectiveness of discrete trial training with young children with ASD.	Randomised controlled trial into intensive behavioural treatment or parent training as control group.	15 children (12 boys) were in the intensive behavioural group. 13 children (11 boys) were in the control group.	Children who received intensive behavioural treatment showed significantly higher IQs, visual spatial skills, and language development as compared to control group. However, no difference in adaptive behaviours in both groups.	Level I

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Cohen, H., Amerine-Dickens, M., Smith, T. (2006).	To replicate Lovaas (1987) study of the early intensive behavioural treatment (EIBT) in the community setting.	Nonrandomised clinical trial into EIBT group and community group as control group.	21 children with ASD received EIBT. 21 children with ASD received community-based services.	EIBT group obtained significantly higher IQ and adaptive behavior scores than did the comparison group. No difference between groups was found in language comprehension or nonverbal skill.	Level II
Smith, T., Lovaas, N.W., & Lovaas, O.I. (2002).	To examine the pattern of interactions of children with high-functioning autism with their peers of children with delayed developmental and autism group and with the children with typical developmental group.	Crossover experimental design.	3 groups of children: Children with high-functioning autism (n=9), children with delayed developmental with autism (n=7) and children with typical developmental (n=8).	Children with high-functioning autism were reported to interact more and displayed more interactive play when paired with the children with typical developmental peers.	Level I

Table A1

Studies involved in the comprehensive systematic review of interventions for children and adolescent with ASD used in or of relevance to occupational therapy practice conducted by Case-Smith & Arbesman (2008)(continued)

Study	Aims of study	Study design	Participants	Results	Study level
Eldevik, S., Eikeseth, S., Jahr, E., & Smith, T. (2006).	To evaluate the effects of intervention programs for children with autism that combines a relatively small amount of one-to-one behavioral treatment and placement with typical peers.	Retrospective comparison of children who had received low-intensity behavioural treatment with children who had received a comparable amount of elective treatment.	13 children in low-intensity behavioural treatment group and 15 children in elective treatment group.	Children in the low-intensity behavioural treatment noted to show improvement in: - intellectual functioning, - language and communication abilities. No difference in adaptive behaviours or daily living skills in children from both groups.	Level II
Horner, R., Carr, E., Strain, P., Todd, A., & Reed, H. (2002).	To investigate interventions designed to improve problem behaviours in young children with ASD.	Research synthesis.	Research synthesis on 9 studies and 5 review papers.	Among the problem behaviours commonly reported in children with ASD were; aggression and destruction, disruption and tantrums, self-injury, and stereotypy. Behavioural intervention reported to reduce problem behaviours. Social and physical environment modifications were able to prevent the occurrence of problem behaviours.	Level I

APPENDIX B

THE PERMISSION FOR FURTHER DEVELOPMENT OF THE ORIGINAL QUESTIONNAIRE BY THE AUTHOR, DR. RENEE WATLING

Subject: RE: Current Practice of Occupational Therapy for Children with Autism
Date: Thu, 28 May 2009 09:03:15 -0700
From: Renee Watling
To: Masne Kadar

Dear Masne,

Thank you for your interest in my work. The survey questionnaire you inquired about was developed over ten years ago and was intended to gather information about occupational therapy practice at that time. Given the explosion of research in autism over the past ten years, I expect that there have been significant changes in service provision for this population. A survey of contemporary practice patterns should reflect those expected changes. That being said, the questionnaire I used was designed for clinic-based services for children 3-9 years because those are the kids that were being identified and served. Today's kids include younger ages and a greater variety of service venues. Two of my students just completed similar investigations of current practice patterns - one in the realm of early intervention, and the other intended for grade-school age children. I am willing to share my questionnaire with you, but my encouragement to you is to consider the current state of knowledge of autism both within and external to OT, and generate your own list of questions regarding those practice patterns you would expect, or hope, to find being implemented by OTs. Let the current literature guide you during this phase, then use the old questionnaire to help with phrasing and formatting of the specific questions. In addition, I strongly recommend the book by Salant & Dillman on survey research methods. Constructing a valid questionnaire that yields meaningful data is more challenging than one might expect!

The survey questionnaire I used is not available as a document file, but I can send a scanned copy. I will try and that to you by end of next week. Let me know if I can be of further assistance, and please keep me in mind when you complete your study. I would be very interested in a copy of your results.

Best,
Dr. Watling

Renee Watling, PhD, OTR/L
Visiting Assistant Professor
University of Puget Sound
School of Occupational Therapy
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APPENDIX C

THE INTRODUCTORY LETTER

MONASH University
Medicine, Nursing and Health Sciences

Dear colleagues,

Thank you for taking the time to read about this study. In this study, we are asking occupational therapists to complete a survey regarding their practices with children with autistic spectrum disorders. The survey aims are:

1) to identify what frames of reference/models of practice, assessments/outcome measures and interventions which are currently being provided to children with autistic spectrum disorders by occupational therapists in Australia and their professional development needs,

2) to identify what frames of reference/models of practice, assessments/outcome measures and interventions which are currently being provided to children with autistic spectrum disorders by occupational therapists in Malaysia and their professional development needs, and

3) to compare the above.

The term **children with autistic spectrum disorders** in this survey are defined as **a person under the age of 18 years old** who has been diagnosed with either **autistic disorder, Asperger's syndrome (AS) or pervasive developmental disorders-not otherwise specified (PDD-NOS)**. It is hope that the information obtained from this survey will provide valuable information for occupational therapy practitioners, educators, researchers, managers as well as employers in ensuring further development of

contemporary professional knowledge in the field of occupational therapy practices for children with autistic spectrum disorders.

There are five (5) sections in this survey which is anticipated that the survey can be completed within 20 to 25 minutes. If you agree to take part in this survey, please complete all five (5) sections of the survey. **Once completed, please return the survey using the stamped self-addressed envelope provided within 2 weeks of receiving them in your mail together with your signed consent form.**

If you never work with children with autistic spectrum disorders, please tick 'No' at the **screening question** and return the incomplete questionnaire using the stamped self-addressed envelope provided. Should you have any enquiries regarding the survey, we can be contacted at [redacted]. Your input and perspective would be much valued. Thank you for your attentions.

Sincerely,

Dr. Rachael McDonald
Senior Lecturer
School of Primary Health Care

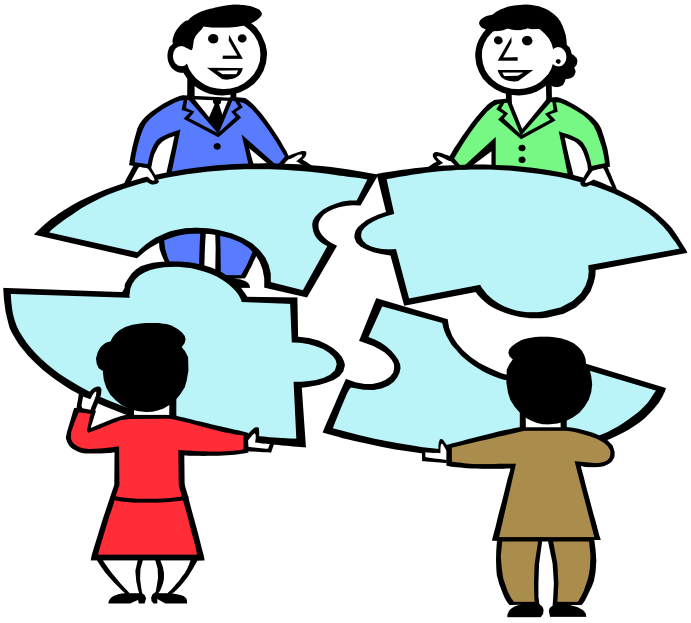
Masne Kadar
(PhD Candidate)

Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC3199, Australia
Building B, Peninsula Campus, McMahons Road, Frankston
[redacted]
www.med.monash.edu.au
ABN 12 377 614 012 CRICOS provider number 00008C

APPENDIX D

THE INITIAL DESIGN OF THE QUESTIONNAIRE

Occupational Therapy Practices Survey for Children with Autistic Spectrum Disorders: A Comparison between Australia and Malaysia



Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
Monash University-Peninsula Campus
PO Box 527, Frankston, Victoria, 3199, Australia

Screening Question: Have you ever worked with <u>children with autistic spectrum disorders</u> in your occupational therapy practice? *(Please place a check mark (√) in the box for your answer).*

Yes☐- (If your answer is 'Yes', please proceed and complete the survey).

No☐- (If your answer is 'No', you are not required to complete the survey. However, please return the survey to the researcher using the stamped self-addressed envelope provided. Thank you very much for your time).

Section A: Frame of Reference & Model of Practice

This section of the survey asks you specifically regarding the <u>frames of reference and models of practice</u> you use in your clinical practice with children with autistic spectrum disorders.

A1) Please indicate which frames of reference and models of practice you use with children with autistic spectrum disorders in your occupational therapy practice by placing a check mark (√) in the column below where applicable.

Please also name the frames of reference and models of practice that you use which are not listed in the table below in the spaces provided.

FRAME OF REFERENCE	If yes, please check (√)
Coping	
Acquisitional	
Psychosocial	
Occupational	
Sensory Integration	
Other (Please specify)	
Other (Please specify)	

MODEL OF PRACTICE	If yes, please check (√)
Canadian Model of Occupational Performance and Engagement (CMOP-E)	
Cognitive Orientation to daily Occupational Performance (CO-OP)	
Ecology of Human Performance Model	
Model of Human Occupation (MOHO)	
Person-Environment-Occupation (PEO)	
Other (Please specify)	
Other (Please specify)	

Section B: Assessments/Outcome Measures

This section of the survey asks you about the assessments/outcome measures you use in your clinical practice with children with autistic spectrum disorders.

B1) How often do you use each of the following methods of assessments/outcome measures when assessing children with autistic spectrum disorders? Please circle the number for your response based on the following indicator:

1 = Never 2= Seldom 3 = Sometimes 4 = Often 5 = Always

Please also state the methods of assessments/outcome measures that you use which are not listed in the table below in the spaces provided and rate them.

	Assessments/Outcome Measures	Never	Seldom	Sometimes	Often	Always
a)	Standardised assessment/screening tools. (Please see question B2)	1	2	3	4	5
b)	Informal assessment/screening tools (including any that you or the service you work in has created). (Please see question B3)	1	2	3	4	5
c)	Observing the child in multiple environments (e.g., home/school).	1	2	3	4	5
d)	Interview with Parents/caregivers.	1	2	3	4	5
e)	Interview with teachers/education staff.	1	2	3	4	5
f)	Other (Please specify)	1	2	3	4	5
g)	Other (Please specify)	1	2	3	4	5

B2) If you use standardised assessments;

B2.1) do you use <u>developmental screenings and evaluations</u> in your assessment with children with autistic spectrum disorders?
(Please place a check mark (√) in the box for your answer).

☐ Yes ☐ No

If you do, please name the tool/tools: _____

B2.2) do you use <u>functional or adaptive skill assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a check mark (√) in the box for your answer).

☐ Yes ☐ No

If you do, please name the tool/tools: _____

B2.3) do you use <u>play and leisure participation assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a check mark (√) in the box for your answer).

☐ Yes ☐ No

If you do, please name the tool/tools: _____

B2.4) do you use <u>gross or fine motor skill assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a check mark (√) in the box for your answer).

☐ Yes ☐ No

If you do, please name the tool/tools: _____

B2.5) do you use <u>sensory processing or sensory integration assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a check mark (√) in the box for your answer).

☐ Yes ☐ No

If you do, please name the tool/tools: _____

B2.6) do you use <u>psychosocial or social interaction skill assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a check mark (√) in the box for your answer).

☐ Yes ☐ No

If you do, please name the tool/tools: _____

B2.7) do you use <u>environmental assessment</u> in your assessment with children with autistic spectrum disorders?
(Please place a check mark (√) in the box for your answer).

☐ Yes ☐ No

If you do, please name the tool/tools: _____

B2.8) do you use a <u>diagnostic assessment</u> in your assessment with children with autistic spectrum disorders?
(Please place a check mark (√) in the box for your answer).

☐ Yes ☐ No

If you do, please name the tool/tools: _____

B3) If you use non-standardised assessments, please describe the tools and the process:

_____

_____

_____

_____

_____

_____

Section C: Interventions & Adaptive Behaviours

This section of the survey asks you specifically regarding the interventions you use in your clinical practice with children with autistic spectrum disorders.

INTERVENTIONS:

The table below lists some of the commonly identified interventions/programmes which are used by occupational therapists and other professionals for children with autistic spectrum disorders (in an alphabetical order).

C1) Please indicate which of the following interventions/programmes you use/have used with children with autistic spectrum disorders in your occupational therapy practice by placing a check mark (√) in the column below where applicable.

Please also name the interventions/programmes that you provide which are not listed in the table below in the spaces provided.

INTERVENTIONS/PROGRAMMES	If yes, please check (√)
Assertiveness Skills Training	
Activities of Daily Living	
Cognitive Orientation to daily Occupational Performance (CO-OP)	
Discrete-Trial Training	
Early Intervention Programme	
Environmental Modifications	
Facilitated Communication Techniques	
Floortime Techniques (Greenspan)	
Picture Exchange Communication System (PECS)	
Play Therapy	
Pre-school Training	
Pre-Vocational/Vocational Skills	
Sand Tray Therapy	
Sensorimotor Stimulation	
Sensory Diet	
Sensory Integration Training	
Social Communication, Emotional Regulation and Transactional Support (SCERTS) Model	
Social Stories Programme	
The Listening Program	
Therapeutic Listening	
Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) Program	
Wilbarger Protocol (joint compression & brushing techniques)	
Other (Please specify)	
Other (Please specify)	

C2) Please list your three (3) most common occupational therapy intervention goals when working with children with autistic spectrum disorders.

a) _____

b) _____

c) _____

C3) How often do you include the following people/professionals in your occupational therapy interventions for children with autistic spectrum disorders? Please circle one number for your response based on the following indicator:

1 = Never 2= Seldom 3 = Sometimes 4 = Often 5 = Always

Please also name the other person/professionals that you include which are not listed in the table below in the spaces provided and rate them.

	People/Professionals	Never	Seldom	Sometimes	Often	Always
a)	Parents/Caregivers	1	2	3	4	5
b)	Teachers/Education Staff	1	2	3	4	5
c)	Speech Therapists/ Speech Pathologists	1	2	3	4	5
d)	Psychologists	1	2	3	4	5
e)	Others (Please specify)	1	2	3	4	5
f)	Others (Please specify)	1	2	3	4	5

C4) What are some of the challenges you encounter when providing interventions for children with autistic spectrum disorders?

_____

_____

_____

_____

<u>ADAPTIVE BEHAVIOURS:</u>

The table below lists areas of adaptive behaviours in daily living activities.

C5) How often do you provide the following adaptive behaviour intervention to children with autistic spectrum disorders in your occupational therapy practices? Please circle one number for your response for each adaptive behaviour area based on the following indicator:

1 = Never 2= Seldom 3 = Sometimes 4 = Often 5 = Always

Please also name the area of adaptive behaviour that you provide which are not listed in the table below in the spaces provided and rate them.

	Area of Adaptive Behaviour	Never	Seldom	Sometimes	Often	Always
a)	Self-care activity	1	2	3	4	5
b)	Home Living (e.g., make bed, prepare breakfast)	1	2	3	4	5
c)	Social Skills	1	2	3	4	5
d)	Communication Skills (including Alternative and Augmentative Communication (AAC))	1	2	3	4	5
e)	School Readiness Skills (e.g., hand writing skills, modifications to accommodate limitations in functional academic activity)	1	2	3	4	5
f)	Community Use (use of facilities in the community, e.g., transportation, recreational centre, local shops)	1	2	3	4	5
g)	Self-determination (e.g., problem solving skills, making decision and choices)	1	2	3	4	5
h)	Play/Leisure Participation (e.g., attend & participate in games)	1	2	3	4	5
i)	Health and Safety Education	1	2	3	4	5
j)	Other (Please specify)	1	2	3	4	5
k)	Other (Please specify)	1	2	3	4	5
l)	Other (Please specify)	1	2	3	4	5

C6) How often do you utilise the following settings when providing adaptive behaviour interventions for children with autistic spectrum disorders? Please circle one number for your response for each setting based on the following indicator:

1 = Never 2= Seldom 3 = Sometimes 4 = Often 5 = Always

Please also name the settings that you utilise which are not listed in the table below in the spaces provided and rate them.

Settings	Never	Seldom	Sometimes	Often	Always
Occupational therapy settings	1	2	3	4	5
Client's natural environments (e.g., home, school, playground)	1	2	3	4	5
Community facilities (e.g., public transportation, cinemas)					
Other (Please specify)	1	2	3	4	5
Other (Please specify)	1	2	3	4	5

Section D: Professional Development Needs

This section of the survey asks you specifically regarding your professional development needs in your clinical practice with children with autistic spectrum disorders. Please answer all of the questions.

D1) Please rate your level of confidence when providing occupational therapy services for children with autistic spectrum disorders? *(Please circle one number for your answer).*

1	2	3	4	5
Very low	Low	Moderate	High	Very high

D2) Have you attended any training/certification courses that are relevant to your occupational therapy services for children with autistic spectrum disorders? *(Please place a check mark (√) in the box for your answer).*

Yes ☐ No ☐

If you have, please name the training/certification courses in the table below and also indicate the year attended.

	Training/certification courses attended	Year attended
1.		
2.		
3.		
4.		
5.		

D3) Please name the training/certification courses that are relevant to your occupational therapy services for children with autistic spectrum disorders which you plan to attend in the table below.

	Training/certification courses would like to attend
1.	
2.	
3.	
4.	
5.	

D4) Please indicate you preferences in the method of obtaining knowledge and skills in increasing your competencies when providing occupational therapy services for children with autistic spectrum disorders based on the following indicator. (Please circle the number for your response).

1 = Not preferred 2 = Low preferences 3 = Moderate 4 = High preferences 5 = Preferred the most

	Method of obtaining knowledge and skills	Not preferred	Low preferences	Moderate	High preferences	Preferred the most
a)	Hands-on mentoring by expert/experience therapist	1	2	3	4	5
b)	Case presentation of intervention and technique	1	2	3	4	5
c)	Multidisciplinary workshop with discussion and problem solving	1	2	3	4	5
d)	Short courses of specialise certification on certain technique/programme	1	2	3	4	5
e)	Literature reviews	1	2	3	4	5
f)	Other (Please specify)	1	2	3	4	5
g)	Other (Please specify)	1	2	3	4	5

Section E: Demographic Information

This section of the survey asks you specifically regarding your personal information, professional qualification and working experiences as an Occupational Therapist and also your experiences of working with children with autistic spectrum disorders. Please answer all of the questions.

E1) Where do you presently reside? ***(Please place a check mark (√) in the box for your answer).***

☐ I am a participant from Australia

I am a participant from Malaysia:

☐ Peninsular Malaysia

☐ East Malaysia (Sabah,Sarawak,Wilayah Persekutuan Labuan)

E2) What is your highest level of academic qualification in the field of occupational therapy? ***(Please place a check mark (√) in the box for your answer).***

☐ Diploma/certificate in occupational therapy

☐ Bachelors degree in occupational therapy

☐ Graduate-entry masters degree in occupational therapy

☐ Course work/research masters

☐ Clinical/Research doctorate in occupational therapy

☐ Other (Please specify) _____

E3) In which setting do you currently practice?
(Please place a check mark (√) in the box for your answer).

- ☐ Hospital
- ☐ Long-Term Residential
- ☐ School
- ☐ Community-Based Care
- ☐ Transitional Centre/Sheltered Workshop
- ☐ Early Intervention Services
- ☐ Private Practice
- ☐ Other (Please specify)

E4) Approximately how many years have you been practicing as an Occupational Therapist?
(Please place a check mark (√) in the box for your answer).

- ☐ Less than 1 year
- ☐ 1-5 years
- ☐ 6-10 years
- ☐ 11-15 years
- ☐ 16-20 years
- ☐ More than 21 years

E5) Approximately how many years have you been working or have you worked with <u>children with autistic spectrum disorders</u> in your occupational therapy practice?
(Please place a check mark (√) in the box for your answer).

- ☐ Less than 1 year
- ☐ 1-5 years
- ☐ 6-10 years
- ☐ 11-15 years
- ☐ 16-20 years
- ☐ More than 21 years

E6) What is the age group of children with autistic spectrum disorders you serve?
(Please place a check mark (√) in the box for your answer).

- ☐ Less than 2 years old
- ☐ 3 to 5 years old
- ☐ 6 to 12 years old
- ☐ 13 to 18 years old

E7) How do you provide the <u>majority of your direct occupational therapy services</u> to children with autistic spectrum disorders? *(Please place a check mark (√) in the box for your answer).*

- ☐ Individual intervention session
- ☐ Group intervention session of less than 5 children
- ☐ Group intervention session of 6 or more children
- ☐ Other (Please specify) _____

E8) How do you provide the <u>majority of your indirect occupational therapy services</u> to children with autistic spectrum disorders? *(Please place a check mark (√) in the box for your answer).*

- ☐ Consultation with parents/caregivers
- ☐ Consultation with education staff
- ☐ Multidisciplinary team conference
- ☐ Professional development
- ☐ Team teaching/Upskilling co-workers
- ☐ Other (Please specify)_____

End of the survey. Please check that you have completed every section of the survey. Thank you for taking the time to participate in this study. Your assistance and input are greatly appreciated.

Please return the completed questionnaire using the stamped self-addressed envelope provided together with your signed consent form

APPENDIX E

THE OPERATIONAL DEFINITIONS OF TERMS USED IN THE SURVEY

Operational definitions of term used in the survey:

1) **Children with autistic spectrum disorders:**

   The term children with autistic spectrum disorders used in this survey are defined as a person under the age of 18 years old who has been diagnosed with either autistic disorder, Asperger's syndrome (AS) or pervasive developmental disorders-not otherwise specified (PDD-NOS).

2) **Frame of reference (FOR):**

   A set of guidelines to use as the basis for practice, which enables the occupational therapist practitioner to shift from theory into practice. Its aim is to help the occupational therapist practitioner identify priorities for intervention to address the problem.

   a) Coping FOR (Williamson & Szczepanski, 1999)– Coping FOR is based on a cognitive behavioural theoretical model. It focuses on the ability of the child to cope with stresses in their daily activity routines by successfully adapt to the demands and expectations put on them.
   b) Acquisitional FOR (Royeen & Duncan, 1999) – Acquistional FOR focuses on development of specific skills required for optimal performance in activities of daily living.
   c) Psychosocial FOR (Olson, 1999) – The psychosocial FOR focuses on facilitating the child's personal development by understanding and considering the child's temperament, ability

to cope, play, attachment, peer interactions and environmental interactions.

d) Occupational FOR (Primeau & Ferguson, 1999)– Occupational FOR focuses on the child's ability to function in their everyday occupations; such as, self-care, leisure and productivity. In this FOR, the occupations are the important aspect in gaining the child's active engagement in their own context.

e) Sensory Integration FOR (Kimball, 1999)- Sensory integration FOR focuses on the child's processing of vestibular, proprioceptive, and tactile sensations in relation to their ability to learn and perform daily living activities. It considers the child's development of function and motor skills from sensory perspectives which conceptualised that difficulties with processing sensory information can obstruct a child's acquisition of concept and motor learning.

3) Model of practice:

A model of practice gives more specific guidance for assessment and intervention planning by providing a perspective to the problems faced by the client.

a) Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko, Townsend & Craik, 2007)- This model views the dynamic, interwoven relationship between persons, environment, and occupation which can either enable or constrain occupational performance and engagement. The key enablement skills, such as, adapt, advocate, coach, collaborate,

consult, coordinate, design/build, educate, engage and specialize may be utilized to achieve occupational engagement in clients.

b) Cognitive Orientation to Daily Occupational Performance (CO-OP) (Polatajko & Mandich, 2004)– CO-OP is a practice model and a therapeutic treatment approach for children who have difficulties performing motor-based skills. It is a highly individualized approach designed to guide children in discovering and developing cognitive strategies to enable them to improve their performance in everyday tasks and activities, such as, writing, skipping, and other daily living activities. The intervention is highly verbal and the objectives are to achieve skill acquisition, develop cognitive strategies, and generalization and transfer of learning.

c) Ecology of Human Performance (Dunn, Brown, & McGuigan, 1994) – This model outlines person, task, and context variables, and states that the interaction among these variables determines clients' performance range. This model focuses on how contextual factors such as physical, temporal, sociocultural and/or phenomenology can influence clients' performance.

d) Model of Human Occupation (MOHO) (Kielhofner, 2008; Kielhofner & Burke, 1980) – This model was first published in 1980 and originated from Dr. Gary Kielhofner's master's thesis and practice in the mid 1970's. This model aims to understand occupation and problems of occupation that occur in terms of its

primary concepts of volition, habituation, performance capacity and environmental context. MOHO is a practice model that focuses on occupation, client-centred approach, applying a holistic view of clients and evidence-based practices.

e) Person-Environment-Occupation (PEO) (Law, et al., 1996) – PEO is a model that illustrates a trans-active approach to understanding a person's occupational performance. This model considers the relationship of the person, their occupations and environments as interrelated and interwoven and seeks to enable optimal occupational performance in occupations that have been prioritized by the client.

4) Adaptive behaviour:

Adaptive behaviour is an ability to adapt and achieve meaningful daily functions in coping with personal and social demands according to a person's age and developmental level, cultural influences and expectations and basic environmental needs. Some of the areas of adaptive behaviours are self-care activity, home living, social skills, communication skills, school readiness skills, community use, self-determination, play/leisure participation and health/safety education (Hagiwara, Cook, & Simpson, 2008; Hallahan, 2000; Heward, 2000) .

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APPENDIX F

THE QUESTIONNAIRE FOR EXPERT REVIEWER

QUESTIONNAIRE FOR EXPERT REVIEWER

Please give your opinion on the following questions

Introductory letter to the respondents.

1) **Were the study objectives stated clearly in the introductory letter to the respondent?**

- ○ Yes.
- ○ No.

If no, how can we improve this?

Section A : Frame of Reference & Model of Practice.

2) **In question A1, we listed a few frames of reference and models of practice for the respondents to choose from. However, the respondents also have the choices of writing their own answer in the spaces given. Should we:**

- ○ Lists more frames of reference and models of practice for the ease of answering to the respondents.
- ○ Do not list any frames of reference and models of practice; however, leave it as an open ended question.
- ○ Our initial design was appropriate and acceptable.
- ○ Other, please give comments:

3) **We separated the frames of reference and models of practice in two different tables.**
Should we:

- ○ List the frames of reference and models of practice in just one table.
- ○ Our initial design was appropriate and acceptable.

How can we improve our design in this section?

Section B : Assessments/Outcome measures

4) **In question B1, we listed the method of assessments/outcome measures which can be used when assessing children with autistic spectrum disorders. There are also spaces for the respondents to write their other methods if any. Are there any other methods of assessments/outcome measures that we should include in the list?**

- ○ No.
- ○ Yes.

If there are, please give your suggestions.

5) **Question B2 (B2.1 to B2.8) in section B are asking respondents about the specific type of standardised assessments they use in their occupational therapy services for children with autistic spectrum disorders.**

5a) Are there any to exclude?

- ○ No.
- ○ Yes.

If yes, which type of assessment should be excluded?

5b) Are there any to include?

- ○ No.
- ○ Yes.

If yes, which type of assessment should be included?

Section C : Interventions & Adaptive Behaviours

6) **In question C1, we listed a few commonly identified interventions/programmes which are used by occupational therapists and other professional for children with autistic spectrum disorders. However, the respondents also have the choices of writing their own answer in the spaces given. Should we:**

- ○ Lists more interventions/programmes for the ease of answering to the respondents.
- ○ Do not list any interventions/programmes; however, leave it as an open ended question.
- ○ Our initial design was appropriate and acceptable.

7) **In question C5, we listed a few areas of adaptive behaviours in daily living activities. However, the respondents also have the choices of writing their own answer in the spaces given.**

7a) Are there any to exclude?

- No.
- Yes.

If yes, what area of adaptive behaviours should be excluded?

7b) Are there any to include?

- No.
- Yes.

If yes, what area of adaptive behaviours should be included?

Section D : Professional Development Needs

8) **Question D1 is asking regarding the level of confidence among respondents when providing services for children with autistic spectrum disorders. We are using the five point Likert scale in order to elicit response to this question. Is this method appropriate?**

- Yes.
- No.

If no, how best can we elicit response to this question?

9) **In question D4, we listed a few methods of obtaining knowledge and skills in increasing occupational therapists' competencies when providing services for children with autistic spectrum disorders. However, the respondents also have the choices of writing their own answer in the spaces given.**

9a) Are there any to include?

- No.
- Yes.

If yes, what other methods should be included?

10) **Are there any other questions pertaining to professional development needs that we should include in the questionnaire?**

Section E : Demographic Information

11) The section on the demographic information should be put:

- At the beginning of the questionnaire.
- Our initial design was appropriate and acceptable.

General Questions

12) We will include the separate sheet of operational definitions on the terms use in the questionnaire for respondents' guideline when answering the survey (Appendix A). Is this necessary?

- Yes.
- No.

If no, what should we do instead?

13) Are there any other suggestions on what we should do in order to improve the quality of our questionnaire?

Thank you for your kind response. Your assistance and input are greatly appreciated.

APPENDIX G

THE QUESTIONS, COMMENTS FROM EXPERTS, CHANGES MADE AND THEIR DISCUSSIONS

The discussions below presented the feedback from the experts on content of the initial questionnaire

Introductory letter to the respondents

Question 1

Question	Yes	No	Comments
1) Were the study objectives stated clearly in the introductory letter to the respondents? **a) Yes.** **b) No.** **If no, how can we improve this?**	**9**	**3**	1. Include statement clarifying that the study has been approved by the University Review Board. 2. Be more explicit about how the information will be used and why it is important to do so. 3. The letter should begin by telling potential participants who you are and how/why they have been chosen to participate. 4. Listing the objectives of the study will probably tire the potential participants and can cause them to trash the survey out right away. 5. To state 'Introductory Letter' on the cover letter for participants. 6. Might be helpful to explain the rationale comparing the practices across two regions. 7. May need to explain the adaptive part explicitly.

Summary:

Nine responses were received which say that the study objectives in the introductory letter to the respondents were stated clearly. However, three experts suggested that some improvements be made to the introductory letter. A total of seven comments were received for question 1.

Changes made:

- The statement clarifying that the study has been approved by the university ethics board in the introductory letter to the respondents was included which will be attached as the front cover of the questionnaire in response to comment number 1.
- Referring to comment number 4, the objectives in the introductory letter were simplified and rephrased into a more compact statement.
- The content and information in the introductory letter to the respondents were improved as suggested in comment number 2, 3, 5, 6, and 7.

Discussion:

The comments and suggestions made by the experts enrich the introductory letter to the respondents. It makes it more useful and informative to be read by the potential respondents.

Section A: Frame of reference & Model of practice

Question 2

Question.	a	b	c	d	Comments.
2) In question A1, we listed a few frames of reference and models of practice for the respondents to choose from. However, the respondents also have the choices of writing their own answers in the spaces given. Should we: **a) List more frames of reference and models of practice for the ease of answering to the respondents.** **b) Do not list any frames of reference and models of practice; however, leave it as an open ended question.** **c) Our initial design was appropriate and acceptable.** **d) Other, please give comments.**	**1**	**0**	**5**	**6**	1. Would not learn much by having the respondents identify which FOR's or Model's they use. Instead, what is important is what guidelines for intervention the respondents use most frequently when treating children with autistic spectrum disorders. 2. There is a 2010 edition of the paediatric text; it has other theoretically based guidelines that might be more commonly used. 3. List names of authors typically associated with frames of reference/models of practice. 4. Include a brief operational definition of terms for the FOR in the table itself. 5. Try to provide an extensive list. Use the last two editions of Paediatric Frames of Reference book by Hinojosa and Kramer, Conceptual Foundations text by Kielhofner and Occupational Therapy for Children edited by Case-Smith. 6. Separate the question on frames of reference and models of practice into two different questions. 7. CO-OP is the frame of reference, not the model of practice. 8. Include definitions in the table so that respondents will answer the question in the more meaningful ways. 9. List names of authors typically associated with frames of reference/models of practice. 10. Some definitions of the terms listed would be useful. 11. Need to specify which occupational frame of reference referred to. This will reduce the possibility that two respondents check the same answer, when each of them meant something different. 12. Put some definitions in the questionnaire.

Summary:

One expert was of the opinion that more frames of reference and models of practice should be listed in the questionnaire. None suggested that this question should be left as an open-

ended question. Five experts consider that the initial design was appropriate and acceptable. However, another six experts give their suggestions on how to improve this question. A total of 12 comments were received for the question.

Changes made:

- Names of authors typically associated with the frames of reference and models of practice listed in the questionnaire were included as suggested by comments number 3 and 9 as this makes it clearer for the respondents to answer.
- Referring to comment number 11, space for respondents to specify which occupational frame of reference that they are referring to was provided.

Discussion:

This question is the most problematic in the questionnaire. As none of the experts reviewing the questionnaire suggested that this question be formatted as an open ended question; it is also important not to make it too cluttered which will probably tire the respondents. Therefore, in reference to comments number 4, 5, 6, 8, 10 and 12, it was decided that the suggested comments will add to the bulk and length of the questionnaire. In conclusion, it was decided that listing some of the most common frames of reference and models of practice and including the names of the authors would be sufficient. In order to further improve this question, the 2010 edition of Frames of Reference for Pediatric Occupational Therapy (3rd edition) was reviewed, as suggested in comment number 2.

Question 3

Question.	a	b	No answer	Comments
3) We separated the frames of reference and models of practice in two different tables. Should we: **a) List the frames of reference and models of practice in just one table.** **b) Our initial design was appropriate and acceptable.** **How can we improve our design in this**	**1**	**7**	**4**	1. Try to provide an extensive list. Should include more; for example, Occupational Adaptation, Occupational Therapy Practice Framework, PRPP by Chapparo.

Summary:

According to one expert, choices for frames of reference and models of practice should be listed in one table instead of in two separate tables. Whereas, seven experts said that the initial design was appropriate and acceptable and another four experts did not provide their answers. Only one comment was received for the question.

Changes made:

No changes applied to this question.

Discussion:

As it was discussed previously in question 2, it was decided not to makes this question too long and cluttered.

Question 4

Section B: Assessments/Outcome measures

Question	a	b	No answer	Comments
4) In question B1, we listed the methods of assessments/outcome measures which can be used when assessing children with autistic spectrum disorders. There are also spaces for the respondents to write their other methods if any. Are there any other methods of assessments/outcome measures that we should include in the list? **a) No** **b) Yes** **If there are, please give your suggestions:**	**6**	**0**	**6**	1. To include interviews with other health professionals. 2. Might be useful to add another two columns asking the respondents to identify whether they use the assessments to set therapy goals or to measures the effectiveness of the therapy. 3. "Fine as it is".

Summary:

According to six experts, there are no other methods of assessments/outcome measures that should be included in the questionnaire. Another six experts did not provide their answers for the question. A total of three comments were received for the question.

Changes made:

- Referring to comment number 1, interview with other health professionals was included in the list.

Discussion:

Referring to comment number 2, it was concluded that perhaps the question asked of the experts was a little confusing to them. The aim of this question was to find out the methods of finding information that the respondents usually used. Therefore, it was

decided not to add another question to it; and additionally, it is also to ensure the questionnaire does not become too long.

Question 5 (5a)

Question	a	b	No answer	Comments
5) Question B2 (B2.1 to B2.8) in section B are asking respondents about the specific type of standardised assessments they use in their occupational therapy services for children with autistic spectrum disorders. **5a) Are there any to exclude?** **a) No** **b) Yes** **If yes, which type of assessment should be excluded?**	**4**	**1**	**7**	1. Looking at this section, it was concerning with how long it would take for the respondents to list the tools they commonly used. Suggestions to: - List the most commonly used assessments and have the respondents to identify if they use them, or - Ask the respondents if they usually use standardised or non-standardised assessments and have them list the 4 most commonly used. 2. Need to only use ones that are most commonly used by the respondents in the target areas. 3. Question B2.4: Gross and fine motor skill assessments; is this different from developmental screenings? 4. Needs to clearly define between 'functional' and 'adaptational' in question B2.2 since those two terms are not related. 5. Would be better to list a few assessments for the respondents to choose and tick-off from the list provided. This will also make it easier for the purpose of data entry and analysis. Therefore, using force choice format will be better. 6. Would be better to separate between the sensory processing and sensory integration since they are separate construct. 7. Should exclude diagnostic assessment or explain what diagnostic assessment is. 8. Should include some prompts with names of assessments.

Summary:

Four experts say that there are no specific types of standardised assessments that should be excluded from the questionnaire. Meanwhile, one expert was of the opinion that there is a

type of assessment which should be excluded. Another seven experts did not provide their answers to the question. A total of eight comments were received for the question.

Changes made:

- Based on the comments received from the experts with regards to this part of the questionnaire, it was decided that the respondents will only have to name one assessment tool that they used most frequently in their occupational therapy practice for each specific type of standardised assessment listed as suggested in comments number 1 and 2.
- In relation to comment number 7, it was decided to include as short definition of diagnostic assessment in the questionnaire which will help to improve the respondents' comprehension of the question.

Discussion:

In order to prevent the questionnaire from becoming too long, it was decided not to make the question into a force choice format as suggested in comments number 5 and 8. It was decided to let the respondents name the tools that they use most frequently and data will be analysed by grouping the tools together. Referring to comment number 3, it was concluded that gross and fine motor skill assessments is different from developmental screenings. Gross and fine motor skill assessments involve more detailed motor assessments, whereas the developmental screenings may sometimes only touch on some major motor developmental aspects. With regard to comment number 6, based on the systematic review by Case-Smith and Arbesman (2008), which groups sensory integration and sensory-based intervention as one intervention category, it was decided not to separate them. Therefore, the initial question for this part was retained.

Question 5 (5b)

Question	a	b	No answer	Comments
5) Question B2 (B2.1 to B2.8) in section B are asking respondents about the specific type of standardised assessments they use in their occupational therapy services for children with autistic spectrum disorders. **5b) Are there any to include?** **a) No** **b) Yes** **If yes, which type of assessment should be included?**	**6**	**0**	**6**	1. Needs to include a few other aspects of assessments; for example, section for activities of daily living or self-care skills, social participation and school-related skills. 2. This section should be modified to allow more space for the respondents to fill in the names of the tools they use. 3. Because some tools are restricted to certain age group only, it may be helpful to restructure the questionnaire to ask about the age group that the respondents serve most frequently and then instruct the respondents to tailor their responses to the remaining questions to only that age group that they serve most frequently. This should result in more robust data related to service provision for each age group.

Summary:

According to six experts there are no other standardised assessments to be included in the questionnaire. None of the experts said that there were any more to include, whereas six experts did not provide answers for the question. A total of three comments were received regarding this question.

Changes made:

- In response to comment number 1, another two assessments were included which are the activity of daily living assessment and school related-skills assessment.
- Referring to comment number 2, it was decided to only ask the respondents to give one tool that they use the most, as stated on the changes made on question 5a.

- As suggested in comment number 3, it was decided to restructure the questionnaire by asking the respondents about the age group of the children with autistic spectrum disorders that they serve most frequently and to have them answer the following questions based on that age group.

Discussion:

The Section B: Assessments/Outcome measures of this questionnaire can be seen as the section with most changes and additions made in an effort to make this section better able to generate more useful data, but also not allow it to become too long and cluttered.

Section C: Interventions & Adaptive Behaviours

Question 6

Question	a	b	c	No answer	Comments
6) In question C1, we listed a few commonly identified interventions/ programmes which are used by occupational therapists and other professional for children with autistic spectrum disorders. However, the respondents also have the choices of writing their own answer in the spaces given. Should we: **a) List more interventions/programmes for the ease of answering to the respondents.** **b) Do not list any interventions/programmes; however, leave it as an open ended question.** **c) Our initial design was appropriate and acceptable.**	**0**	**0**	**6**	**6**	1. Identifying whether the respondents are using certain interventions/programmes does not telling much. Therefore by having the respondents to rank the frequency of the interventions/programmes used will produce more useful data. 2. "It seems fine but make sure both areas have been sufficiently targeted". 3. Should include some additions to the list; for example, sensory integration treatment, therapeutic touch, snoezelen, behavioural interventions. 4. Activities of daily living are not an intervention, but are a performance area that might be addressed through intervention. Therefore, should remove activities of daily living from the list since it does not fit with the other answer choices. 5. In addition, the format of this question will yield data that reveal how many respondents use each method identified, but it will not address how frequently those respondents use the methods. Having the respondents rank the methods might yield more useful data.

Summary:

None of the experts suggested that this question should have a more extensive list of interventions or programmes, or should be left in an open-ended format. Six experts felt that the initial design was appropriate and acceptable and another six experts did not answer the question. Five comments were received for this question.

Changes made:

- In response to comments number 1 and 5, it was decided to have the respondents rank their answers in terms of the frequency that they use the interventions or programmes listed.
- Referring to comments numbers 2 and 3; additional interventions and programmes were added to the list as suggested by the experts.
- Based on comment number 4, activities of daily living were excluded from the list.

Discussion:

In order to improve the quality of the questionnaire, a few changes and additions to this question were performed to achieve more useful and meaningful data from respondents.

Question 7 (7a)

Question	a	b	No answer	Comments
7) In question C5, we listed a few areas of adaptive behaviours in daily living activities. However, the respondents also have the choices of writing their own answer in the spaces given. **7a) Are there any to exclude?** **a) No** **b) Yes** **If yes, what area of adaptive behaviours should be excluded?**	**5**	**0**	**7**	1. Question C2: Would be better to ask for areas in which goals are usually written. Another checklist is suggested. 2. Question C4: "This question seems very vague. Should be more specific of what areas of challenges, e.g., challenges with the children themselves, the system, parents." 3. Question C5: "How is this different from Question C2 (Occupational therapy goals)?" 4. Do not separate the section for adaptive behaviour with interventions/programs. 5. Should include some other skill areas; for example, play, education, vocational, social participation. 6. "This question should be rephrased from 'How often do you provide the following adaptive behaviour interventions...?' to 'How often do you address the following adaptive behaviour interventions...?'.

Summary:

According to five experts, there are no areas of adaptive behaviours in daily living activities which should be excluded from the list and none of the experts was of the opinion that there are areas of adaptive behaviours which should be excluded. Meanwhile, another seven experts did not provide their answers for the question. A total of six comments were received regarding this question.

Changes made:

- Based on comments numbers 1 and 3, it can be seen that there is some redundancy in both questions. Therefore, it was decided to make question C2 more specific by asking the respondents to list their 3 most common short term occupational therapy intervention goals when working with children with autistic spectrum disorders.
- Referring to comment number 2, question C4 was amended to make it more comprehensible by asking specifically the challenges with children with autistic spectrum disorders that the respondents encounter when providing services for them.
- Based on comment number 5, work or vocational skills was another area added to the list as the other suggested areas were already listed.
- Question C5 was rephrased as suggested in comment number 6.

Discussion:

It was decided not to combine the interventions/programmes and adaptive behaviours into one table as suggested in comment number 4 as it can be seen as two separate components.

Question 7(7b)

Question	a	b	No answer	Comments
7) In question C5, we listed a few areas of adaptive behaviours in daily living activities. However, the respondents also have the choices of writing their own answer in the spaces given. **7b) Are there any to include?** **a) No** **b) Yes** **If yes, what area of adaptive behaviours should be included?**	**5**	**0**	**7**	

Summary:

Five experts were of the opinion that there are no other areas of adaptive behaviours that should be included in the list. Meanwhile, a total of seven experts did not provide their answer for this question.

Changes made:

No changes were made to the initial question.

Section D : Professional Development Needs

Question 8

Question	a	b	No answer	Comments
8) Question D1 is asking regarding the level of confidence among respondents when providing services for children with autistic spectrum disorders. We are using the five point Likert scale in order to elicit response to this question. Is this method appropriate? a) Yes b) No If no, how best can we elicit response to this question?	**8**	**0**	**4**	1. Respondents tend to choose the middle category the most when given the odd number of choices. Therefore, even numbers of categories are suggested.

Summary:

None of the experts said that the initial design of using the 5-point Likert scale in order to elicit response regarding the level of confidence among respondents was inappropriate. In contrast, eight experts were of the opinion that the use of the 5-point Likert scale is appropriate. Four experts did not answer the question. However, one comment was received for this question.

Changes made:

No changes made to the initial question.

Discussion:

Even number of categories will limit the answer choices available for the respondents to choose from, because it forms a force choice answer format. Therefore, it was decided to use the 5-point Likert scale with the middle point as the neutral category.

Question 9

Question	a	b	No answer	Comments
9) In question D4, we listed a few methods of obtaining knowledge and skills in increasing occupational therapists' competencies when providing services for children with autistic spectrum disorders. However, the respondents also have the choices of writing their own answer in the spaces given. Are there any to include? **a) No** **b) Yes** **If yes, what other methods should be included?**	**4**	**2**	**6**	1. Might include advanced post-professional academic degrees. 2. Might include online courses, workshop or conference. 3. "I like the answer choices you have provided for this question." 4. "Should you include online courses?" 5. "My concern with the way it is described here is that you are not including plain continuing education courses that do not result in certification."

Summary:

In this question, four responses were received from the experts saying that there are no other methods of obtaining knowledge and skills in increasing occupational therapists' competencies which should be included in the list. However, two experts were of the opinion that there are other methods that should be included. Six experts did not answer the question. A total of five comments were received for this question.

Changes made:

- Some additional methods of obtaining knowledge and skills in increasing occupational therapists' competencies were included as suggested in comments numbers 1, 2 and 4.

- As suggested in comment number 5, continuing education courses were included in question D2 of the questionnaire.

Question 10

Question	Comments
10) Are there any other questions pertaining to professional development needs that we should include in the questionnaire?	1. "None". 2. "Listed questions are adequate".

Summary:

Two comments were received for the question. No comment suggested that there are other questions pertaining to professional development needs that should be included in the questionnaire.

Section E : Demographic Information

Question 11

Question	a	b	No answer	Comments
11) The section on the demographic information should be put: **a) At the beginning of the questionnaire.** **b) Our initial design was appropriate and acceptable.**	**2**	**5**	**5**	1. Separate out the entry level master's degrees, post-professional master's degrees, clinical doctorates and research doctorates. 2. Might consider splitting the demographics questions so that the questions about years worked with children with autistic spectrum disorders and ages of children with autistic spectrum disorders are at the beginning which then can be used as screening questions for inclusion/exclusion purposes.

Summary:

Two responses were received from the experts saying that the demographic information section should be put at the beginning of the questionnaire; meanwhile, another five experts felt that the initial design of the questionnaire was appropriate and acceptable. Five experts did not provide answers for the question. Two comments were received for the question.

Changes made:

- Referring to comment number 1, it was decided to separate out the clinical doctorate and research doctorate in occupational therapy into two separate answer choices to generate more useful data. However, the other category separation as

suggested in the comment was not applied as the option for the respondents to write their own answers in the ‘Other’ category was provided.

- As stated in changes made in Question 5(5b), the question of asking the age group of children with autistic spectrum disorders that the respondents serve most frequently was restructured into the Section B: Assessments/Outcome Measures section.

Discussion:

It was decided to retain the question on years of working with children with autistic spectrum disorders in Section E: Demographic Information, as it was not aimed to use this question as a screening question.

Question 12

Question	a	b	No answer	Comments
12) We will include the separate sheet of operational definitions on the terms use in the questionnaire for respondents' guideline when answering the survey (Appendix A). Is this necessary? **a) Yes** **b) No** **If no, what should we do instead?**	**6**	**5**	**1**	1. "I don't think they will read it – if they do not understand the terms, they probably are not using the intervention." 2. List names of authors typically associated with frames of reference/models of practice. 3. "It might add to the length and bulk of the survey." 4. Put the reference in the questionnaire.

Summary:

Six responses were received from the experts saying that the separate sheet of operational definitions on the terms used in the questionnaire should be included as a guideline for respondents' when answering the survey. However, another five experts said that it is not necessary to include it and one expert did not provide an answer for the question. A total of four comments were received for the question.

Changes made:

- As suggested in comments numbers 2 and 4, the names of authors typically associated with frames of reference and models of practice were listed in the table as stated in changes made in Question 2.

Discussion:

Almost an equal number of responses were received from the experts saying that it is either necessary or unnecessary to include the separate sheet of operational definitions in the questionnaire. Therefore, based on the strong and practical comments given by the experts who opposed it, it was decided not to include the separate sheet of operational definitions in the questionnaire in order to prevent it from becoming too long and bulky.

Question 13

Question	Comments
13) Are there any other suggestions on what we should do in order to improve the quality of our questionnaire?	1. Put the question in regular type and the answer in bold. 2. Return of the survey is considering consent to participate. 3. Consider to allow the respondents to answer the open-ended question in bilingual, i.e., either in Malay or English languages. 4. Put questionnaire developers' names and copyright at the front cover. 5. Consider specifying whether to include the respondents that have at time worked with children with autistic spectrum disorders or those that currently are working with this population. Specifying which group will yield more reliable and current data. 6. "Some people may not be in practice now, but were in the past – the survey participants should be able to list that."

Summary:

A total of six comments were received for the question.

Changes made:

- The questions were put in regular type and the answers in bold as suggested in comment number 1.
- Based on comment number 2, the statement at the end of the survey to include that the return of the questionnaire is considered as the respondents' consent to participate in the study was amended.

- Referring to comment number 4, the questionnaire developers' names and copyright were included on the front cover.
- Based on comments number 5 and 6, the screening question at the beginning of the survey to ask the respondents whether they have worked or currently are working with children with autistic spectrum disorders in their occupational therapy practices or whether they have never worked with children with autistic spectrum disorders in their occupational therapy practices was amended.

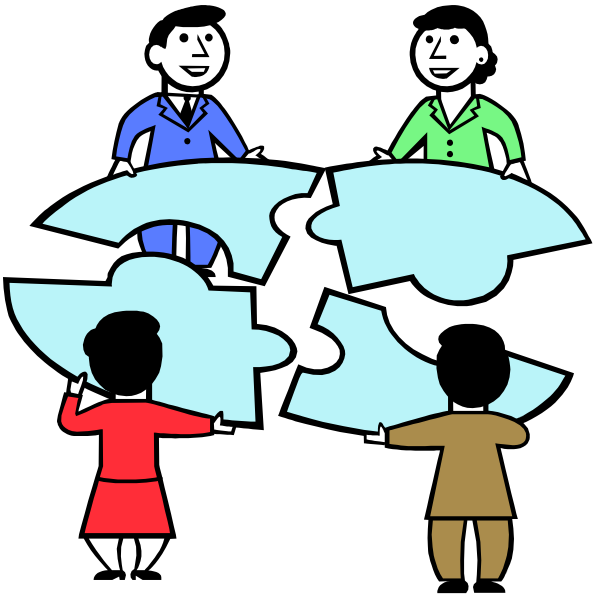
Discussion:

All the comments suggested by the experts in order to improve the initial questionnaire and generating more useful and reliable data were applied. Referring to suggestion number 3; as occupational therapists in Malaysia receive most of their training and lectures in English and proficiency in English language is one of the requirements to enter the course, the option of answering in either English or Malay languages was not applied. However, to address this expert's concern about the option of allowing the respondents to answer the open-ended questions either in English or Malay languages, the modified initial version of the questionnaire was further tested with six occupational therapists in Malaysia to seek feedback about ease of answering, comprehension of the questions and the time taken to complete them. These occupational therapists were a sample of convenience in which all of them have experience in working with children with ASD in various settings. The feedback received in terms of the ease of answering was positive and the time taken to complete the questionnaire ranged between 10 and 25 minutes depending on the amount of qualitative information given in the open-ended questions. No further suggestions were received regarding the face and content validity of the questionnaire and no-one suggested that the option should be given to answer the open-ended questions in either the English or Malay language.

APPENDIX H

THE FINAL QUESTIONNAIRE

Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders



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Screening Question: Please place a Tick (√) in the box for your answer.

☐ **I have worked with children with autistic spectrum disorders?**
(Please proceed and complete the survey).

☐ **I am currently are working with children with autistic spectrum disorders?**
(Please proceed and complete the survey).

☐ **I have never worked with children with autistic spectrum disorders?**
(If this is your answer, you are not required to complete the survey. However, we would very much appreciate if you would return the survey to the researchers using the stamped self-addressed envelope provided. Thank you very much for your time).

Section A: Frame of Reference & Model of Practice

This section of the survey asks you specifically regarding the frames of reference and models of practice you use in your clinical practice with children with autistic spectrum disorders.

A1) Please indicate which frames of reference and models of practice you use with children with autistic spectrum disorders in your occupational therapy practice by placing a Tick (√) in the column below where applicable.

Please also name the frames of reference and models of practice that you use which are not listed in the table below in the spaces provided.

Frame of reference	If yes, please Tick (√)
Coping (Williamson & Szczepanski, 1999)	
Acquisitional (Royeen & Duncan, 1999)	
Psychosocial (Olson, 1999)	
Occupational (Primeau & Ferguson, 1999) **Please specify which occupational** **FOR:**_____	
Sensory Integration (Kimball, 1999)	
Other (Please specify)	
Other (Please specify)	

Model of practice	If yes, please Tick (√)
Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko, Townsend & Craik, 2007)	
Cognitive Orientation to daily Occupational Performance (CO-OP) (Polatajko & Mandich, 2004)	
Ecology of Human Performance Model (Dunn, Brown, & McGuigan, 1994)	
Model of Human Occupation (MOHO) (Kielhofner, 2008; Kielhofner & Burke, 1980)	
Person-Environment-Occupation (PEO) (Law, et al., 1996)	
Other (Please specify)	
Other (Please specify)	

Section B: Assessments/Outcome Measures

This section of the survey asks you about the assessments/outcome measures you use in your clinical practice with children with autistic spectrum disorders.

B1) How often do you use each of the following methods of assessments/outcome measures when assessing children with autistic spectrum disorders? Please circle the number for your response based on the following indicator:

1 = Never **2= Seldom** **3 = Sometimes** **4 = Often** **5 = Always**

Please state any other methods of assessments/outcome measures that you use which are not listed in the table below in the spaces provided.

	Assessments/Outcome Measures	Never	Seldom	Sometimes	Often	Always
a)	**Standardised assessment/screening tools. (Please see question B3)**	**1**	**2**	**3**	**4**	**5**
b)	**Informal assessment/screening tools (including any that you or the service you work in has created). (Please see question B4)**	**1**	**2**	**3**	**4**	**5**
c)	**Observation in multiple environments (e.g., home/school).**	**1**	**2**	**3**	**4**	**5**
d)	**Interview with Parents/caregivers.**	**1**	**2**	**3**	**4**	**5**
e)	**Interview with teachers/education staff.**	**1**	**2**	**3**	**4**	**5**
f)	**Interview with other health professionals.**	**1**	**2**	**3**	**4**	**5**
f)	**Other (Please specify)**	**1**	**2**	**3**	**4**	**5**
g)	**Other (Please specify)**	**1**	**2**	**3**	**4**	**5**

B2) What is the age group of children with autistic spectrum disorders you serve most frequently?
(Please place a check mark (√) in the box for your answer).

☐ **Less than 2 years old** ☐ **6 to 12 years old**

☐ **3 to 5 years old** ☐ **13 to 18 years old**

B3) If you use standardised assessments in your occupational therapy practices, please answer questions B3.1 to B3.10 based on the age group of children with autistic spectrum disorders that you serve most frequently as your answer in question B2.

B3.1) Do you use <u>developmental screenings and evaluations</u> in your assessment with children with autistic spectrum disorders?
(Please place a Tick (√) in the box for your answer).

☐ Yes ☐ No

Please name the tool that you use most frequently: _____

B3.2) Do you use <u>functional or adaptive skill assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a Tick (√) in the box for your answer).

☐ Yes ☐ No

Please name the tool that you use most frequently: _____

B3.3) Do you use <u>activities of daily living skill assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a Tick (√) in the box for your answer).

☐ Yes ☐ No

Please name the tool that you use most frequently: _____

B3.4) Do you use <u>school-related skill assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a Tick (√) in the box for your answer).

☐ Yes ☐ No

please name the tool that you use most frequently: _____

B3.5) Do you use <u>play and leisure participation assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a Tick (√) in the box for your answer).

☐ Yes ☐ No

Please name the tool that you use most frequently: _____

B3.6) Do you use <u>gross or fine motor skill assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a Tick (√) in the box for your answer).

☐ Yes ☐ No

Please name the tool that you use most frequently: _____

B3.7) Do you use <u>sensory processing or sensory integration assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a Tick (√) in the box for your answer).

☐ Yes ☐ No

please name the tool that you use most frequently: _____

B3.8) Do you use <u>psychosocial or social interaction skill assessments</u> in your assessment with children with autistic spectrum disorders?
(Please place a Tick (√) in the box for your answer).

☐ Yes ☐ No

Please name the tool that you use most frequently: _____

B3.9) Do you use <u>environmental assessment</u> in your assessment with children with autistic spectrum disorders?
(Please place a Tick (√) in the box for your answer).

☐ Yes ☐ No

Please name the tool that you use most frequently: _____

B3.10) Do you use a <u>diagnostic assessment*</u> in your assessment with children with autistic spectrum disorders?
(Please place a Tick (√) in the box for your answer).

☐ Yes ☐ No

Please name the tool that you use most frequently: _____

**Diagnostic assessment is an assessment used to identify or confirm the diagnosis of the children.*

B4) If you use non-standardised assessments, please describe them:

_____

_____

_____

_____

_____

_____

Section C: Intervention

This section of the survey asks you specifically regarding *interventions* you use in your clinical practice with children with autistic spectrum disorders.

INTERVENTIONS:

The table below lists some of the commonly identified interventions which are used by occupational therapists and other professionals for children with autistic spectrum disorders.

C1) Please indicate which of the following interventions/programmes you use/have used with children with autistic spectrum disorders in your occupational therapy practice. Please circle one number for your response based on the following indicator:

1 = Never 2= Seldom 3 = Sometimes 4 = Often 5 = Always

Please also name the interventions that you provide which are not listed in the table below in the spaces provided.

Interventions/Programmes	Never	Seldom	Sometimes	Often	Always
Assertiveness Skills Training	**1**	**2**	**3**	**4**	**5**
Cognitive Orientation to daily Occupational Performance (CO-OP)	**1**	**2**	**3**	**4**	**5**
Discrete-Trial Training	**1**	**2**	**3**	**4**	**5**
Early Intervention Programme	**1**	**2**	**3**	**4**	**5**
Environmental Modifications	**1**	**2**	**3**	**4**	**5**
Facilitated Communication Techniques	**1**	**2**	**3**	**4**	**5**
Floortime Techniques (Greenspan)	**1**	**2**	**3**	**4**	**5**
Picture Exchange Communication System (PECS)	**1**	**2**	**3**	**4**	**5**
Play Therapy	**1**	**2**	**3**	**4**	**5**
Pre-school Training	**1**	**2**	**3**	**4**	**5**
Pre-Vocational/Vocational Skills	**1**	**2**	**3**	**4**	**5**
Sand Tray Therapy	**1**	**2**	**3**	**4**	**5**
Sensorimotor Stimulation	**1**	**2**	**3**	**4**	**5**
Sensory Diet	**1**	**2**	**3**	**4**	**5**
Sensory Integration Training	**1**	**2**	**3**	**4**	**5**
Snoezelen	**1**	**2**	**3**	**4**	**5**
Social Communication, Emotional Regulation and Transactional Support (SCERTS) Model	**1**	**2**	**3**	**4**	**5**
Social Stories Programme	**1**	**2**	**3**	**4**	**5**
The Listening Program	**1**	**2**	**3**	**4**	**5**
Therapeutic Listening	**1**	**2**	**3**	**4**	**5**

Interventions/Programmes (Continued)	Never	Seldom	Sometimes	Often	Always
Therapeutic Touch	**1**	**2**	**3**	**4**	**5**
Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) Program	**1**	**2**	**3**	**4**	**5**
Wilbarger Protocol (joint compression & brushing techniques)	**1**	**2**	**3**	**4**	**5**
Other (Please specify)	**1**	**2**	**3**	**4**	**5**
Other (Please specify)	**1**	**2**	**3**	**4**	**5**

C2) Please list your three (3) most common short term occupational therapy intervention goals when working with children with autistic spectrum disorders.

a) _____

b) _____

c) _____

C3) How often do you work with the following people/professionals? Please circle one number for your response based on the following indicator:

1 = Never **2= Seldom** **3 = Sometimes** **4 = Often** **5 = Always**

Please also name the other person/professionals that you include which are not listed in the table below in the spaces provided.

	People/Professionals	Never	Seldom	Sometimes	Often	Always
a)	**Parents/Caregivers**	**1**	**2**	**3**	**4**	**5**
b)	**Teachers/Education Staff**	**1**	**2**	**3**	**4**	**5**
c)	**Speech Therapists/ Speech Pathologists**	**1**	**2**	**3**	**4**	**5**
d)	**Psychologists**	**1**	**2**	**3**	**4**	**5**
e)	**Others (Please specify)**	**1**	**2**	**3**	**4**	**5**
f)	**Others (Please specify)**	**1**	**2**	**3**	**4**	**5**

C4) What are three of the most common challenges you experience when working with children with autistic spectrum disorders?

_____

_____

_____

_____

_____

Section D: Adaptive Behaviours

The table below lists areas of adaptive behaviours in daily living activities.

D1) How often do you address the following adaptive behaviours with children with autistic spectrum disorders in your occupational therapy practice? Please circle one number for your response for each adaptive behaviour area based on the following indicator:

1 = Never 2= Seldom 3 = Sometimes 4 = Often 5 = Always

Please also name the area of adaptive behaviour that you provide which are not listed in the table below in the spaces provided.

	Area of Adaptive Behaviour	Never	Seldom	Sometimes	Often	Always
a)	Self-care activities (e.g., bathing, toileting)	1	2	3	4	5
b)	Home Living (e.g., make bed, prepare breakfast)	1	2	3	4	5
c)	Social Skills	1	2	3	4	5
d)	Communication Skills (including Alternative and Augmentative Communication (AAC))	1	2	3	4	5
e)	School Readiness Skills (e.g., hand writing skills, modifications to accommodate limitations in functional academic activity)	1	2	3	4	5
f)	Community Use (use of facilities in the community, e.g., transportation, recreational centre, local shops)	1	2	3	4	5
g)	Self-determination (e.g., problem solving skills, making decision and choices)	1	2	3	4	5
h)	Play/Leisure Participation (e.g., attend & participate in games)	1	2	3	4	5
i)	Health and Safety Education	1	2	3	4	5
j)	Work or Vocational Skills	1	2	3	4	5
k)	Other (Please specify)	1	2	3	4	5
l)	Other (Please specify)	1	2	3	4	5
m)	Other (Please specify)	1	2	3	4	5

D2) How often do you utilise the following settings when providing adaptive behaviour interventions for children with autistic spectrum disorders? Please circle one number for your response for each setting based on the following indicator:

1 = Never 2= Seldom 3 = Sometimes 4 = Often 5 = Always

Please also name the settings that you utilise which are not listed in the table below in the spaces provided.

Settings	Never	Seldom	Sometimes	Often	Always
Occupational therapy settings	**1**	**2**	**3**	**4**	**5**
Client's natural environments (e.g., home, school, playground)	**1**	**2**	**3**	**4**	**5**
Community facilities (e.g., public transportation, cinemas)	**1**	**2**	**3**	**4**	**5**
Other (Please specify)	**1**	**2**	**3**	**4**	**5**
Other (Please specify)	**1**	**2**	**3**	**4**	**5**

Section E: Professional Development Needs

This section of the survey asks you specifically regarding your professional development needs in your clinical practice with children with autistic spectrum disorders. Please answer all of the questions.

E1) Please rate your level of confidence when providing occupational therapy services for children with autistic spectrum disorders? *(Please circle one number for your answer).*

1	2	3	4	5
Very low	**Low**	**Moderate**	**High**	**Very high**

E2) Have you attended any training/certification courses or continuing education courses that are relevant to your occupational therapy services for children with autistic spectrum disorders? *(Please place a Tick (√) in the box for your answer).*

Yes ☐ **No** ☐

If you have, please name the training/certification courses or continuing education courses in the table below and also indicate the year attended.

	Training/certification courses attended	**Year attended**
1.		
2.		
3.		
4.		
5.		

E3) Please name the training/certification courses that are relevant to your occupational therapy services for children with autistic spectrum disorders which you plan to attend in the table below.

	Training/certification courses would like to attend
1.	
2.	
3.	
4.	
5.	

E4) Please indicate you preferences in the method of obtaining knowledge and skills. (Please circle the number for your response).

1 = Not preferred 2 = Low preferences 3 = Moderate 4 = High preferences 5 = Preferred the mosT

	Method of obtaining knowledge and skills	Not preferred	Low preferences	Moderate	High preferences	Preferred the most
a)	Hands-on mentoring by expert/experience therapist	1	2	3	4	5
b)	Case presentation of intervention and technique	1	2	3	4	5
c)	Multidisciplinary workshop with discussion and problem solving	1	2	3	4	5
d)	Short courses of specialise certification on certain technique/programme	1	2	3	4	5
e)	Online courses	1	2	3	4	5
f)	Conferences or seminars	1	2	3	4	5
g)	Literature reviews	1	2	3	4	5
h)	Advanced post-professional academic degrees	1	2	3	4	5
i)	Other (Please specify)	1	2	3	4	5
j)	Other (Please specify)	1	2	3	4	5

Section F: Demographic Information

This section of the survey asks you specifically regarding your personal information, professional qualification and working experiences as an Occupational Therapist and also your experiences of working with children with autistic spectrum disorders. Please answer all of the questions.

F1) Where do you presently reside? *(Please place a Tick (√) in the box for your answer).*

☐ **I am a participant from Australia**

I am a participant from Malaysia:

☐ **Peninsular Malaysia**

☐ **East Malaysia (Sabah,Sarawak,Wilayah Persekutuan Labuan)**

F2) What is your highest level of academic qualification in the field of occupational therapy? *(Please place a Tick (√) in the box for your answer).*

☐ **Diploma/certificate in occupational therapy**

☐ **Bachelors degree in occupational therapy**

☐ **Graduate-entry masters degree in occupational therapy**

☐ **Course work/research masters**

☐ **Clinical doctorate in occupational therapy**

☐ **Research doctorate in occupational therapy**

☐ **Other (Please specify)** _____

F3) In which setting do you currently practice?
(Please place a Tick (√) in the box for your answer).

☐ **Hospital**

☐ **Long-Term Residential Care setting**

☐ **School**

☐ **Community-Based Care**

☐ **Transitional Centre/Sheltered Workshop**

☐ **Early Intervention Services**

☐ **Private Practice**

☐ **Other (Please specify)**_____

F4) Approximately how many years have you been practicing as an Occupational Therapist? *(Please place a Tick (√) in the box for your answer).*

☐ **Less than 1 year**

☐ **1-5 years**

☐ **6-10 years**

☐ **11-15 years**

☐ **16-20 years**

☐ **More than 21 years**

F5) Approximately how many years have you been working or have you worked with children with autistic spectrum disorders in your occupational therapy practice?
(Please place a Tick (√) in the box for your answer).

- ☐ **Less than 1 year**
- ☐ **1-5 years**
- ☐ **6-10 years**
- ☐ **11-15 years**
- ☐ **16-20 years**
- ☐ **More than 21 years**

F6) How do you provide the majority of your direct occupational therapy services to children with autistic spectrum disorders? *(Please place a Tick (√) in the box for your answer).*

- ☐ **Individual intervention session**
- ☐ **Group intervention session of less than 5 children**
- ☐ **Group intervention session of 6 or more children**
- ☐ **Other (Please specify)** _____

F7) How do you provide the majority of your indirect occupational therapy services to children with autistic spectrum disorders? *(Please place a Tick (√) in the box for your answer).*

- ☐ **Consultation with parents/ caregivers**
- ☐ **Consultation with education staff**
- ☐ **Multidisciplinary team conference**
- ☐ **Professional development**
- ☐ **Team teaching**
- ☐ **Other (Please specify)**_____

END OF THE SURVEY.

Please check that you have completed every section of the survey. Thank you for taking the time to participate in this study. Your assistance and input are greatly appreciated.

Please return the questionnaire using the stamped self-addressed envelope provided. The return of the questionnaire considered as your consent to participate in the study. Thank you.

APPENDIX I

THE FINAL INTRODUCTORY LETTER

MONASH University
Medicine, Nursing and Health Sciences

INTRODUCTORY LETTER

Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders

Dear colleagues,

My name is Masne Kadar and I am a fulltime PhD student in the Department of Occupational Therapy at Monash University, Australia. My supervisors are Dr. Rachael McDonald and Dr. Primrose Lentin, senior lecturers in the Department of Occupational Therapy at Monash University, Australia. As an occupational therapist, you are invited to participate in this survey. You have been forwarded this survey via the membership departments of Australian Association of Occupational Therapists, Victoria (OT Australia, Victoria) or Malaysian Occupational Therapists Association (MOTA). This survey has been approved by Monash University Human Research Ethics Committee (MUHREC) Review Board.

Thank you for taking the time to read about this survey. We are interested in occupational therapists' practice with children with Autistic Spectrum Disorders (ASD). We are exploring models of practice, outcome measures, intervention methods and professional development needs among occupational therapists working in this area. Watling et al. (1999) explored occupational therapy practice patterns for 2 to 12-year-old children with ASD, however, since then the explosion of information regarding ASD demands more current information. A systematic review by Case-Smith and Arbesman (2008) on intervention for autism used by occupational therapists highlighted the need for more information regarding these.

In this survey, we are investigating current practice in occupational therapy services provided to children with ASD. We will compare practice in Australia and Malaysia. Information will be collected to identify similarities and differences between the two countries. This information will form a baseline for future research and practice. We will further investigate parents/caregivers goals in regards to their children with ASD and match these with the occupational therapy practice.

We have developed a questionnaire titled ***'Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders'***. The term **children with autistic spectrum disorders** in this survey are defined as **a person under the age of 18 years old** who has been diagnosed with either **autistic disorder, Asperger's syndrome (AS) or pervasive developmental disorders-not otherwise specified (PDD-NOS)**. It is hope that the information obtained from this survey will

provide valuable information for occupational therapy practitioners, educators, researchers, managers as well as employers in ensuring further development of contemporary professional knowledge in the field of occupational therapy practices for children with autistic spectrum disorders.

There are six (6) sections in this survey which is anticipated that the survey can be completed within 20 to 25 minutes. If you agree to take part in this survey, please complete all six (6) sections of the survey. **Once completed, please return the survey using the stamped self-addressed envelope provided within 2 weeks of receiving them in your mail.** The returned of the survey are considered as your consent to participate in the survey.

If you have never worked with children with autistic spectrum disorders in your occupational therapy practice, please tick the appropriate box at the **screening question at the beginning of the questionnaire** and we would very much appreciate if you would return the incomplete questionnaire using the stamped self-addressed envelope provided. Should you have any enquiries regarding the survey, we can be contacted at [redacted] Your input and perspective would be much valued. Thank you for your attentions.

Sincerely,

.....
Masne Kadar
PhD Student
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC 3199, Australia
[redacted]

.....
Dr. Rachael McDonald
Senior Lecturer
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC 3199, Australia
Phone:[redacted]

.....
Dr. Primrose Lentin
Senior Lecturer
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC 3199, Australia
[redacted]

APPENDIX J

THE APPLICATION LETTER TO THE OCCUPATIONAL THERAPY ASSOCIATION – MOTA, OT VICTORIA BRANCH AND PERMISSION LETTER FROM MOTA

MONASH University
Medicine, Nursing and Health Sciences

29th of OCTOBER 2009.

To The President of the Malaysian Occupational Therapists Association (MOTA),

Dear Mr. Mohd Amir Mohd Hashim,

Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders

My name is Masne Kadar and I am a fulltime PhD student in the Department of Occupational Therapy at Monash University, Australia. My supervisors are Dr. Rachael McDonald and Dr. Primrose Lentin, senior lecturers in the Department of Occupational Therapy at Monash University, Australia. Thank you for taking the time to read about this study. We are interested in occupational therapists' practice with children with Autistic Spectrum Disorders (ASD). We are exploring models of practice, outcome measures, intervention methods and professional development needs among occupational therapists working in this area. Watling et al. (1999) explored occupational therapy practice patterns for 2 to 12-year-old children with ASD, however, since then the explosion of information regarding ASD demands more current information. A systematic review by Case-Smith and Arbesman (2008) on intervention for autism used by occupational therapists highlighted the need for more information regarding these.

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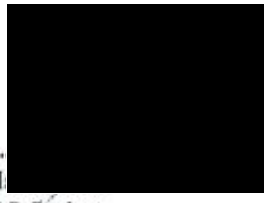
We have developed a questionnaire titled ***'Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders'***. We would like to request permission to access your association members in order for us to mail out the survey. All occupational therapists' participants involved in this survey will remain anonymous and we would like to ensure you that there will be no identifiable information collected from participants. We are writing to find out what is the best process for us to access your members.

Your help in this matter are greatly appreciated and we can be contacted at mkad7@student.monash.edu.au or (+61) 04 50565194 if you have any questions regarding this study. Thank you for your kind attentions.

Sincerely,



M
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References.

Case-Smith, J., & Arbesman, M. (2008). Evidence-based review of interventions for autism used in or relevance to occupational therapy. *American Journal of Occupational Therapy, 62*(4), 416-429.

Watling, R., Deitz, J., Kanny, E. M., & McLaughlin, J. F. (1999). Current practice of occupational therapy for children with autism. *American Journal of Occupational Therapy, 53*(5), 498-505.

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MONASH University
Medicine, Nursing and Health Sciences

29th of OCTOBER 2009.

To The President of the Australian Association of Occupational Therapists (Victoria),

Dear Ms. Susan Giles,

Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders

My name is Masne Kadar and I am a fulltime PhD student in the Department of Occupational Therapy at Monash University, Australia. My supervisors are Dr. Rachael McDonald and Dr. Primrose Lentin, senior lecturers in the Department of Occupational Therapy at Monash University, Australia. Thank you for taking the time to read about this study. We are interested in occupational therapists' practice with children with Autistic Spectrum Disorders (ASD). We are exploring models of practice, outcome measures, intervention methods and professional development needs among occupational therapists working in this area. Watling et al. (1999) explored occupational therapy practice patterns for 2 to 12-year-old children with ASD, however, since then the explosion of information regarding ASD demands more current information. A systematic review by Case-Smith and Arbesman (2008) on intervention for autism used by occupational therapists highlighted the need for more information regarding these.

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We have developed a questionnaire titled ***'Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders'***. We would like to request permission to access your association members in order for us to mail out the survey. All occupational therapists' participants involved in this survey will remain anonymous and we would like to ensure you that there will be no identifiable information collected from participants. We are writing to find out what is the best process for us to access your members.

Your help in this matter are greatly appreciated and we can be contacted at mkad7@student.monash.edu.au or (+61) 04 50565194 if you have any questions regarding this study. Thank you for your kind attentions.

Sincerely,

Masne
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References.

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MALAYSIAN OCCUPATIONAL THERAPISTS ASSOCIATION
Persatuan Terapi Carakerja Malaysia

P.O Box 11715
50754 KUALA LUMPUR
E: info@ot-malaysia.org

Tarikh : 14th December 2009
Rujukan: 300- MOTA (09/11/ 24)

Masne Kadar
PhD Student
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and
Health Sciences
PO Box 527, Frankston, VIC 3199,
Australia

Dear Sir/Madam

APPROVAL TO CONDUCT STUDY WITH MEMBERS OF MALAYSIAN OCCUPATIONAL THERAPY ASSOCIATION

We received the permission requesting letter recently. This is a good topic which involves Malaysian Occupational Therapists who registered with the association.

The association has no objection in conducting the survey among our members. Therefore we will try to provide as much information you need from the association. However the anonymity of the members is important and the researcher should know better.

For further inquiries regarding the member's particulars, please email Miss Sangetavani Manoharan (Vice Secretary) at sangeta_vani@yahoo.com or contact at +06019-2361027. She will assist you throughout the study.

Hope you can complete your study soon and Good Luck.

Thank You

Regards,

[redacted]
Vi oo
Se aysia
Vi .com

APPENDIX K

THE HUMAN ETHICS CERTIFICATE OF APPROVAL FROM MUHREC

MONASH University

Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

Date:	**16 November 2009**
Project Number:	**CF09/3131 - 2009001710**
Project Title:	**Occupational Therapy Practice Survey for Children With Autistic Spectrum Disorders**
Chief Investigator:	**Dr Rachael McDonald**
Approved:	**From: 16 November 2009** **To: 16 November 2014**

Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to MUHREC before any data collection can occur at the specified organisation. **Failure to provide permission letters to MUHREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

[redacted]

Professor Ben Canny
Chair, MUHREC

cc: Dr Primrose Lentin; Mrs Masne Kadar

Postal – Monash University, Vic 3800, Australia
Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton
Telephone +61 3 9905 5490 Facsimile +61 3 9905 3831
Email muhrec@adm.monash.edu.au www.monash.edu/research/ethics/human/index/html
ABN 12 377 614 012 CRICOS Provider #00008C

APPENDIX L

THE APPROVAL LETTER TO CONDUCT RESEARCH IN MALAYSIA FROM EPU

UNIT PERANCANG EKONOMI
Economic Planning Unit
JABATAN PERDANA MENTERI
Prime Minister's Department
BLOK B5 & B6
PUSAT PENTADBIRAN KERAJAAN PERSEKUTUAN
62502 PUTRAJAYA
MALAYSIA

EPU

Telefon : 603-8888 3333
Telefax : 603-888

Ruj. Tuan:
Your Ref.: UPE: 40/200/19/2505

Ruj. Kami:
Our Ref.:

Tarikh:
Date: 15 December 2009

Masne Kadar
21, Queen Street,
Frankston, 3199,
Victoria,
Australia
Email: masne_kadar@yahoo.co.uk

APPLICATION TO CONDUCT RESEARCH IN MALAYSIA

With reference to your application, I am pleased to inform you that your application to conduct research in Malaysia has been *approved* by the **Research Promotion and Co-Ordination Committee, Economic Planning Unit, Prime Minister's Department.** The details of the approval are as follows:

Researcher's name	:	**MASNE KADAR**
Passport No. / I. C No:		**740430-01-6736**
Nationality	:	**MALAYSIAN**
Title of Research	:	**"OCCUPATIONAL PERFORMANCE IN CHILDREN WITH AUTISTIC SPECTRUM DISORDERS: OCCUPATIONAL THERAPY SERVICES AND PARENTS'S GOALS."**

Period of Research Approved: **18 MONTHS**

2. Please collect your Research Pass in person from the Economic Planning Unit, Prime Minister's Department, Parcel B, Level 1 Block B5, Federal Government Administrative Centre, 62502 Putrajaya and bring along two (2) passport size photographs. You are also required to comply with the rules and regulations stipulated from time to time by the agencies with which you have dealings in the conduct of your research.

3. I would like to draw your attention to the undertaking signed by you that you will submit without cost to the Economic Planning Unit the following documents:

a) A brief summary of your research findings on completion of your research and before you leave Malaysia; and

b) Three (3) copies of your final dissertation/publication.

4. Lastly, please submit a copy of your preliminary and final report directly to the State Government where you carried out your research. Thank you.

Yours sincerely,

(**MUNIRAH ABD. MANAN**)
For Director General,
Economic Planning Unit.
E-mail: munirah@epu.gov.my
Tel: 88725281/88725272
Fax: 88883961

ATTENTION

This letter is only to inform you the status of your application and **cannot be used as a research pass**.

Cc:

Pengarah
Pusat Pengurausan Penyelidkan dan Inovasi
Aras 3, Bangunan Perpustakaan Tun Seri Lanang
Universiti Kebangsaan Malaysia
43600 UKM Bangi, Selangor D.E..

APPENDIX M

THE EXPLANATORY STATEMENT

MONASH University
Medicine, Nursing and Health Sciences

Explanatory Statement
Occupational Therapists (Victoria, Australia and Malaysia)

Title: Occupational therapy practice survey for children with autistic spectrum disorders

This information sheet is for you to keep.

My name is Masne Kadar and for my PhD, I am conducting a research project with Dr. Rachael McDonald and Dr. Primrose Lentin, Senior Lecturers in the Department of Occupational Therapy at Monash University. This means that I will be writing a thesis based on this research. This research is investigating the occupational therapy practices for children with autistic spectrum disorders. We are asking occupational therapists to complete a survey regarding their frames of reference/models of practice, assessments/outcome measures, intervention methods and their professional development needs.

Why and how you have been chosen as participants

As occupational therapists, you have been invited to participate in this survey. This has been forwarded to you via the membership department of OT Australia, Victoria or the Malaysian Occupational Therapists Association (MOTA).

The aim/purpose of the research

The aims of this survey are:

1) to identify the frames of reference/models of practice, assessments/outcome measures and interventions that are currently being provided to children with autistic spectrum disorders by occupational therapists in Australia,
2) to identify the frames of reference/models of practice, assessments/outcome measures and interventions that are currently being provided to children with autistic spectrum disorders by occupational therapists in Malaysia,
3) to compare the practices of occupational therapy services for children with autistic spectrum disorders between both regions in order to find similarities and differences between both practices, and
4) to identify professional development needs of occupational therapists in Australia and Malaysia.

Possible benefits
There is no immediate benefit for the participants. However it is anticipated that the information obtained from this survey will provide valuable information for occupational therapy practitioners, educators, researchers, managers, as well as employers in ensuring further development of contemporary professional knowledge in the field of occupational therapy practices for children with autistic spectrum disorders.

What does the research involve?
The project deals with gathering information regarding the occupational therapy practice for children with autistic spectrum disorders in Australia and Malaysia. Occupational Therapists will be asked to complete the questionnaire titled *Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders* in order to gather information regarding their services.

How much time will the research take?

It is anticipated that the questionnaire can be completed within 20-25 minutes.

Inconvenience/discomfort
There is minimal inconvenience and/or discomfort for the study participants. The questionnaire may make you feel uncomfortable, because it is asking questions regarding your practices and demographic information and also demand an extra time allocation from you daily routine. However, there are no physical/psychological inconveniences or discomfort beyond normal everyday life anticipated from participating in this survey.

Payment
No payment will be given and your participation is on a voluntary basis.

Can I withdraw from the research?
Participation in the study is voluntary, and you are under no obligation to consent to take part. However, if you do consent to participate, your participation is anonymous and no personal information will be identifiable. You do not have to answer any questions in the survey which you feel too personal or intrusive. The return of the anonymous questionnaire is considered as your consent to participate and it will not be possible to withdraw once the questionnaire has been submitted to the researchers.

Confidentiality
Your participation is anonymous. No form of personal identifications will be collected and therefore no individual participants will be identifiable.

Storage of data
Storage of the data collected during the study will adhere to Monash University regulations and will be kept at Monash University premises in a locked cupboard/filing cabinet for 5 years and on a password protected computer which is only accessible to the researchers. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Use of data for other purposes
The collected data in this research project will not be used for other purposes.

Result
If you would like to be informed of the aggregate research finding, please contact Mrs. Masne Kadar [redacted]

Contact details

If you would like to contact the researchers about any aspect of this study, please contact the Chief investigator:	If you have a complaint concerning the manner in which this research is being conducted, please contact:
Rachael McDonald, PhD Senior Lecturer Department of Occupational Therapy Faculty of medicine, Nursing and Health Sciences Monash University – Peninsula Campus PO Box 527, Frankston, Victoria, 3199, Australia [redacted] Or Masne Kadar, PhD Candidate Department of Occupational Therapy Faculty of medicine, Nursing and Health Sciences Monash University – Peninsula Campus PO Box 527, Frankston, Victoria, 3199, Australia [redacted]	Executive Officer Monash University Human Research Ethics Committee (MUHREC) Building 3e Room 111 Research Office Monash University VIC 3800 [redacted] Local contact person for Malaysian Occupational Therapists; Puan Rohana Mukahar Head of Occupational Therapy Department Universiti Kebangsaan Malaysia Medical Centre (UKMMC) Jalan Yaacob Latif, 56000 Cheras, Kuala Lumpur MALAYSIA [redacted]

Thank you

Dr. Rachael McDonald Senior Lecturer	Dr. Primrose Lentin Senior Lecturer	Mrs. Masne Kadar PhD Candidate

School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC3199, Australia
Building B, Peninsula Campus, McMahons Road, Frankston
[redacted]
www.med.monash.edu.au
ABN 12 377 614 012 CRICOS provider number 00008C

APPENDIX N

THE LETTER OF REMINDER 1 AND 2

MONASH University
Medicine, Nursing and Health Sciences

Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders

Dear colleagues,

My name is Masne Kadar and I am a fulltime PhD student in the Department of Occupational Therapy at Monash University, Australia. My supervisors are Dr. Rachael McDonald and Dr. Primrose Lentin, senior lecturers in the Department of Occupational Therapy at Monash University, Australia.

As an occupational therapist, you have been invited to participate in our survey on current practice in occupational therapy services provided to children with ASD. The questionnaire titled ***'Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders'*** has been mailed to your registered address approximately two weeks ago. You have been forwarded the survey via the membership departments of Australian Association of Occupational Therapists, Victoria (OT Australia, Victoria) or Malaysian Occupational Therapists Association (MOTA). The survey has been approved by Monash University Human Research Ethics Committee (MUHREC) Review Board.

We would very much appreciate if you could complete the survey and return them to us using the stamped self-addressed envelope provided together with the survey. However, if you have done so, kindly accept our sincere thank you for your time and attention.

Should you have any enquiries regarding the survey, we can be contacted at [redacted]. Thank you for your attentions.

Sincerely,

……
Masne Kadar
PhD Student
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC 3199, Australia
[redacted]

……..
Dr. Rachael McDonald
Senior Lecturer
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC 3199, Australia
[redacted]3

…….
Dr. Primrose Lentin
Senior Lecturer
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC 3199, Australia
[redacted]

MONASH University
Medicine, Nursing and Health Sciences

Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders

Dear colleagues,

My name is Masne Kadar and I am a fulltime PhD student in the Department of Occupational Therapy at Monash University, Australia. My supervisors are Dr. Rachael McDonald and Dr. Primrose Lentin, senior lecturers in the Department of Occupational Therapy at Monash University, Australia.

As an occupational therapist, you have been invited to participate in our survey on current practice in occupational therapy services provided to children with ASD. The questionnaire titled ***'Occupational Therapy Practice Survey for Children with Autistic Spectrum Disorders'*** has been mailed to your registered address approximately four weeks ago. You have been forwarded the survey via the membership departments of Australian Association of Occupational Therapists, Victoria (OT Australia, Victoria) or Malaysian Occupational Therapists Association (MOTA). The survey has been approved by Monash University Human Research Ethics Committee (MUHREC) Review Board.

We would very much appreciate if you could complete the survey and return them to us using the stamped self-addressed envelope provided together with the survey. However, if you have done so, kindly accept our sincere thank you for your time and attention.

Should you have any enquiries regarding the survey, we can be contacted at [redacted] Thank you for your attentions.

Sincerely,

……
Masne Kadar
PhD Student
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC 3199, Australia
[redacted]

……..
Dr. Rachael McDonald
Senior Lecturer
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC 3199, Australia
[redacted]

…….
Dr. Primrose Lentin
Senior Lecturer
Department of Occupational Therapy
School of Primary Health Care
Faculty of Medicine, Nursing and Health Sciences
PO Box 527, Frankston, VIC 3199, Australia
[redacted]

APPENDIX O

RESULTS ON THE QUESTIONNAIRE

Result on the Question B3 – If you use standardised assessments in your occupational therapy practices, please answer questions B3.1 to B3.10 based on the age group of children with autistic spectrum disorders that you serve most frequently as your answer in question B2. The results are shown in Table O1 below.

Table O.1

The top five standardised assessments tools used by the participants in Victoria and Malaysia in 10 assessment areas and its number of response.

Standardised assessments tools used				
	Participants in Victoria	Number of response	Participants in Malaysia	Number of response
Developmental screenings and evaluations				
1)	Beery-Buktenica Developmental Test of Visual-Motor Integration (BEERY VMI)	6	Denver Developmental Screening Test	24
	Hawaii Early Learning Profile (HELP)	5	The Peabody Developmental Motor Scales (PDMS)	2
2)	Peabody Developmental Motor Scales (PDMS)/ -Second Edition (PDMS-2)	4	Pediatric Evaluation of Disability Inventory (PEDI)	1
3)	Psychoeducational Profile-Third Edition (PEP-3)	3		
4)	Bruininks-Oseretsky Test of Motor Proficiency (BOT)/ -Second Edition (BOT-2)	3		
Functional or adaptive skill assessments				
1)	Adaptive Behavior Assessment System-Second Edition (ABAS-II)	4	Portage assessment scales	1
2)	Child Initiated Pretend Play Assessment (ChIPPA)	3	Canadian Occupational Performance Measure (COPM)	1
3)	Peabody Developmental Motor Scales (PDMS)/ -Second Edition (PDMS-2)	3	Sensory profile	1
4)	Sensory Profile	3	Peabody Developmental Motor Scales (PDMS).	1
5)	Miller Function and Participation Scales (M-FUN).	3		
Activities of daily living skill assessments				
1)	Canadian Occupational Performance Measure (COPM).	3	Modified Barthel Index of Activities of Daily Living.	9
2)	Pediatric Evaluation of Disability Inventory (PEDI).	2	Pediatric Evaluation of Disability Inventory (PEDI).	7

Table O.1

The top five standardised assessments tools used by the participants in Victoria and Malaysia in 10 assessment areas and its number of response (continued).

Standardised assessments tools used				
	Participants in Victoria	Number of response	Participants in Malaysia	Number of response
Activities of daily living skill assessments (continued)				
3)	Sensory Profile.	1	Functional Independence Measure for Children (Wee FIM).	1
4)	Adaptive Behaviour Assessment System (ABAS-I) –Second Edition (ABAS-II).	1	Denver Developmental Screening Test.	1
5)	Autism Detection in Early Childhood (ADEC).	1		
School-related skill assessments				
1)	School Function Assessment (SFA).	8	School Function Assessment (SFA).	2
2)	Beery-Buktenica Developmental Test of Visual-Motor Integration (BEERY VMI).	4	Test of Handwriting Skill (THS).	1
3)	Miller Function and Participation Scales (M-FUN).	4	Evaluation Tool of Children's Handwriting (ETCH).	1
4)	Sensory Profile/Sensory Profile School Companion	4		
5)	Evaluation Tool of Children's Handwriting (ETCH).	3		
Play and leisure participation assessments				
1)	Child Initiated Imaginative Play Assessment (ChIPPA).	5	KNOX pre-school play scale	1
2)	Functional Emotional Assessment Scales (FEAS).	2	Test of Playfulness (ToP)	1
3)	Symbolic and Imaginative Play Developmental Checklist (SIPDC).	1		
4)	Miller Function and Participation Scales (M-FUN).	1		
5)	Sensory Profile.	1		
Gross or fine motor skill assessments				
1)	Bruininks-Oseretsky Test of Motor Proficiency (BOT)/ -Second Edition (BOT-2).	16	Denver Developmental Screening Test.	8
2)	Peabody Developmental Motor Scales (PDMS)/ -Second Edition (PDMS-2).	14	Peabody Developmental Motor Scales (PDMS)/ -Second Edition (PDMS-2).	7
3)	Beery-Buktenica Developmental Test of Visual-Motor Integration (BEERY VMI).	12	Bruininks-Oseretsky Test of Motor Proficiency (BOT)/ -Second Edition (BOT-2).	2

Table O.1

The top five standardised assessments tools used by the participants in Victoria and Malaysia in 10 assessment areas and its number of response (continued)

Standardised assessments tools used				
	Participants in Victoria	Number of response	Participants in Malaysia	Number of response
Gross or fine motor skill assessments (continued)				
4)	Miller Function and Participation Scales (M-FUN).	9	Pre-school Visual Motor Integration Assessment	1
5)	Movement Assessment Battery for Children (MOVEMENT ABC).	6		
Sensory processing or sensory integration assessments				
1)	Sensory Profile/Sensory Profile School Companion	53	Sensory Profile/Sensory Profile School Companion	18
2)	Sensory Processing Measure (SPM).	5		
3)	Sensory Integration and Praxis Test (SIPT).	3		
4)	Functional Listening Questionnaire/Evaluation	1		
5)	Sensory-Motor History Questionnaire	1		
Psychosocial or social interaction skill assessments				
1)	Assessment of Motor and Process Skills (AMPS).	1	Denver Developmental Screening Test.	2
2)	Functional Emotional Assessment Scale (FEAS).	3	Pediatric Evaluation of Disability Inventory (PEDI).	1
3)	Pragmatic Observation Checklist.	1	Social Skills Group Assessment Questionnaire.	1
Environmental assessments				
1)	School Version of the Assessment of Motor and Process Skills (SCHOOL AMPS).	1	School Function Assessment (SFA).	1
2)	Home safety checklist.	1		
Diagnostic assessments				
	Respondents in Victoria	Number of response	Respondents in Malaysia	Number of response
1)	Childhood Autism Rating Scale (CARS).	3	Sensory profile.	2
2)	Psychoeducational Profile-Third Edition (PEP-3).	2	The Modified Checklist for Autism in Toddlers (M-CHAT™)	1
3)			The Gilliam Autism Rating Scale	1
4)			The Naglieri Nonverbal Ability Test	1

Result on the Question C1 – Please indicate which of the following interventions/ programmes you use/have used with children with autistic spectrum disorders in your occupational therapy practice. The results are shown in Table O2 below.

Table O.2

Result on the interventions or programmes utilised by the participants in Victoria and Malaysia

Interventions/Programmes	n†		Never (%)		Seldom (%)		Sometimes (%)		Often (%)		Always (%)		*p*
	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	
Assertiveness skills training	60	51	60.0	11.8	18.3	13.7	15.0	43.1	5.0	23.5	1.7	7.8	<.001*
Cognitive Orientation to daily Occupational Performance (CO-OP)	58	50	48.3	18.0	20.7	12.0	10.3	32.0	20.7	30.0	0.0	8.0	<.001*
Discrete-trial training	55	50	74.5	38.0	10.9	28.0	14.5	26.0	0.0	8.0	0.0	0.0	<.001*
Early intervention programme	58	52	12.1	3.8	6.9	7.7	15.5	23.1	36.2	42.3	29.3	23.1	.930
Environmental modifications	64	51	1.6	13.7	4.7	13.7	35.9	25.5	45.3	35.3	12.5	11.8	.072
Facilitated communication techniques	61	51	31.1	17.6	11.5	15.7	18.0	29.4	27.9	31.4	11.5	5.9	.618
Floortime techniques	59	48	37.3	37.5	6.8	25.0	22.0	20.8	27.1	8.3	6.8	8.3	.219
Picture Exchange Communication System (PECS)	62	47	12.9	21.3	12.9	21.3	25.8	29.8	35.5	17.0	12.9	10.6	.040*
Play therapy	58	52	6.9	1.9	10.3	3.8	27.6	7.7	48.3	40.4	6.9	46.2	<.001*
Pre-school training	55	52	20.0	1.9	10.9	5.8	32.7	15.4	32.7	46.2	3.6	30.8	<.001*
Pre-vocational/vocational training	56	51	57.1	25.5	17.9	33.3	16.1	23.5	7.1	9.8	1.8	7.8	.003*
Sand tray therapy	56	51	69.6	41.2	16.1	17.6	5.4	17.6	8.9	19.6	0.0	3.9	.001*
Sensorimotor stimulation	61	52	11.5	5.8	6.6	5.8	29.5	9.6	41.0	44.2	11.5	34.6	.001*
Sensory diet	64	51	4.7	31.4	6.3	7.8	26.6	19.6	48.4	21.6	14.1	19.6	.018*

Table O.2

Result on the interventions or programmes utilised by the participants in Victoria and Malaysia (continued)

Interventions/Programmes	n†		Never (%)		Seldom (%)		Sometimes (%)		Often (%)		Always (%)		*p*
	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	Victorian	Malaysian	
Sensory integration training	62	52	11.3	1.9	9.7	1.9	22.6	17.3	41.9	34.6	14.5	44.2	<.001*
Snoezelen	57	51	80.7	33.3	7.0	3.9	5.3	2.0	7.0	21.6	0.0	39.2	<.001*
Social Communication, Emotional Regulation and Transactional Support (SCERTS) model	57	50	89.5	60.0	3.5	22.0	1.8	8.0	3.5	4.0	1.8	6.0	.001*
Social stories programme	62	49	4.8	38.8	8.1	32.7	51.6	18.4	30.6	8.2	4.8	2.0	<.001*
The Listening Programme	58	48	79.3	52.1	10.3	22.9	8.6	18.8	1.7	4.2	0.0	2.1	.003*
Therapeutic listening	59	50	61.0	46.0	11.9	24.0	15.3	22.0	11.9	4.0	0.0	4.0	.272
Therapeutic touch	56	51	60.7	21.6	17.9	17.6	10.7	35.3	10.7	13.7	0.0	11.8	<.001*
Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) programme	59	51	86.4	56.9	8.5	21.6	1.7	13.7	3.4	5.9	0.0	2.0	.001*
Wilbarger Protocol (joint compression & brushing techniques)	63	51	31.7	11.8	23.8	9.8	23.8	33.3	17.5	19.6	3.2	25.5	<.001*

Note. n† Represents number of participants providing rating. In a five-point Lickert scale ranging from 1 (Never), 2 (seldom), 3 (sometimes), 4 (often) and 5 (always). *p<.05

Fifteen occupational therapist participants indicated that they used other interventions or programmes:

1. Social skills group/training
2. ‘The Transporters’
3. Psychotherapy
4. Solution-focused therapy
5. Parent educations
6. Motor skills trainings
7. Applied Behavioural Analysis (ABA)/Behavioural strategies
8. Sensory modulation
9. The ALERT programme®
10. Creative activities
11. Repetitive functional training.

Result on the Question C2 – Please list your three (3) most common short-term occupational therapy intervention goals when working with children with autistic spectrum disorders. The results are shown in Table O3 below.

Table O.3

Results of qualitative responses to the question "Please list your three (3) most common short term occupational therapy intervention goals when working with children with autistic spectrum disorders", presented in 17 categories

Short-term goals	Participants in Victoria (n= 66) Responses= 143	Participants in Malaysia (n= 52) Responses= 143	Greater frequency of responses
Improving joint attention skills	4	12	OT Malaysia
Improving cooperation, compliance, following instructions	6	6	Equal
Improving play skills	11	7	OT Victoria
Improving self-care skills	16	13	OT Victoria
Improving communication and social skills	15	26	OT Malaysia
Improving emotional state	4	3	OT Victoria
Improving/enhancing vocational/educational/school readiness skills	5	14	OT Malaysia
Managing issues related to sensory difficulties	26	18	OT Victoria
Improving attention and concentration skills	19	26	OT Malaysia
Improving fine and/or gross motor skills/strength/developmental level skills	15	4	OT Victoria
Environmental modification	1	0	OT Victoria
Expanding interest and preferences in activities/foods	5	0	OT Victoria

Table O.3

Results of qualitative responses to the question "Please list your three (3) most common short term occupational therapy intervention goals when working with children with autistic spectrum disorders", presented in 17 categories (continued)

Short-term goals (continued)	Participants in Victoria (n= 66) Responses= 143	Participants in Malaysia (n= 52) Responses= 143	Greater frequency of responses
Managing challenging behaviour	4	13	OT Malaysia
Safety education	1	0	OT Victoria
Improving handwriting/pre-writing skills	8	1	OT Victoria
Finding meaningful activity	1	0	OT Victoria
Introducing routine/structure with visual aides	1	0	OT Victoria

Result on the Question C4 – What are three (3) of the most common challenges you experience when working with children with autistic spectrum disorders?

Table O.4

Results of qualitative responses to the question "What are three (3) of the most common challenges you experience when working with children with autistic spectrum disorders?" presented in six categories

Area of challenges	Participants in Victoria (n= 66) Responses= 100	Participants in Malaysia (n= 52) Responses= 71
Difficulties in dealing and working with children with ASD (slow or no progress made by the children, difficulties in achieving independent in self-care, difficulties in engaging children with ASD with planned tasks, lack of play skills, challenging behaviours, e.g.: temper tantrum, limited communication skills, poor cognitive abilities).	33	33
Difficulties in dealing and working with parents/caregivers (managing stressed parents, parents' high expectation to see instant changes and rapid improvement in their child's performance, failed to adhere to the appointment given for therapy due to other commitment, unable to commit to the home programme given, not willing to actively involved in the programme, family dysfunction, parents' lack of understanding about ASD).	18	25
Challenges in providing occupational therapy services (unsuitable settings, limited funding or resources – lack of equipment and facilities, big caseload, difficulty in communicating with all the key people in the child with ASD life, lack of knowledge/experience in providing services for children with ASD, dilemma in choosing the correct approach/interventions).	27	11

Table O.4

Results of qualitative responses to the question "What are three (3) of the most common challenges you experience when working with children with autistic spectrum disorders?" presented in six categories(continued)

Area of challenges (continued)	Participants in Victoria (n= 66) Responses= 100	Participants in Malaysia (n= 52) Responses= 71
Working in a multidisciplinary team and/or other professionals (poor understanding of other professional on the nature of occupational therapy services and job's scope, difficulty to get cooperation from school to implement recommended approach, lack of communication with team members, pressure to diagnosed a child with ASD because of funding, lack of understanding of ASD by teachers and educational staff).	13	0
Challenges in self-development (lack of opportunity for postgraduate intensive education and training, lack of funding for professional development, difficulty with keeping-up with literature and research, very few evidence-based options available to do evidence-based practice).	4	1
Challenges from community/social and learning environment (environment that not accommodate the need of children with ASD, lack of funding or resources to implement the recommendation).	5	1

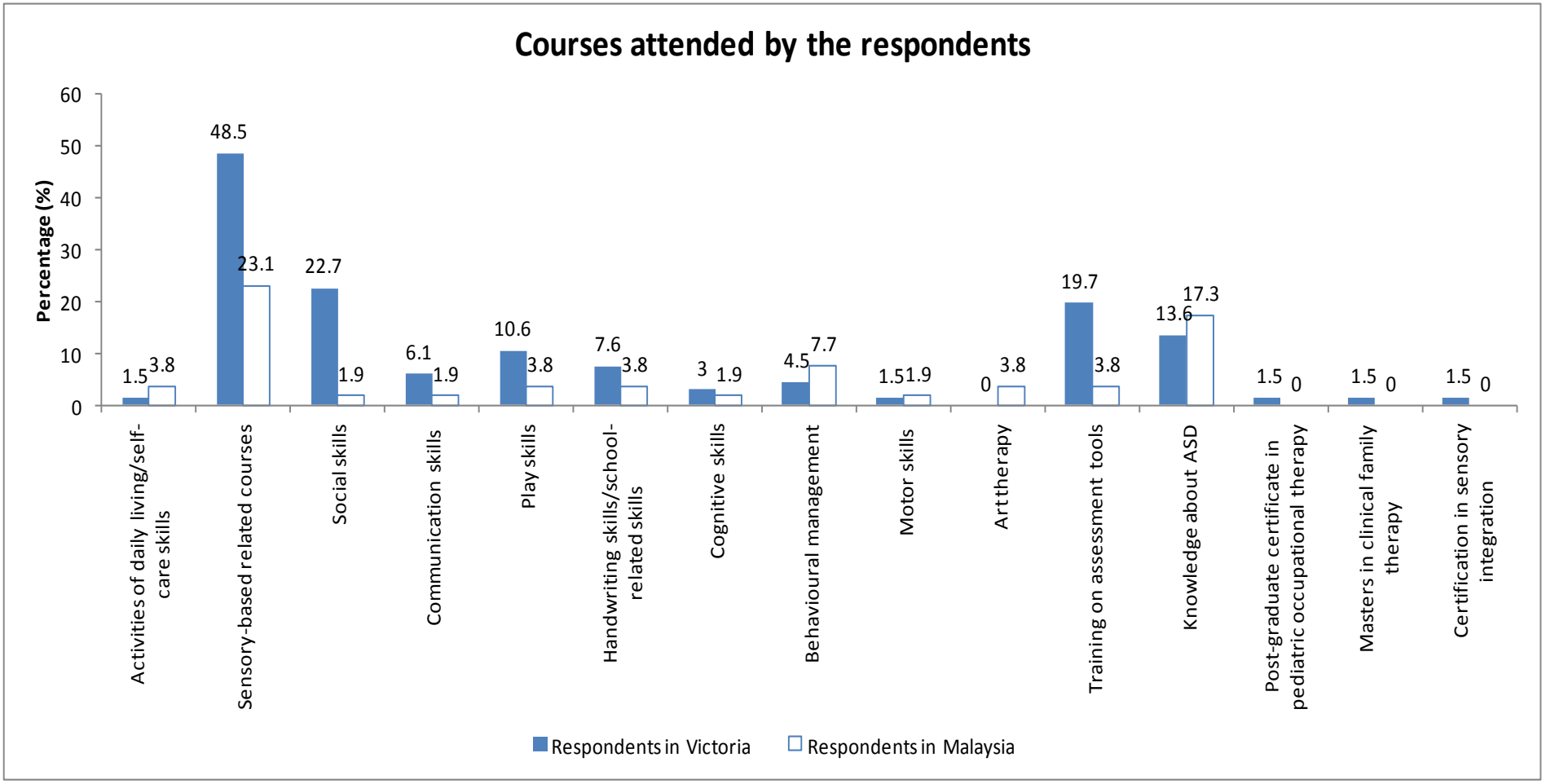


Figure O.1. Bar chart showing the percentages of the courses or certification or continuing education courses that are relevant to the participants' occupational therapy services with children with ASD in Victoria and Malaysia.

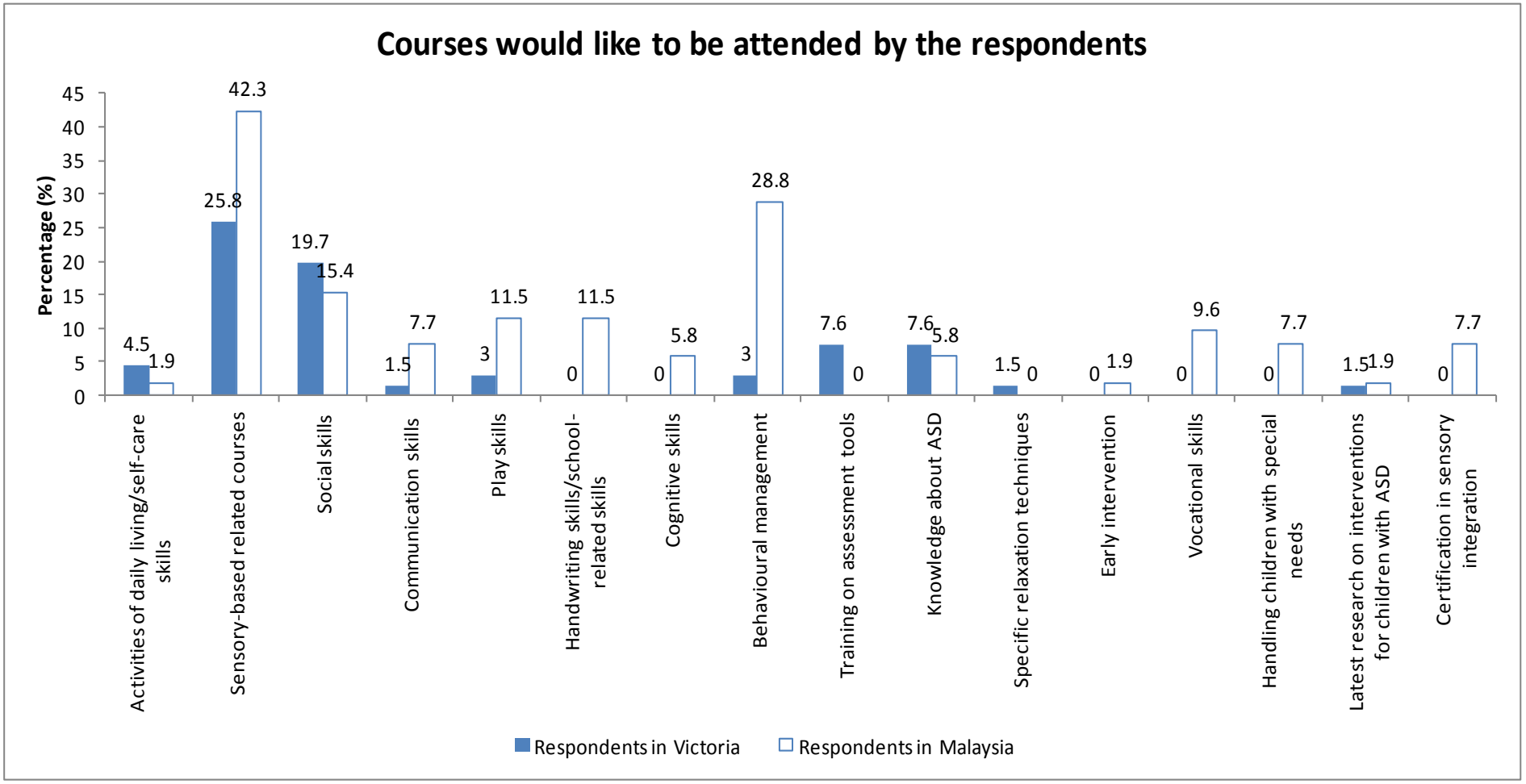
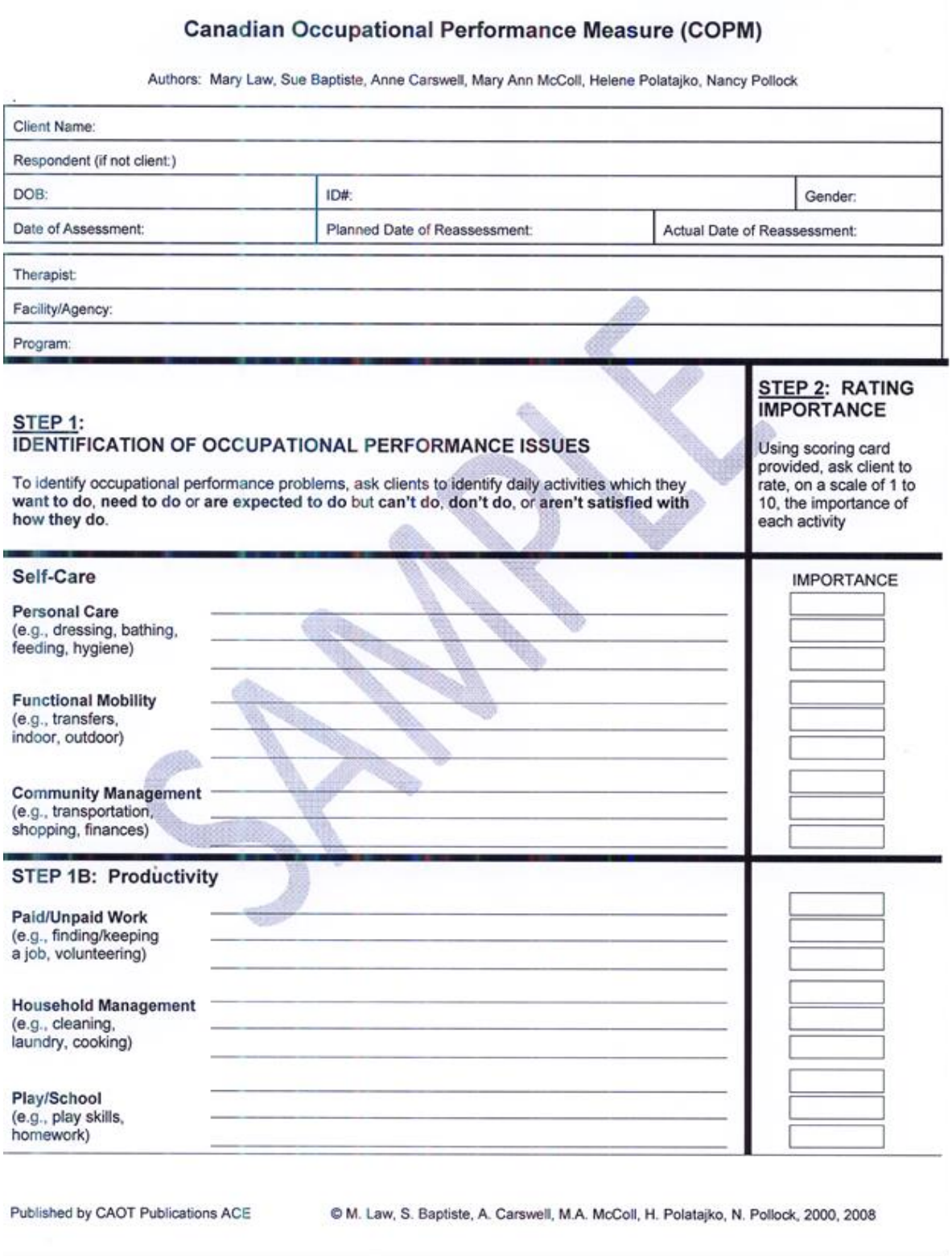


Figure O.2. Bar chart showing the percentages of the courses or certification or continuing education courses that are relevant to the participants' occupational therapy services with children with ASD that they would like to attend in Victoria and Malaysia.

APPENDIX P

THE CANADIAN OCCUPATIONAL PERFORMANCE MEASURE FORM AND THE SCORING CARDS



Canadian Occupational Performance Measure (COPM)

Authors: Mary Law, Sue Baptiste, Anne Carswell, Mary Ann McColl, Helene Polatajko, Nancy Pollock

Client Name:		
Respondent (if not client:)		
DOB:	ID#:	Gender:
Date of Assessment:	Planned Date of Reassessment:	Actual Date of Reassessment:
Therapist:		
Facility/Agency:		
Program:		

STEP 1:
IDENTIFICATION OF OCCUPATIONAL PERFORMANCE ISSUES

To identify occupational performance problems, ask clients to identify daily activities which they **want to do**, **need to do** or **are expected to do** but **can't do**, **don't do**, or **aren't satisfied with how they do**.

STEP 2: RATING IMPORTANCE

Using scoring card provided, ask client to rate, on a scale of 1 to 10, the importance of each activity

Self-Care

IMPORTANCE

Personal Care
(e.g., dressing, bathing, feeding, hygiene)

Functional Mobility
(e.g., transfers, indoor, outdoor)

Community Management
(e.g., transportation, shopping, finances)

STEP 1B: Productivity

Paid/Unpaid Work
(e.g., finding/keeping a job, volunteering)

Household Management
(e.g., cleaning, laundry, cooking)

Play/School
(e.g., play skills, homework)

SAMPLE

Published by CAOT Publications ACE

DOB: | ID#

STEP 1C: Leisure

	IMPORTANCE
Quiet Recreation (e.g., hobbies, crafts, reading)	
Active Recreation (e.g., sports, outings, travel)	
Socialization (e.g., visiting, phone calls, parties, correspondence)	

STEP 3: SCORING

Confirm with the client the 5 most important problems and record them below. Using the scoring cards, ask the client to rate each problem on performance and satisfaction, then calculate the total scores. Total scores are calculated by adding together the performance or satisfaction scores for all problems and dividing by the number of problems.

STEP 4: RE-ASSESSMENT

At an appropriate interval for re-assessment, the client again scores each of the problems selected for performance and satisfaction.

Initial Assessment:			Reassessment:	
Occupational Performance Problems:	PERFORMANCE 1	SATISFACTION 1	PERFORMANCE 2	SATISFACTION 2
1.				
2.				
3.				
4.				
5.				
SCORING:	PERFORMANCE SCORE 1	SATISFACTION SCORE 1	PERFORMANCE SCORE 2	SATISFACTION SCORE 2
Total score = Total performance or satisfaction scores / # of problems (1-5)	/ =	/ =	/ =	/ =

STEP 5: COMPUTING CHANGE SCORES

CHANGE IN PERFORMANCE = Performance Score 2 [ ] - Performance Score 1 [ ] = [ ]

CHANGE IN SATISFACTION = Satisfaction Score 2 [ ] - Performance Score 1 [ ] = [ ]

ADDITIONAL NOTES AND OBSERVATION:
Initial Assessment:

Reassessment:

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IMPORTANCE

1 2 3 4 5 6 7 8 9 10

not important at all

extremely important

PERFORMANCE

1 2 3 4 5 6 7 8 9 10

not able to do it

able to do it extremely well

SATISFACTION

1 2 3 4 5 6 7 8 9 10

not satisfied at all

extremely satisfied

APPENDIX Q

THE VINELAND ADAPTIVE BEHAVIOUR SCALES, SECOND EDITION

(PARENT/CAREGIVER RATING FORM)

About the Individual:

Name: _____ Telephone: _____

Current or Highest Grade Completed (if applicable): _____

School or Other Facility (if applicable): _____

Language Spoken at Home: _____

Does the individual have any disabling conditions? _____

Sex (circle one): F M

	Year	Month	Day
Test Date:	_____	_____	_____
Birth Date:	_____	_____	_____
Chronological Age:	_____	_____	_____

Vineland-II

Record Booklet

Vineland Adaptive Behavior Scales, Second Edition

Parent/Caregiver Rating Form

Sara S. Sparrow, Domenic V. Cicchetti, and David A. Balla

A revision of the *Vineland Social Maturity Scale* by Edgar A. Doll

About the Respondent:

Name: _____ Sex: _____

Relationship to Individual: _____ Telephone: _____

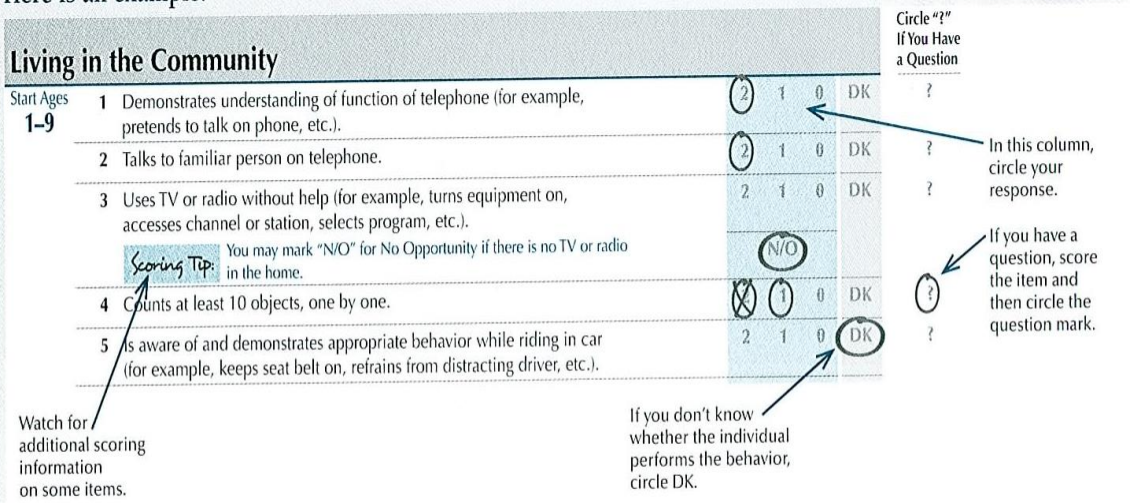
Directions:

This booklet contains phrases that describe many different behaviors that people show at home, school, work, or other settings. The behaviors range from those appropriate for infants to those appropriate for adults. Some may be too hard for younger children, and some may be too easy for older children or for adults. Thus, the child, adolescent, or adult you are rating may not show all the behaviors described in the items.

In each section, find the starting point (Start Ages **0–5**) for the individual's age. Read each phrase, and mark the response that best describes the individual's behavior. The response that you choose should reflect how often the individual performs the behavior without help, when the behavior is needed. Mark your scores in this booklet by circling one response option for each item.

- Circle "2" if the individual **usually** performs the behavior without help or reminders.
- Circle "1" if the individual **sometimes** performs the behavior without help or reminders or **partially** performs the behavior without help or reminders.
- Circle "0" if the individual **never** performs the behavior or never performs it without help or reminders.
- If you have never seen the individual perform a behavior and don't know whether he or she performs it, circle "DK" for **Don't Know.**
- If an item has a Scoring Tip, use the tip to help you decide which response option to circle.
- If an item has a Scoring Tip that says you may circle "N/O" for **No Opportunity,** you may circle that option, if appropriate, instead of a "2," "1," "0," or "DK."
- Some sections do not apply to children younger than 3 years of age. If the child you are rating is younger than the age of the first start point, do not mark any items in that section.

Here is an example:



Continued on next page

Directions continued

If you want to change a response, mark an X through it, and circle your new choice.

If you have a question about any item, **first mark the response** that best describes the individual's behavior, and then circle the question mark (?) to the right of the response options.

Use the following table to help you choose the response that best describes the behavior of the individual you are rating.

RATING	THE INDIVIDUAL:
2 Usually	Usually performs the behavior without help or reminders when it is needed; or Performed the behavior at a younger age but now has outgrown it
1 Sometimes or Partially	Sometimes performs the behavior without help or reminders when it is needed; or Sometimes does it without help but sometimes needs help; or Sometimes does it without help but needs reminders; or Performs part of the behavior without help or reminders
0 Never	Never performs the behavior without help or reminders; or Never performs the behavior, because he or she is unable; or Never performs the behavior, because he or she is too young; or Never performs the behavior, because he or she is not allowed to; or Never performs the behavior, because he or she has a physical disability that prevents the behavior

Remember to respond in each section to every item after the start point for the individual's age.

4

Communication

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know

Listening and Understanding

							Circle "?" If You Have a Question
Start Ages 0–4	1	Turns eyes and head toward sound.	2	1	0	DK	?
	2	Looks toward parent or caregiver when hearing parent's or caregiver's voice.	2	1	0	DK	?
	3	Responds to his or her name spoken (for example, turns toward speaker, smiles, etc.).	2	1	0	DK	?
	4	Demonstrates understanding of the meaning of *no*, or word or gesture with the same meaning (for example, stops current activity briefly).	2	1	0	DK	?
	5	Demonstrates understanding of the meaning of *yes*, or word or gesture with the same meaning (for example, continues activity, smiles, etc.).	2	1	0	DK	?
	6	Listens to story for at least 5 minutes (that is, remains relatively still and directs attention to the storyteller or reader).	2	1	0	DK	?
	7	Points to at least three major body parts when asked (for example, nose, mouth, hands, feet, etc.).	2	1	0	DK	?
Start Ages 5+	8	Points to common objects in a book or magazine as they are named (for example, dog, car, cup, key, etc.).	2	1	0	DK	?
	9	Listens to instructions.	2	1	0	DK	?
	10	Follows instructions with one action and one object (for example, "Bring me the book"; "Close the door"; etc.).	2	1	0	DK	?
	11	Points to at least five minor body parts when asked (for example, fingers, elbows, teeth, toes, etc.).	2	1	0	DK	?
	12	Follows instructions with two actions or an action and two objects (for example, "Bring me the crayons and the paper"; "Sit down and eat your lunch"; etc.).	2	1	0	DK	?
	13	Follows instructions in "if-then" form (for example, "If you want to play outside, then put your things away"; etc.).	2	1	0	DK	?
	14	Listens to a story for at least 15 minutes.	2	1	0	DK	?
	15	Listens to a story for at least 30 minutes.	2	1	0	DK	?
	16	Follows three-part instructions (for example, "Brush your teeth, get dressed, and make your bed"; etc.).	2	1	0	DK	?
	17	Follows instructions or directions heard 5 minutes before.	2	1	0	DK	?
	18	Understands sayings that are not meant to be taken word for word (for example, "Button your lip"; "Hit the road"; etc.).	2	1	0	DK	?
	19	Listens to an informational talk for at least 15 minutes.	2	1	0	DK	?
	20	Listens to an informational talk for at least 30 minutes.	2	1	0	DK	?

Talking

							Circle "?" If You Have a Question
Start Ages 0–4	1	Cries or fusses when hungry or wet.	2	1	0	DK	?
	2	Smiles when you smile at him or her.	2	1	0	DK	?
	3	Makes sounds of pleasure (for example, coos, laughs, etc.).	2	1	0	DK	?
	4	Makes nonword baby sounds (that is, babbles).	2	1	0	DK	?
	5	Makes sounds or gestures (for example, waves arms) to get parent's or caregiver's attention.	2	1	0	DK	?
	6	Makes sounds or gestures (for example, shakes head) if he or she wants an activity to stop or keep going.	2	1	0	DK	?

Response Options: 2 = Usually, 1 = Sometimes or Partially, 0 = Never, DK = Don't Know

Talking, *continued*

						Circle "?" If You Have a Question
	7 Waves good-bye when another person waves or parent or caregiver tells him or her to wave.	2	1	0	DK	?
	8 Says "Da-da," "Ma-ma," or another name for parent or caregiver (including parent's or caregiver's first name or nickname).	2	1	0	DK	?
	9 Points to object he or she wants that is out of reach.	2	1	0	DK	?
	10 Points or gestures to indicate preference when offered a choice (for example, "Do you want this one or that one?"; etc.).	2	1	0	DK	?
	11 Repeats or tries to repeat common words immediately upon hearing them (for example, *ball, car, go,* etc.).	2	1	0	DK	?
	12 Names at least three objects (for example, bottle, dog, favorite toy, etc.).	2	1	0	DK	?
	13 Says one-word requests (for example, *up, more, out,* etc.).	2	1	0	DK	?
	14 Uses first names or nicknames of brothers, sisters, or friends, or says their names when asked.	2	1	0	DK	?
	15 Answers or tries to answer with words when asked a question.	2	1	0	DK	?
	16 Names at least 10 objects.	2	1	0	DK	?
	17 States own first name or nickname (for example, Latesha, Little Sister, etc.) when asked.	2	1	0	DK	?
	18 Uses phrases with a noun and a verb (for example, "Katie stay"; "Go home"; etc.).	2	1	0	DK	?
	19 Asks questions by changing inflection of words or simple phrases ("Mine?"; "Me go?"; etc.); grammar is not important.	2	1	0	DK	?
	20 Says at least 50 recognizable words.	2	1	0	DK	?
	21 Uses simple words to describe things (for example, *dirty, pretty, big, loud,* etc.).	2	1	0	DK	?
	22 Asks questions beginning with *what* or *where* (for example, "What's that?"; "Where doggie go?"; etc.).	2	1	0	DK	?
	23 Uses negatives in sentences (for example, "Me no go"; "I won't drink it"; etc.); grammar is not important.	2	1	0	DK	?
	24 Tells about experiences in simple sentences (for example, "Ginger and I play"; "Dan read me a book"; etc.).	2	1	0	DK	?
Start Ages 5–13	25 Says correct age when asked.	2	1	0	DK	?
	26 Says at least 100 recognizable words.	2	1	0	DK	?
	27 Uses *in, on,* or *under* in phrases or sentences (for example, "Ball go under chair"; "Put it on the table"; etc.).	2	1	0	DK	?
	28 Uses *and* in phrases or sentences (for example, "Mom and Dad"; "I want ice cream and cake"; etc.).	2	1	0	DK	?
	29 Says first and last name when asked.	2	1	0	DK	?
	30 Identifies and names most common colors (that is, red, blue, green, yellow, orange, purple, brown, and black). **Scoring Tip:** Mark a "2" if the individual names 6 to 8 colors; mark a "1" if the individual names 2 to 5 colors; mark a "0" if the individual names 0 or 1 color.	2	1	0	DK	?
	31 Asks questions beginning with *who* or *why* (for example, "Who's that?"; "Why do I have to go?"; etc.).	2	1	0	DK	?
	32 Uses present tense verbs ending in *ing* (for example, "Is singing"; "Is playing"; etc.).	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know

Talking, *continued*

						Circle "?" If You Have a Question
	33	Uses possessives in phrases or sentences (for example, "That's her book"; "This is Carlos's ball"; etc.).	2	1	0	DK	?
	34	Uses pronouns in phrases or sentences; must use correct gender and form of the pronoun, but sentences need not be grammatically correct (for example, "He done it"; "They went"; etc.).	2	1	0	DK	?
	35	Asks questions beginning with *when* (for example, "When is dinner?"; "When can we go home?"; etc.).	2	1	0	DK	?
	36	Uses regular past tense verbs (for example, *walked, baked,* etc.); may use irregular past tense verbs ungrammatically (for example, "I runned away"; etc.).	2	1	0	DK	?
	37	Uses *behind* or *in front* of in phrases or sentences (for example, "I walked in front of her"; "Terrell is behind you"; etc.).	2	1	0	DK	?
	38	Pronounces words clearly without sound substitutions (for example, does not say "wabbit" for "rabbit," "Thally" for "Sally," etc.).	2	1	0	DK	?
	39	Tells basic parts of a story, fairy tale, or television show plot; does not need to include great detail or recount in perfect order.	2	1	0	DK	?
Start Ages 14+	**40**	Says month and day of birthday when asked.	2	1	0	DK	?
	41	Modulates tone of voice, volume, and rhythm appropriately (for example, does not consistently speak too loudly, too softly, or in a monotone, etc.).	2	1	0	DK	?
	42	Tells about experiences in detail (for example, tells who was involved, where activity took place, etc.).	2	1	0	DK	?
	43	Gives simple directions (for example, on how to play a game or how to make something). Scoring Tip: Mark a "2" if the directions are clear enough to follow; mark a "1" if the individual articulates directions but they are not clear enough to follow; mark a "0" if the individual never attempts to articulate directions.	2	1	0	DK	?
	44	Uses *between* in phrases or sentences (for example, "The ball went between the cars; etc.).	2	1	0	DK	?
	45	Says own telephone number when asked.	2	1	0	DK	?
	46	Easily moves from one topic to another in conversation.	2	1	0	DK	?
	47	Stays on topic in conversations; does not go off on tangents.	2	1	0	DK	?
	48	Explains ideas in more than one way (for example, "This was a good book. It was exciting and fun to read"; etc.).	2	1	0	DK	?
	49	Has conversations that last 10 minutes (for example, relates experiences, contributes ideas, shares feelings, etc.).	2	1	0	DK	?
	50	Uses irregular plurals correctly (for example, *children, geese, mice, women,* etc.).	2	1	0	DK	?
	51	Says complete home address (that is, street or rural route, apartment number, city, and state), with or without zip code, when asked.	2	1	0	DK	?
	52	Describes a short-term goal and what he or she needs to do to reach it (for example, says, "I want to get an A on my test, so I'm going to study hard"; etc.).	2	1	0	DK	?
	53	Gives complex directions to others (for example, to a distant location, for recipe with many ingredients or steps, etc.). Scoring Tip: Mark a "2" if the directions are clear enough to follow; mark a "1" if the individual articulates directions but they are not clear enough to follow; mark a "0" if the individual never attempts to articulate directions.	2	1	0	DK	?
	54	Describes a realistic long-range goal that can be done in 6 months or more (for example, says, "I want to buy a bike, so I'll babysit and run errands to earn enough money to buy it"; etc.).	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know

Reading and Writing

							Circle "?" If You Have a Question
Start Ages 3–13	1	Identifies one or more alphabet letters as letters and distinguishes them from numbers.	2	1	0	DK	?
	2	Recognizes own name in printed form.	2	1	0	DK	?
	3	Identifies at least 10 printed letters of the alphabet.	2	1	0	DK	?
	4	Prints or writes using correct orientation (for example, in English from left to right; in some languages from right to left or top to bottom).	2	1	0	DK	?
	5	Copies own first name.	2	1	0	DK	?
	6	Identifies all printed letters of the alphabet, upper- and lowercase.	2	1	0	DK	?
	7	Prints at least three simple words from example (for example, *cat, see, bee,* etc.).	2	1	0	DK	?
	8	Prints or writes own first and last name from memory.	2	1	0	DK	?
	9	Reads at least 10 words aloud.	2	1	0	DK	?
	10	Prints at least 10 simple words from memory (for example, *hat, ball, the,* etc.).	2	1	0	DK	?
	11	Reads simple stories aloud (that is, stories with sentences of three to five words).	2	1	0	DK	?
	12	Prints simple sentences of three or four words; may make small errors in spelling or sentence structure.	2	1	0	DK	?
	13	Prints more than 20 words from memory; may make small spelling errors.	2	1	0	DK	?
Start Ages 14+	14	Reads and understands material of at least second-grade level.	2	1	0	DK	?
	15	Puts lists of words in alphabetical order.	2	1	0	DK	?
	16	Writes simple correspondence at least three sentences long (for example, postcards, thank-you notes, e-mail, etc.).	2	1	0	DK	?
	17	Reads and understands material of at least fourth-grade level.	2	1	0	DK	?
	18	Writes reports, papers, or essays at least one page long; may use computer.	2	1	0	DK	?
	19	Writes complete mailing and return addresses on letters or packages.	2	1	0	DK	?
	20	Reads and understands material of at least sixth-grade level.	2	1	0	DK	?
	21	Edits or corrects own written work before handing it in (for example, checks punctuation, spelling, grammar, etc.).	2	1	0	DK	?
	22	Writes advanced correspondence at least 10 sentences long; may use computer.	2	1	0	DK	?
	23	Reads and understands material of at least ninth-grade level.	2	1	0	DK	?
	24	Reads at least two newspaper articles weekly (print or electronic version).	2	1	0	DK	?
	25	Writes business letters (for example, requests information, makes complaint, places order, etc.); may use computer.	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know

Caring for Self

							Circle "?" If You Have a Question
Start Ages 0–8	1	Opens mouth when food is offered.	2	1	0	DK	?
	2	Eats solid foods (for example, cooked vegetables, chopped meats, etc.).	2	1	0	DK	?
	3	Sucks or chews on finger foods (for example, crackers, cookies, toast, etc.).	2	1	0	DK	?
	4	Drinks from a cup or glass; may spill.	2	1	0	DK	?
	5	Lets someone know when he or she has wet or soiled diaper or pants (for example, points, vocalizes, pulls at diaper, etc.).	2	1	0	DK	?
	6	Feeds self with spoon; may spill.	2	1	0	DK	?
	7	Sucks from straw.	2	1	0	DK	?
	8	Takes off clothing that opens in the front (for example, a coat or sweater); does not have to unbutton or unzip the clothing.	2	1	0	DK	?
	9	Pulls up clothing with elastic waistbands (for example, underwear or sweatpants).	2	1	0	DK	?
	10	Feeds self with fork; may spill.	2	1	0	DK	?
	11	Drinks from a cup or glass without spilling.	2	1	0	DK	?
	12	Feeds self with spoon without spilling.	2	1	0	DK	?
	13	Urinates in toilet or potty chair.	2	1	0	DK	?
	14	Puts on clothing that opens in the front (for example, a coat or sweater); does not have to zip or button the clothing.	2	1	0	DK	?
	15	Asks to use toilet.	2	1	0	DK	?
	16	Defecates in toilet or potty chair.	2	1	0	DK	?
	17	Is toilet-trained during the day. *Scoring Tip:* Mark "2" if the individual uses the toilet without help and without accidents; mark "1" if the individual needs help, such as with wiping, or has some accidents; mark "0" if the individual always needs help or has frequent accidents.	2	1	0	DK	?
	18	Zips zippers that are fastened at the bottom (for example, in pants, on backpacks, etc.).	2	1	0	DK	?
	19	Wipes or blows nose using tissue or handkerchief.	2	1	0	DK	?
	20	Is toilet-trained during the night.	2	1	0	DK	?
	21	Puts shoes on correct feet; does not need to tie laces.	2	1	0	DK	?
	22	Fastens snaps.	2	1	0	DK	?
Start Ages 9+	23	Holds spoon, fork, and knife correctly.	2	1	0	DK	?
	24	Washes and dries face using soap and water.	2	1	0	DK	?
	25	Brushes teeth. *Scoring Tip:* Mark a "2" if the individual brushes teeth without help, including putting toothpaste on the brush, and without being told to brush; mark "1" if the individual needs help brushing or putting toothpaste on the brush or needs frequent reminders; mark "0" if the individual never brushes without help or without being reminded.	2	1	0	DK	?
	26	Buttons large buttons in front, in correct buttonholes.	2	1	0	DK	?
	27	Covers mouth and nose when coughing and sneezing.	2	1	0	DK	?

Response Options: 2 = Usually, 1 = Sometimes or Partially, 0 = Never, DK = Don't Know N/O = No Opportunity

Caring for Self, *continued*

						Circle "?" If You Have a Question
28	Buttons small buttons in front, in correct buttonholes.	2	1	0	DK	?
29	Connects and zips zippers that are not fastened at the bottom (for example, in jackets, sweatshirts, etc.).	2	1	0	DK	?
30	Turns faucets on and adjusts temperature by adding hot or cold water.	2	1	0	DK	?
31	Wears appropriate clothing during wet or cold weather (for example, raincoat, boots, sweater, etc.).	2	1	0	DK	?
32	Bathes or showers and dries self.	2	1	0	DK	?
	Scoring Tip: Mark a "2" if the individual bathes or showers without help, including turning the water on and off; mark a "1" if the individual needs help with any part of bathing or drying or with turning the water on and off; mark "0" if the individual never bathes or showers without help or without reminders.					
33	Finds and uses appropriate public restroom for his or her gender.	2	1	0	DK	?
34	Washes and dries hair (with towel or hair dryer).	2	1	0	DK	?
35	Cares for minor cuts (for example, cleans wound, puts on bandage, etc.).	2	1	0	DK	?
36	Takes medicine as directed (that is, follows directions on label).	2	1	0	DK	?
37	Uses thermometer to take own or another's temperature.	2	1	0	DK	?
38	Seeks medical help in an emergency (for example, recognizes symptoms of serious illness or injury, such as shortness of breath, chest pain, uncontrolled bleeding, etc.).	2	1	0	DK	?
	Scoring Tip: You may mark "N/O" for No Opportunity if the individual has not been in a medical emergency.	N/O				
39	Follows directions for health care procedures, special diet, or medical treatments.	2	1	0	DK	?
	Scoring Tip: You may mark "N/O" for No Opportunity if the individual does not have a health concern that requires special procedures, diet, or treatments.	N/O				
40	Keeps track of medications (nonprescription and prescription) and refills them as needed.	2	1	0	DK	?
41	Makes appointments for regular medical and dental checkups.	2	1	0	DK	?

Caring for Home

						Circle "?" If You Have a Question
Start Ages 1–13	1 Is careful around hot objects (for example, the stove or oven, an open fire, etc.).	2	1	0	DK	?
	2 Helps with simple household chores (for example, dusts, picks up clothes or toys, feeds pet, etc.).	2	1	0	DK	?
	3 Clears unbreakable items from own place at table.	2	1	0	DK	?
	4 Cleans up play or work area at end of an activity (for example, finger painting, model building, etc.).	2	1	0	DK	?
	5 Puts away personal possessions (for example, toys, books, magazines, etc.).	2	1	0	DK	?
	6 Is careful when using sharp objects (for example, scissors, knives, etc.).	2	1	0	DK	?
Start Ages 14+	7 Clears breakable items from own place at table.	2	1	0	DK	?
	8 Helps prepare foods that require mixing and cooking (for example, cake or cookie mixes, macaroni and cheese, etc.).	2	1	0	DK	?
	9 Uses simple appliances (for example, a toaster, can opener, bottle opener, etc.).	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know **N/O** = No Opportunity

Caring for Home, *continued*

						Circle "?" If You Have a Question
10	Uses microwave oven for heating, baking, or cooking (that is, sets time and power setting, etc.).	2	1	0	DK	?
	Scoring Tip: You may mark "N/O" for No Opportunity if there is no microwave in the home.		N/O			
11	Puts clean clothes away in proper place (for example, in drawers or closet, on hooks, etc.).	2	1	0	DK	?
12	Uses tools (for example, a hammer to drive nails, a screwdriver to screw and unscrew screws, etc.).	2	1	0	DK	?
13	Washes dishes by hand, or loads and uses dishwasher.	2	1	0	DK	?
14	Sweeps, mops, or vacuums floors thoroughly.	2	1	0	DK	?
	Scoring Tip: Mark "2" if the individual mops, sweeps, or vacuums so well that the task does not have to redone; mark a "1" if the individual doesn't consistently complete the task well; mark a "0" if the individual never mops, sweeps, or vacuums, or does the task so poorly that it always needs to be redone.					
15	Clears table completely (for example, scrapes and stacks dishes, throws away disposable items, etc.).	2	1	0	DK	?
16	Uses household products correctly (for example, laundry detergent, furniture polish, glass cleaner, etc.).	2	1	0	DK	?
17	Prepares basic foods that do not need mixing but require cooking (for example, rice, soup, vegetables, etc.).	2	1	0	DK	?
18	Cleans one or more rooms other than own bedroom.	2	1	0	DK	?
19	Uses sharp knife to prepare food.	2	1	0	DK	?
20	Uses stove or oven for heating, baking, or cooking (that is, turns burners on and off, sets oven temperature, etc.).	2	1	0	DK	?
21	Prepares food from ingredients that require measuring, mixing, and cooking.	2	1	0	DK	?
22	Washes clothing as needed.	2	1	0	DK	?
23	Performs maintenance tasks as needed (for example, replaces light bulbs, changes vacuum cleaner bag, etc.).	2	1	0	DK	?
24	Plans and prepares main meal of the day.	2	1	0	DK	?

Living in the Community

						Circle "?" If You Have a Question
Start Ages 1–9	1 Demonstrates understanding of function of telephone (for example, pretends to talk on phone, etc.).	2	1	0	DK	?
	2 Talks to familiar person on telephone.	2	1	0	DK	?
	3 Uses TV or radio without help (for example, turns equipment on, accesses channel or station, selects program, etc.).	2	1	0	DK	?
	Scoring Tip: You may mark "N/O" for No Opportunity if there is no TV or radio in the home.		N/O			
	4 Counts at least 10 objects, one by one.	2	1	0	DK	?
	5 Is aware of and demonstrates appropriate behavior while riding in car (for example, keeps seat belt on, refrains from distracting driver, etc.).	2	1	0	DK	?
	6 Demonstrates understanding of the function of money (for example, says, "Money is what you need to buy things at the store"; etc.).	2	1	0	DK	?
	7 Uses sidewalk (where available) or shoulder of road when walking or using wheeled equipment (skates, scooter, tricycle, etc.).	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know **N/O** = No Opportunity

Living in the Community, *continued*

							Circle "?" If You Have a Question
	8	Demonstrates understanding of function of clock (for example, says, "Clocks tell time"; "What time can we go?"; etc.).	2	1	0	DK	?
	9	Follows household rules (for example, no running in the house, no jumping on the furniture, etc.).	2	1	0	DK	?
	10	Demonstrates computer skills necessary to play games or start programs with computer turned on; does not need to turn computer on by self.	2	1	0	DK	?
		Scoring Tip: You may mark "N/O" for No Opportunity if there is no computer in the home.	N/O				
	11	Summons to the telephone the person receiving a call or indicates that the person is not available.	2	1	0	DK	?
Start Ages 10–15	12	Identifies penny, nickel, dime, and quarter by name when asked; does not need to know the value of coins.	2	1	0	DK	?
	13	Looks both ways when crossing streets or roads.	2	1	0	DK	?
	14	Says current day of the week when asked.	2	1	0	DK	?
	15	Demonstrates understanding of right to personal privacy for self and others (for example, while using restroom or changing clothes, etc.).	2	1	0	DK	?
	16	Demonstrates knowledge of what phone number to call in an emergency when asked.	2	1	0	DK	?
	17	Tells time using a digital clock or watch.	2	1	0	DK	?
	18	States value of penny (1 cent), nickel (5 cents), dime (10 cents), and quarter (25 cents).	2	1	0	DK	?
	19	Discriminates between bills of different denominations (for example, refers to $1 bills, $5 bills, etc., in conversation; etc.).	2	1	0	DK	?
	20	Obeys traffic lights and *Walk* and *Don't Walk* signs.	2	1	0	DK	?
	21	Points to current or other date on calendar when asked.	2	1	0	DK	?
	22	Demonstrates understanding that some items cost more than others (for example, says, "I have enough money to buy gum but not a candy bar"; "Which pencil costs less?"; etc.).	2	1	0	DK	?
Start Ages 16+	23	Tells time by the half hour on analog clock (for example, 1:30, 2:00, etc.).	2	1	0	DK	?
	24	Makes telephone calls to others, using standard or cell phone.	2	1	0	DK	?
	25	Orders a complete meal in a fast-food restaurant.	2	1	0	DK	?
		Scoring Tip: You may mark "N/O" for No Opportunity if the individual has never eaten at a fast-food restaurant.	N/O				
	26	Carries or stores money safely (for example, in wallet, purse, money belt, etc.).	2	1	0	DK	?
	27	Tells time by 5-minute segments on analog clock (for example, 1:05, 1:10, etc.).	2	1	0	DK	?
	28	Obeys curfew parent or caregiver sets.	2	1	0	DK	?
	29	Watches or listens to programs for information (for example, weather report, news, educational program, etc.).	2	1	0	DK	?
		Scoring Tip: You may mark "N/O" for No Opportunity if there is no TV or radio in the home.	N/O				
	30	Counts change from a purchase.	2	1	0	DK	?
	31	Demonstrates computer skills necessary to carry out complex tasks (for example, word processing, accessing the Internet, installing software, etc.).	2	1	0	DK	?
		Scoring Tip: You may mark "N/O" for No Opportunity if there is no computer in the home.	N/O				
	32	Evaluates quality and price when selecting items to purchase.	2	1	0	DK	?
	33	Obeys time limits for breaks (for example, lunch or coffee breaks, etc.).	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know **N/O** = No Opportunity

Living in the Community, *continued*

						Circle "?" If You Have a Question
34	Travels at least 5 to 10 miles to familiar destination (that is, bikes, uses public transportation, or drives self).	2	1	0	DK	?
35	Demonstrates understanding of right to complain or report legitimate problems when dissatisfied with services or situations.	2	1	0	DK	?
36	Notifies school or supervisor when he or she will be late or absent.	2	1	0	DK	?
37	Uses savings or checking account responsibly (for example, keeps some money in account, tracks balance carefully, etc.).	2	1	0	DK	?
38	Travels at least 5 to 10 miles to unfamiliar destination (that is, bikes, uses public transportation, or drives self).	2	1	0	DK	?
39	Earns money at part-time job (that is, at least 10 hours a week) for 1 year. *Scoring Tip:* Do not mark 1.	2	~~1~~	0	DK	?
40	Attempts to improve job performance after receiving constructive criticism from supervisor. *Scoring Tip:* You may mark "N/O" for No Opportunity if the individual has not held a job.	2	1	0	DK N/O	?
41	Manages own money (for example, pays most or all own expenses, uses checks or money orders for purchases as needed, etc.).	2	1	0	DK	?
42	Has held full-time job for 1 year. *Scoring Tip:* Do not mark 1.	2	~~1~~	0	DK	?
43	Budgets for monthly expenses (for example, utilities, rent, etc.).	2	1	0	DK	?
44	Applies for and uses personal credit card responsibly (for example, does not exceed credit limit, pays on time, etc.).	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know

Relating to Others

			2	1	0	DK	Circle "?" If You Have a Question
Start Ages 0–4	1	Looks at face of parent or caregiver.	2	1	0	DK	?
	2	Watches (that is, follows with eyes) someone moving by crib or bed for 5 seconds or more.	2	1	0	DK	?
	3	Shows two or more emotions (for example, laughs, cries, screams, etc.).	2	1	0	DK	?
	4	Smiles or makes sounds when approached by a familiar person.	2	1	0	DK	?
	5	Makes or tries to make social contact (for example, smiles, makes noises, etc.).	2	1	0	DK	?
	6	Reaches for familiar person when person holds out arms to him or her.	2	1	0	DK	?
	7	Shows preference for certain people and objects (for example, smiles, reaches for or moves toward person or object, etc.).	2	1	0	DK	?
	8	Shows affection to familiar persons (for example, touches, hugs, kisses, cuddles, etc.).	2	1	0	DK	?
	9	Imitates or tries to imitate parent's or caregiver's facial expressions (for example, smiles, frowns, etc.).	2	1	0	DK	?
	10	Moves about looking for parent or caregiver or other familiar person nearby.	2	1	0	DK	?
	11	Shows interest in children the same age, other than brothers or sisters (for example, watches them, smiles at them, etc.).	2	1	0	DK	?
Start Ages 5–15	12	Imitates simple movements (for example, claps hands, waves good-bye, etc.).	2	1	0	DK	?
	13	Uses actions to show happiness or concern for others (for example, hugs, pats arm, holds hands, etc.).	2	1	0	DK	?
	14	Shows desire to please others (for example, shares a snack or toy, tries to help even if not capable, etc.).	2	1	0	DK	?
	15	Demonstrates friendship-seeking behavior with others the same age (for example, says, "Do you want to play?" or takes another child by the hand, etc.).	2	1	0	DK	?
	16	Imitates relatively complex actions as they are being performed by another person (for example, shaving, putting on makeup, hammering nails, etc.).	2	1	0	DK	?
	17	Answers when familiar adults make small talk (for example, if asked, "How are you?" says, "I'm fine"; if told, "You look nice," says, "Thank you"; etc.).	2	1	0	DK	?
	18	Repeats phrases heard spoken before by an adult (for example, "Honey, I'm home"; "No dessert until you clean your plate"; etc.).	2	1	0	DK	?
	19	Uses words to express own emotions (for example, "I'm happy"; "I'm scared"; etc.).	2	1	0	DK	?
	20	Has best friend or shows preference for certain friends (of either sex) over others.	2	1	0	DK	?
	21	Imitates relatively complex actions several hours after watching someone else perform them (for example, shaving, putting on makeup, hammering nails, etc.).	2	1	0	DK	?
Start Ages 16+	22	Uses words to express happiness or concern for others (for example, says, "Yeah! You won"; "Are you all right?"; etc.).	2	1	0	DK	?
	23	Acts when another person needs a helping hand (for example, holds door open, picks up dropped items, etc.).	2	1	0	DK	?
	24	Recognizes the likes and dislikes of others (for example, says, "Chow likes soccer"; "Susie doesn't eat pizza"; etc.).	2	1	0	DK	?
	25	Shows same level of emotion as others around him or her (for example, does not downplay or overdramatize a situation, etc.).	2	1	0	DK	?
	26	Keeps comfortable distance between self and others in social situations (for example, does not get too close to another person when talking, etc.).	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know

Relating to Others, *continued*

						Circle "?" If You Have a Question
27	Talks with others about shared interests (for example, sports, TV shows, summer plans, etc.).	2	1	0	DK	?
28	Starts small talk when meets people he or she knows (for example, says, "How are you?"; "What's up?"; etc.).	2	1	0	DK	?
29	Meets with friends regularly.	2	1	0	DK	?
30	Chooses not to say embarrassing or mean things or ask rude questions in public.	2	1	0	DK	?
31	Places reasonable demands on friendship (for example, does not expect to be a person's only friend or to have the friend always available, etc.).	2	1	0	DK	?
32	Understands that others do not know his or her thoughts unless he or she says them.	2	1	0	DK	?
33	Is careful when talking about personal things.	2	1	0	DK	?
34	Cooperates with others to plan or be part of an activity (for example, a birthday party, sports event, etc.).	2	1	0	DK	?
35	Demonstrates understanding of hints or indirect cues in conversation (for example, knows that yawns may mean, "I'm bored," or a quick change of subject may mean, "I don't want to talk about that"; etc.).	2	1	0	DK	?
36	Starts conversations by talking about things that interest others (for example, "Tyrone tells me you like computers"; etc.).	2	1	0	DK	?
37	Goes on group dates.	2	1	0	DK	?
38	Goes on single dates.	2	1	0	DK	?

Playing and Using Leisure Time

							Circle "?" If You Have a Question
Start Ages 0–7	1	Responds when parent or caregiver is playful (for example, smiles, laughs, claps hands, etc.).	2	1	0	DK	?
	2	Shows interest in where he or she is (for example, looks or moves around, touches objects or people, etc.).	2	1	0	DK	?
	3	Plays simple interaction games with others (for example, peekaboo, patty-cake, etc.).	2	1	0	DK	?
	4	Plays near another child, each doing different things.	2	1	0	DK	?
	5	Chooses to play with other children (for example, does not stay on the edge of a group or avoid others).	2	1	0	DK	?
	6	Plays cooperatively with one or more children for up to 5 minutes.	2	1	0	DK	?
	7	Plays cooperatively with more than one child for more than 5 minutes.	2	1	0	DK	?
	8	Continues playing with another child with little fussing when parent or caregiver leaves.	2	1	0	DK	?
	9	Shares toys or possessions when asked.	2	1	0	DK	?
Start Ages 8–15	10	Plays with others with minimal supervision.	2	1	0	DK	?
	11	Uses common household objects or other objects for make-believe activities (for example, pretends a block is a car, a box is a house, etc.).	2	1	0	DK	?
	12	Protects self by moving away from those who destroy things or cause injury (for example, those who bite, hit, throw things, pull hair, etc.).	2	1	0	DK	?
	13	Plays simple make-believe activities with others (for example, plays dress-up, pretends to be superheroes, etc.).	2	1	0	DK	?

Response Options: 2 = Usually, 1 = Sometimes or Partially, 0 = Never, DK = Don't Know

Playing and Using Leisure Time, *continued*

						Circle "?" If You Have a Question
	14	Seeks out others for play or companionship (for example, invites others home, goes to another's home, plays with others on the playground, etc.).	2	1	0	DK	?
	15	Takes turns when asked while playing games or sports.	2	1	0	DK	?
	16	Plays informal, outdoor group games (for example, tag, jump rope, catch, etc.).	2	1	0	DK	?
	17	Shares toys or possessions without being asked.	2	1	0	DK	?
	18	Follows rules in simple games (relay races, spelling bees, electronic games, etc.).	2	1	0	DK	?
	19	Takes turns without being asked.	2	1	0	DK	?
	20	Plays simple card or board game based only on chance (for example, Go Fish, Crazy Eights, Sorry™, etc.).	2	1	0	DK	?
	21	Goes places with friends during the day with adult supervision (for example, to a shopping mall, park, community center, etc.).	2	1	0	DK	?
Start Ages 16+	22	Asks permission before using objects belonging to or being used by another.	2	1	0	DK	?
	23	Refrains from entering group when nonverbal cues indicate that he or she is not welcome.	2	1	0	DK	?
	24	Plays simple games that require keeping score (for example, kickball, pickup basketball, etc.).	2	1	0	DK	?
	25	Shows good sportsmanship (that is, follows rules, is not overly aggressive, congratulates other team on winning, and does not get mad when losing).	2	1	0	DK	?
	26	Plays more than one board, card, or electronic game requiring skill and decision making (for example, Monopoly™, Cribbage, etc.).	2	1	0	DK	?
	27	Goes places with friends in evening with adult supervision (for example, to a concert, lecture, sporting event, movie, etc.).	2	1	0	DK	?
	28	Follows rules in complex games or sports (for example, football, soccer, volleyball, etc.).	2	1	0	DK	?
	29	Goes places with friends during the day without adult supervision (for example, to a shopping mall, park, community center, etc.).	2	1	0	DK	?
	30	Plans fun activities with more than two things to be arranged (for example, a trip to a beach or park that requires planning transportation, food, recreational items, etc.).	2	1	0	DK	?
	31	Goes places with friends in evening without adult supervision (for example, to a concert, lecture, sporting event, movie, etc.).	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know

Adapting

							Circle "?" If You Have a Question
Start Ages 1+	1	Changes easily from one at-home activity to another.	2	1	0	DK	?
	2	Says "thank you" when given something.	2	1	0	DK	?
	3	Changes behavior depending on how well he or she knows another person (for example, acts differently with family member than with stranger, etc.).	2	1	0	DK	?
	4	Chews with mouth closed.	2	1	0	DK	?
	5	Says "please" when asking for something.	2	1	0	DK	?
	6	Ends conversations appropriately (for example, says, "Good-bye"; "See you later"; etc.).	2	1	0	DK	?
	7	Cleans or wipes face and hands during and/or after meals.	2	1	0	DK	?
	8	Responds appropriately to reasonable changes in routine (for example, refrains from complaining, etc.).	2	1	0	DK	?
	9	Says that he or she is sorry for unintended mistakes (for example, bumping into someone, etc.).	2	1	0	DK	?
	10	Chooses not to taunt, tease, or bully.	2	1	0	DK	?
	11	Acts appropriately when introduced to strangers (for example, nods, smiles, shakes hands, greets them, etc.).	2	1	0	DK	?
	12	Changes voice level depending on location or situation (for example, in a library, during a movie or play, etc.).	2	1	0	DK	?
	13	Says he or she is sorry after hurting another's feelings.	2	1	0	DK	?
	14	Refrains from talking with food in mouth.	2	1	0	DK	?
	15	Talks with others without interrupting or being rude.	2	1	0	DK	?
	16	Accepts helpful suggestions or solutions from others.	2	1	0	DK	?
	17	Controls anger or hurt feelings when plans change for reason(s) that cannot be helped (for example, bad weather, car trouble, etc.).	2	1	0	DK	?
	18	Keeps secrets or confidences for longer than one day.	2	1	0	DK	?
	19	Says he or she is sorry after making unintentional mistakes or errors in judgment (for example, when unintentionally leaving someone out of a game, etc.).	2	1	0	DK	?
	20	Shows understanding that gentle teasing with family and friends can be a form of humor or affection.	2	1	0	DK	?
	21	Tells parent or caregiver about his or her plans (for example, what time he or she is leaving and returning, where he or she is going, etc.).	2	1	0	DK	?
	22	Chooses to avoid dangerous or risky activities (for example, jumping off high places, picking up a hitchhiker, driving recklessly, etc.).	2	1	0	DK	?
	23	Controls anger or hurt feelings when he or she does not get his or her way (for example, when not allowed to watch television or attend a party; when suggestion is rejected by friend or supervisor; etc.).	2	1	0	DK	?
	24	Follows through with arrangements (for example, if promises to meet someone, meets that person; etc.).	2	1	0	DK	?
	25	Stops or stays away from relationships or situations that are hurtful or dangerous (for example, being bullied or made fun of, being taken advantage of sexually or financially, etc.).	2	1	0	DK	?
	26	Controls anger or hurt feelings due to constructive criticism (for example, correction of misbehavior, discussion of test score or grade, performance review, etc.).	2	1	0	DK	?
	27	Keeps secrets or confidences for as long as needed.	2	1	0	DK	?
	28	Thinks about what could happen before making decisions (for example, refrains from acting impulsively, thinks about important information, etc.).	2	1	0	DK	?
	29	Is aware of potential danger and uses caution when encountering risky social situations (for example, binge drinking parties, Internet chat rooms, personal ads, etc.).	2	1	0	DK	?
	30	Shows respect for co-workers (for example, does not distract or interrupt others who are working, is on time for meetings, etc.).	2	1	0	DK	?

Physical Activity

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know **N/O** = No Opportunity

Using Large Muscles

							Circle "?" If You Have a Question
Start Ages 0–1	1	Holds head erect for at least 15 seconds when held upright in parent's or caregiver's arms.	2	1	0	DK	?
	2	Sits supported (for example, in a chair, with pillows, etc.) for at least 1 minute.	2	1	0	DK	?
	3	Sits without support for at least 1 minute.	2	1	0	DK	?
	4	Creeps or moves on stomach across floor.	2	1	0	DK	?
	5	Sits without support for at least 10 minutes.	2	1	0	DK	?
	6	Raises self to sitting position and sits without support for at least 1 minute.	2	1	0	DK	?
	7	Crawls at least 5 feet on hands and knees, without stomach touching floor.	2	1	0	DK	?
	8	Pulls self to standing position.	2	1	0	DK	?
	9	Crawls up stairs.	2	1	0	DK	?
	10	Takes at least two steps.	2	1	0	DK	?
	11	Stands alone for 1 to 3 minutes.	2	1	0	DK	?
	12	Rolls ball while sitting.	2	1	0	DK	?
	13	Climbs on and off low objects (for example, chair, step stool, slide, etc.).	2	1	0	DK	?
	14	Crawls down stairs.	2	1	0	DK	?
	15	Stands for at least 5 minutes.	2	1	0	DK	?
Start Ages 2–4	16	Walks across room; may be unsteady and fall occasionally.	2	1	0	DK	?
	17	Throws ball.	2	1	0	DK	?
	18	Walks to get around; does not need to hold on to anything.	2	1	0	DK	?
	19	Climbs on and off adult-sized chair.	2	1	0	DK	?
	20	Runs without falling; may be awkward and uncoordinated.	2	1	0	DK	?
	21	Walks up stairs, putting both feet on each step; may use railing.	2	1	0	DK	?
	22	Kicks ball.	2	1	0	DK	?
	23	Runs smoothly without falling.	2	1	0	DK	?
	24	Walks down stairs, facing forward, putting both feet on each step; may use railing.	2	1	0	DK	?
	25	Jumps with both feet off floor.	2	1	0	DK	?
Start Ages 5–6	26	Throws ball of any size in specific direction.	2	1	0	DK	?
	27	Catches beach ball-sized ball with both hands from a distance of 2 or 3 feet.	2	1	0	DK	?
	28	Walks up stairs, alternating feet; may use railing.	2	1	0	DK	?
	29	Pedals tricycle or other three-wheeled toy for at least 6 feet.	2	1	0	DK	?
		Scoring Tip: You may mark "N/O" for No Opportunity if the individual does not have a tricycle or three-wheeled toy. However, if the individual has such a vehicle but does not ride it for any reason, including parent or caregiver does not think he or she is ready, mark "0."			N/O		
	30	Jumps or hops forward at least three times.	2	1	0	DK	?
	31	Hops on one foot at least once without falling; may hold on to something for balance.	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know **N/O** = No Opportunity

Using Large Muscles, *continued*

						Circle "?" If You Have a Question
32	Climbs on and off high objects (for example, jungle gym, 4-foot slide ladder, etc.).	2	1	0	DK	?
33	Walks down stairs, alternating feet; may use railing.	2	1	0	DK	?
34	Runs smoothly, with changes in speed and direction.	2	1	0	DK	?
35	Rides bicycle with training wheels for at least 10 feet.	2	1	0	DK	?
	Scoring Tip: You may mark "N/O" for No Opportunity if the individual does not have a bicycle. However, if the individual has a bike but does not ride it for any reason, including parent or caregiver does not think he or she is ready, mark "0."	N/O				
36	Catches beach ball-sized ball (from at least 6 feet away) with both hands.	2	1	0	DK	?
37	Hops forward on one foot with ease.	2	1	0	DK	?
38	Skips at least 5 feet.	2	1	0	DK	?
39	Catches tennis or baseball-sized ball (from at least 10 feet away), moving to catch it if necessary.	2	1	0	DK	?
40	Rides bicycle with no training wheels without falling.	2	1	0	DK	?
	Scoring Tip: You may mark "N/O" for No Opportunity if the individual does not have a bicycle. However, if the individual has a bike but does not ride it for any reason, including parent or caregiver does not think he or she is ready, mark "0."	N/O				

Using Small Muscles

						Circle "?" If You Have a Question
Start Ages 0–4	**1** Reaches for toy or object.	2	1	0	DK	?
	2 Picks up small objects (no larger than 2 inches on any side); may use both hands.	2	1	0	DK	?
	3 Moves object from one hand to the other.	2	1	0	DK	?
	4 Squeezes squeaky toy or object.	2	1	0	DK	?
	5 Picks up small object with thumb and fingers.	2	1	0	DK	?
	6 Removes object (for example, a block or clothespin) from a container.	2	1	0	DK	?
	7 Puts object (for example, a block or clothespin) into a container.	2	1	0	DK	?
	8 Turns pages of board, cloth, or paper book, one at a time.	2	1	0	DK	?
	9 Stacks at least four small blocks or other small objects; stack must not fall.	2	1	0	DK	?
	10 Opens doors by turning doorknobs.	2	1	0	DK	?
Start Ages 5–6	**11** Unwraps small objects (for example, gum or candy).	2	1	0	DK	?
	12 Completes simple puzzle of at least two pieces or shapes.	2	1	0	DK	?
	13 Turns book or magazine pages one by one.	2	1	0	DK	?
	14 Uses twisting hand-wrist motion (for example, winds up toy, screws/unscrews lid of jar, etc.).	2	1	0	DK	?
	15 Holds pencil in proper position (not with fist) for writing or drawing.	2	1	0	DK	?
	16 Colors simple shapes; may color outside lines.	2	1	0	DK	?
	17 Builds three-dimensional structures (for example, a house, bridge, vehicle, etc.) with at least five small blocks.	2	1	0	DK	?
	18 Opens and closes scissors with one hand.	2	1	0	DK	?

Response Options: **2** = Usually, **1** = Sometimes or Partially, **0** = Never, **DK** = Don't Know **N/O** = No Opportunity

Using Small Muscles, *continued*

			Circle "?" If You Have a Question
19	Glues or pastes two or more pieces together (for example, for art or science projects, etc.).	2 1 0 DK	?
20	Uses tape to hold things together (for example, torn page, art project, etc.).	2 1 0 DK	?
21	Draws more than one recognizable form (for example, person, house, tree, etc.).	2 1 0 DK	?
	Scoring Tip: Mark a "2" if the individual draws two or more recognizable forms; mark a "1" if the individual draws one form; mark a "0" if the individual does not draw any recognizable forms.		
22	Makes recognizable letters or numbers.	2 1 0 DK	?
23	Draws circle freehand while looking at example.	2 1 0 DK	?
24	Uses scissors to cut across paper along a straight line.	2 1 0 DK	?
25	Colors simple shapes; colors inside the lines.	2 1 0 DK	?
26	Cuts out simple shapes (for example, circles, squares, rectangles, etc.).	2 1 0 DK	?
27	Uses eraser without tearing paper.	2 1 0 DK	?
28	Draws square freehand while looking at example.	2 1 0 DK	?
29	Draws triangle freehand while looking at example.	2 1 0 DK	?
30	Ties knot.	2 1 0 DK	?
31	Draws straight line using a ruler or straightedge.	2 1 0 DK	?
32	Unlocks dead-bolt, key, or combination locks that require twisting.	2 1 0 DK	?
	Scoring Tip: You may mark "N/O" for No Opportunity if there are no dead-bolt, key, or combination locks in the home.	N/O	
33	Cuts out complex shapes (for example, stars, animals, alphabet letters, etc.).	2 1 0 DK	?
34	Uses keyboard, typewriter, or touch screen to type name or short words; may look at keys.	2 1 0 DK	?
	Scoring Tip: You may mark "N/O" for No Opportunity if there is no computer in the home.	N/O	
35	Ties secure bow.	2 1 0 DK	?
36	Uses a keyboard to type up to 10 lines; may look at the keys.	2 1 0 DK	?
	Scoring Tip: You may mark "N/O" for No Opportunity if there is no computer in the home.	N/O	

Problem Behaviors Part 1

Response Options: 2 = Often, 1 = Sometimes, 0 = Never

Section A

					Circle "?" If You Have a Question
1	Is overly dependent (that is, clings to caregiver, teacher, brother, or sister).	0	1	2	?
2	Avoids others and prefers to be alone.	0	1	2	?
3	Has eating difficulties (for example, eats too fast or too slowly, hoards food, overeats, refuses to eat, etc.).	0	1	2	?
4	Has sleep difficulties (for example, sleepwalks, has frequent nightmares, sleeps significantly more or less than typical for his or her age).	0	1	2	?
5	Refuses to go to school or work because of fear, feelings of rejection or isolation, etc.	0	1	2	?
6	Is overly anxious or nervous.	0	1	2	?
7	Cries or laughs too easily.	0	1	2	?
8	Has poor eye contact (that is, does not look at or face others when speaking or spoken to).	0	1	2	?
9	Is sad for no clear reason.	0	1	2	?
10	Avoids social interaction.	0	1	2	?
11	Lacks energy or interest in life.	0	1	2	?

Section B

					Circle "?" If You Have a Question
1	Is impulsive (that is, acts without thinking).	0	1	2	?
2	Has temper tantrums.	0	1	2	?
3	Intentionally disobeys and defies those in authority.	0	1	2	?
4	Taunts, teases, or bullies.	0	1	2	?
5	Is inconsiderate or insensitive to others.	0	1	2	?
6	Lies, cheats, or steals.	0	1	2	?
7	Is physically aggressive (for example, hits, kicks, bites, etc.).	0	1	2	?
8	Is stubborn or sullen.	0	1	2	?
9	Says embarrassing things or asks embarrassing questions in public (for example, "You're fat," or "What's that big red thing on your nose?").	0	1	2	?
10	Behaves inappropriately at the urging of others.	0	1	2	?

Section C

					Circle "?" If You Have a Question
1	Sucks thumb or fingers.	0	1	2	?
2	Wets bed or must wear diapers at night.	0	1	2	?
3	Acts overly familiar with strangers (for example, holds hands, hugs, sits on lap, etc.).	0	1	2	?
4	Bites fingernails.	0	1	2	?
5	Has tics (that is, involuntary blinking, twitching, head shaking, etc.).	0	1	2	?

Problem Behaviors Part 1, continued

Response Options: 2 = Often, 1 = Sometimes, 0 = Never

Section C, *continued*

			Circle "?" If You Have a Question
6	Grinds teeth during the day or night.	0 1 2	?
7	Has a hard time paying attention.	0 1 2	?
8	Is more active or restless than others of same age.	0 1 2	?
9	Uses school or work property (for example, telephone, Internet access, office supplies, etc.) for unapproved personal purposes.	0 1 2	?
10	Swears.	0 1 2	?
11	Runs away (that is, is missing for 24 hours or longer).	0 1 2	?
12	Is truant from school or work.	0 1 2	?
13	Ignores or doesn't pay attention to others around him or her.	0 1 2	?
14	Uses money or gifts to "buy" affection.	0 1 2	?
15	Uses alcohol or illegal drugs during the school or work day.	0 1 2	?

Problem Behaviors Part 2

Response Options: 2 = Often, 1 = Sometimes, 0 = Never, S = Severe, M = Moderate

Section D

				Circle "?" If You Have a Question
Start Ages 3+	1	Engages in inappropriate sexual behavior (for example, exposes self, masturbates in public, makes improper sexual advances, etc.).	0 1 2 S M	?
	2	Is obsessed with objects or activities (for example, constantly repeats words or phrases, is preoccupied with mechanical objects, etc.).	0 1 2 S M	?
	3	Expresses thoughts that do not make sense (for example, talks about hearing voices, seems delusional, etc.).	0 1 2 S M	?
	4	Has strange habits or ways (for example, makes repetitive noises, odd hand movements, etc.).	0 1 2 S M	?
	5	Consistently prefers objects to people (for example, pays more attention to objects than to people, etc.).	0 1 2 S M	
	6	Displays behaviors that cause injury to self (for example, bangs head, hits or bites self, tears at skin, etc.).	0 1 2 S M	?
	7	Destroys own or another's possessions on purpose.	0 1 2 S M	?
	8	Uses bizarre speech (for example, has conversations with self in public, speaks in phrases or sentences that have no meaning, repeats same word or phrase over and over, etc.).	0 1 2 S M	?
	9	Is unaware of what is happening around him or her (for example, seems to be in a "fog," stares blankly, etc.).	0 1 2 S M	?
	10	Rocks back and forth repeatedly.	0 1 2 S M	?
	11	Is unusually fearful of ordinary sounds, objects, or situations.	0 1 2 S M	?
	12	Remembers odd information in detail years later.	0 1 2 S M	?
	13	Is unable to complete a normal school or work day because of chronic pain or fatigue.	0 1 2 S M	?
	14	Is unable to complete a normal school or work day because of psychological symptoms.	0 1 2 S M	?

Individual: _____ Date: _____ Age: _____ Form: ____ Survey Interview
____ Parent/Caregiver Rating

VINELAND–II SCORE SUMMARY

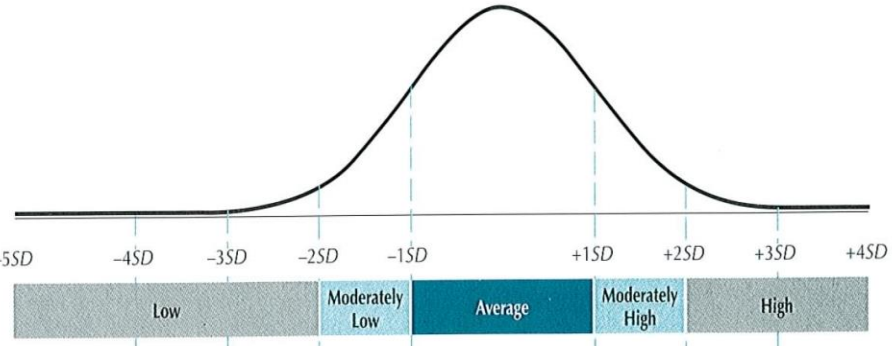
SUBDOMAIN and DOMAIN SCORES

SUBDOMAIN/ DOMAIN	Raw Score	*v*-Scale Score Table B.1	Domain Standard Score Table B.2	___% Conf. Interval Table C.1/C.2	%ile Rank Table C.3	Adaptive Level Table C.4	Age Equivalent Table C.5	Stanine Table C.3
Receptive				±				
Expressive				±				
Written				±				
Communication	Sum: ____			±				
Personal				±				
Domestic				±				
Community				±				
Daily Living Skills	Sum: ____			±				
Interpersonal Relationships				±				
Play and Leisure Time				±				
Coping Skills				±				
Socialization	Sum: ____			±				
Gross				±				
Fine				±				
Motor Skills	Sum: ____			±				

STRENGTHS and WEAKNESSES

Score Minus *Median**	S(trength) or W(eakness)

VINELAND–II SCORE PROFILE



Domain Score Profile

	Std. Score	___% Conf. Int.
Adaptive Behavior Composite	___	___
Communication	___	___
Daily Living Skills	___	___
Socialization	___	___
Motor Skills	___	___

20 30 40 50 60 70 80 90 100 110 120 130 140 150 160

Subdomain Score Profile

	v-Scale Score	___% Conf. Int.
Receptive	___	___
Expressive	___	___
Written	___	___
Personal	___	___
Domestic	___	___
Community	___	___
Interpersonal Relationships	___	___
Play and Leisure Time	___	___
Coping Skills	___	___
Gross	___	___
Fine	___	___

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24

VINELAND–II PAIRWISE COMPARISONS

Domain Comparisons	Standard Score	<, >, or =	Standard Score		Standard Score Difference	Stat. Sign. Level (.05 or .01) Table D.1	Freq. of Difference (Extreme 16, 10, 5, or 1%) Table D.2
Communication				Daily Living Skills			
Communication				Socialization			
Daily Living Skills				Socialization			
Communication				Motor Skills			
Socialization				Motor Skills			
Daily Living Skills				Motor Skills			

Subdomain Comparisons	*v*-Scale Score	<, >, or =	*v*-Scale Score		*v*-Scale Score Difference	Stat. Sign. Level (.05 or .01) Table D.3 or D.5	Freq. of Difference (Extreme 16, 10, 5, or 1%) Table D.4
Communication							
Receptive				Expressive			
Receptive				Written			
Expressive				Written			
Daily Living Skills							
Personal				Domestic			
Personal				Community			
Domestic				Community			
Socialization							
Interpersonal Relationships				Play and Leisure Time			
Interpersonal Relationships				Coping Skills			
Play and Leisure Time				Coping Skills			
Motor Skills							
Gross				Fine			

Selected Across-Domain Subdomain Comparisons	*v*-Scale Score	<, >, or =	*v*-Scale Score		*v*-Scale Score Difference	Stat. Sign. Level (.05 or .01) Table D.3 or D.5	Freq. of Difference (Extreme 16, 10, 5, or 1%) Table D.4
Expressive				Interpersonal Relationships			
Expressive				Coping Skills			
Fine				Written			
Fine				Domestic			
Fine				Personal			

Vineland-II

Parent/Caregiver Rating Form Score Report

Vineland Adaptive Behavior Scales, Second Edition

Individual: _____

Chronological Age: ____ – ____ – ____ Assessment Date: ____ – ____ – ____

Grade (if applicable): _____ Highest Grade Completed: _____

Respondent: _____ Examiner: _____

Data from Other Tests: Intelligence: _____ Achievement: _____

Adaptive Behavior: _____ Other: _____

Domains:

Communication

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
Sum of 2s and 1s + ☐
Receptive Raw Score = ☐ SUM

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
Sum of 2s and 1s + ☐
Expressive Raw Score = ☐ SUM

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
Sum of 2s and 1s + ☐
Written Raw Score = ☐ SUM

Daily Living Skills

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
N/O Total + ☐
Sum of 2s and 1s + ☐
Personal Raw Score = ☐ SUM

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
N/O Total + ☐
Sum of 2s and 1s + ☐
Domestic Raw Score = ☐ SUM

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
N/O Total + ☐
Sum of 2s and 1s + ☐
Community Raw Score = ☐ SUM

Socialization

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
Sum of 2s and 1s + ☐
Interpersonal Relationships Raw Score = ☐ SUM

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
Sum of 2s and 1s + ☐
Play and Leisure Time Raw Score = ☐ SUM

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
Sum of 2s and 1s + ☐
Coping Skills Raw Score = ☐ SUM

Motor Skills

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
N/O Total + ☐
Sum of 2s and 1s + ☐
Gross Raw Score = ☐ SUM

Item Before Basal ___ × 2 = ☐
Basal Item Through Ceiling Item:
DK and/or Missing Total* + ☐
N/O Total + ☐
Sum of 2s and 1s + ☐
Fine Raw Score = ☐ SUM

Problem Behaviors

Section A Sum of 2s and 1s ☐
Section B Sum of 2s and 1s ☐
Section C Sum of 2s and 1s ☐
Problem Behaviors Raw Score = ☐ SUM

**If the total of DK and/or Missing is greater than 2, do not score subdomain.*

APPENDIX R

PERMISSION TO TRANSLATE AND USE THE CANADIAN OCCUPATIONAL PERFORMANCE MEASURE

PUBLISHING AGREEMENT BETWEEN

AUTHORS OF THE CANADIAN OCCUPATIONAL PERFORMANCE MEASURE:

SUE BAPTISTE

ANNE CARSWELL

MARY LAW

MARY ANN McCOLL

HELEN POLATAJKO

NANCY POLLOCK

(hereinafter referred to collectively, the "Authors" and individually as "Author")

AND

Masne Kadar, Monash University, Australia

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Masne Kadar [redacted] Mary Law [redacted]

Page 1 of 1

APPENDIX S

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10. Ethical Standards. Licensee shall administer, score, interpret and otherwise use the Test(s) and Translated Test(s) in accordance with the principles of Ethical Standards of Psychologists established by the American Psychological Association. Licensee further agrees that in exercising the rights under this Agreement it shall maintain the standards of test security, confidentiality and quality required by Licensee's own profession for the content, condition, and accuracy of all individual score reports prepared by Licensee.

11. Limitation of Liability. PEARSON WILL NOT BE LIABLE FOR ANY CONSEQUENTIAL, INCIDENTAL OR SPECIAL DAMAGES, OR FOR ANY LOST BUSINESS, LOST PROFITS OR LOST SAVINGS ARISING OUT OF THIS AGREEMENT, EVEN IF ADVISED OF SUCH DAMAGES. EXCEPT FOR THE INDEMNIFICATION RESPONSIBILITIES SET FORTH IN SECTION 12, IN NO EVENT WILL PEARSON'S LIABILITY UNDER THIS AGREEMENT EXCEED THE TOTAL AMOUNT OF LICENSE FEES RECEIVED BY PEARSON PURSUANT TO THIS AGREEMENT. PEARSON SHALL HAVE NO RESPONSIBILITY FOR THE QUALITY OF THE TEST(S), THE TRANSLATED TEST(S), OR THE RESULTS OBTAINED THROUGH LICENSEE'S USE OF THE TEST(S) OF THE TRANSLATED TEST(S).

12. Indemnification.

12.1. Indemnification Responsibility of Licensee. Licensee will indemnify, defend, and hold Pearson harmless against any and all third party claims and resulting expenses (including attorneys' fees) and damages awarded by a court of competent jurisdiction, where such third party claim results from: (a) Licensee's use of the Test(s), Test(s) IP or Translated Test(s); (b) the exercise of the license granted hereunder; (c) any breach of the warranty against infringement made by Licensee under this Agreement; (d) any representation or warranty that Licensee makes as to the quality, reliability, functionality, applicability of the Test(s), Test(s) IP, or Translated Test(s), except for any representation or warranty expressly authorized by Pearson in writing; or (e) any other breach of Licensee's obligations and responsibilities under this Agreement. Pearson shall notify Licensee promptly of any such claim. Licensee will not be responsible for any claims arising from negligence or willful misconduct on the part of Pearson as it relates to this Agreement.

12.2. Indemnification Responsibility of Pearson. Pearson agrees to indemnify and hold Licensee harmless from any and all third party claims (including attorneys' fees incurred in defense or awarded by a court of competent jurisdiction) arising out of any breach of the warranty against infringement made by Pearson in Section 6.1 of this Agreement.

13. Termination.

13.1. Termination for Default. Either party will have the right to terminate this Agreement in the event the other party is in material breach of this Agreement and fails to cure such breach within thirty (30) days after receipt of written notice specifying the breach from the party not in breach. Notwithstanding the foregoing, Pearson will have the right to terminate this Agreement immediately upon prior written notice and a ten day right to cure, in the event Licensee is in breach of any portions of Sections 3, 4 or 15.6 of this Agreement.

13.2. Termination for Insolvency and Business Dissolution. This Agreement may be terminated by either party upon written notice to the other in the event the other party becomes insolvent or bankrupt, or if any proceedings are instituted by or against it for relief under laws relating to bankruptcy or insolvency, or upon a general assignment by the other party for the benefit of its creditors, or upon the appointment of the receiver or trustee or any of such party's property or assets, or if such party's business is dissolved or if such party ceased to do business.

13.3. Termination for Assignment of Rights. This Agreement may be terminated by Pearson in the event that Licensee assigns or transfers to any third party, any rights granted hereunder. In the event that Licensee, or the assets of Licensee are acquired by a third party, an assignment of rights will be deemed to have occurred and Pearson may, at its sole discretion, terminate the Agreement.

13.4. Other Termination. Pearson will have the right to terminate this Agreement upon thirty (30) days advance written notice to Licensee if Pearson's right to sublicense the Test(s) or Test(s) IP to Licensee is or is about to be terminated for any reason. Termination of this Agreement pursuant to this Section will not be deemed a breach of contract and all rights and responsibility will revert to the copyright owner.

14. Effect of Termination. In the event of any termination or expiration of this Agreement or the License granted herein, Licensee agrees:
    14.1. To immediately cease all exercise of any rights granted under this Agreement, including Use of the Test(s), Test(s) IP, Translated Test(s), and destroy the Test(s) IP, and all unused copies of the Test(s) and Translated Test(s), including but not limited to survey forms.
    14.2. Upon Pearson's request, to provide Pearson with written certification with respect to Licensee's compliance with the terms of this Section.

15. General.
    15.1. Relationship of the Parties. The relationship between the parties established by this Agreement is that of independent contractors, and does not involve any community of interest between the parties. Pearson and Licensee will each conduct its respective businesses at its own initiative, responsibility and expense, and will have no authority to incur any obligations on behalf of the other. Neither party intends there to be any third party beneficiaries to this Agreement.
    15.2. Modifications. Licensee shall have no right to make modifications to the Test(s) or the Translated Test(s) without the express written authorization of Licensor.
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    15.4. Obligation to Monitor. Licensee has the obligation to monitor its facilities and research sites to ensure that no use of the Test(s) or Translated Test(s), other than that authorized by the Agreement, occurs. Pearson will have the right to make the final determination, in its sole discretion, as to whether Licensee's facilities are engaged in commercial scoring and other unauthorized use.
    15.5. Paragraph Headings. The paragraph and section headings throughout this Agreement are for reference purposes only and will not be held to explain or aid in the interpretation, construction or meaning of the provisions of this Agreement.
    15.6. Assignment. Neither this Agreement nor any right, license or privilege with respect to the intellectual property licensed hereunder may be assigned, conveyed, sublicensed or otherwise transferred by Licensee to a third party, without the express consent of Pearson. Any attempt to do so will be void. Subject to the limitations of this Section, this Agreement will be binding on and will inure to the benefit of, the parties and their respective successors and assigns.
    15.7. Waiver. No waiver of any provisions of this Agreement by either party shall be deemed to be an ongoing waiver of such provisions or rights unless the parties otherwise expressly agree in writing.
    15.8. Survival of Rights and Obligations. In the event of any termination of this Agreement, all rights, obligations and duties under this Agreement will terminate, provided, however, that:
        15.8.1. Subject to the limitations contained in this Agreement, termination of this Agreement will not constitute any waiver of a party's rights or remedies at law or in equity to redress any breach of this Agreement by the other party.

15.8.2. In addition to any provisions of this Agreement, which by their express terms survive any termination of this Agreement, the following Sections of this Agreement will survive any termination of this Agreement: 4.5, 6.2, 7, 8, 9, 10, 11, 12, 13, 14 and 15.

15.9. Governing Law. This Agreement will be governed by, construed, and interpreted exclusively in accordance with the laws of the State of Minnesota, without reference to its choice of law rules. Copyright, Trademark and Patent issues will be construed exclusively under U.S. Federal law, with the parties expressly consenting to forum in the U.S. 8th Circuit.

15.10. Equitable Relief. In the event either party is in breach of any of the provisions of Sections 7, 8, 9 or 15.6 of this Agreement, the other party will be entitled to equitable relief without proving actual damages.

15.11. Severability. In the event any provision of this Agreement is held to be unenforceable by a court of competent jurisdiction, this Agreement will be enforced to the maximum extent possible.

15.12. Notices. All notices required or permitted under this Agreement will be made in writing and will be deemed to have been duly given, when delivered, to the parties at the addresses set forth below:

If to Pearson:	If to Licensee:
Pearson IP Licensing Clinical Assessment, North America 19500 Bulverde Road San Antonio, TX 78259 Pas.licensing@pearson.com	MASNE KADAR Department of occupational Therapy - Bldg G, Level 4 Monash University - Peninsula Campus Mc Mahon Road Frankston, 3199, Victoria, Australia

15.13. Entire Agreement. This Agreement contains the entire Agreement between the parties related to the matters set forth herein and supersedes all previous agreements, proposals, negotiations and correspondence between them whether oral or written related to the subject matter of this Agreement. This Agreement will not be modified, varied, waived or otherwise changed without the mutual, written consent of both parties.

IN WITNESS WHEREOF, the parties have executed this Agreement as of the date the Agreement is signed below by Pearson.

NCS PEARSON, INC. [redacted]

By: _____ *Authorized Signature*

Name: Carol Watson

Title: President, Clinical Assessment, North America

Date: 11/3/09

By: [redacted] *Authorized Signature*

Name: Dr. Rachael McDonald

Title: Senior Lecturer

Date: 26/10/09

APPENDIX T

THE CANADIAN OCCUPATIONAL PERFORMANCE MEASURE FORM AND SCORING CARDS IN THE MALAY LANGUAGE VERSION

Ukuran Prestasi Pekerjaan Kanada (COPM)

Penulis: Mary Law, Sue Baptiste, Anne Carswell, Mary Ann McColl, Helene Polatajko, Nancy Pollock

Nama Klien:

Responden (jika bukan klien:)

Tarikh Lahir:	No. Pengenalan:	Jantina:
Tarikh Penilaian:	Tarikh Penilaian Semula yang Dirancang:	Tarikh Sebenar Penilaian Semula:

Terapist:

Fasiliti/Agensi:

Program:

LANGKAH 1: **MENGENAL PASTI ISU PRESTASI PEKERJAAN** Untuk mengenal pasti masalah prestasi pekerjaan, minta klien mengenal pasti aktiviti seharian yang mereka **ingin lakukan, perlu lakukan** atau **diharapkan untuk melakukan** tetapi **tidak dapat dilakukan, tidak dilakukan,** atau **tidak puas dengan prestasi mereka.**	**LANGKAH 2:** **MENGKADARKAN KEPENTINGAN** Dengan menggunakan kad pengkadaran yang disediakan, minta klien mengkadarkan dengan skala 1 hingga 10, kepentingan setiap aktiviti
Penjagaan Diri **Penjagaan Peribadi** (cth., berpakaian, mandi, makan, kebersihan) **Mobiliti Fungsi** (cth., beralih, di luar, di dalam) **Pengurusan Masyarakat** (cth., pengangkutan, membeli-belah, kewangan)	KEPENTINGAN
LANGKAH 1B: Produktiviti **Pekerjaan Bergaji/Tidak Bergaji** (cth., mencari pekerjaan/ mengekalkan pekerjaan, menjadi sukarelawan) **Pengurusan Rumahtangga** (cth., membersih, membasuh, memasak) **Bermain/Bersekolah** (cth., kemahiran bermain, kerja rumah)	

Tarikh Lahir: | No. Pengenalan:

LANGKAH 1C: Masa Lapang

KEPENTINGAN

Rekreasi Tenang
(cth., hobi, kraf, membaca)

Rekreasi Aktif
(cth., sukan, lawatan, melancong)

Sosialisasi
(cth., berkunjung, panggilan telefon, pesta, surat-menyurat)

LANGKAH 3: SKOR

Pastikan dengan klien 5 masalah yang paling penting dan catatkan di bawah. Dengan menggunakan kad pengkadaran, minta klien mengkadarkan setiap masalah prestasi dan kepuasan, dan kira jumlah skor. Jumlah skor dikira dengan menjumlahkan skor prestasi atau kepuasan untuk semua masalah dan dibahagikan dengan bilangan masalah.

LANGKAH 4: PENILAIAN SEMULA

Pada selang masa yang sesuai untuk penilaian semula, klien sekali lagi mengkadarkan setiap masalah yang dipilih untuk prestasi dan kepuasan.

Penilaian Permulaan:			**Penilaian Semula:**	
Masalah Prestasi Pekerjaan:	PRESTASI 1	KEPUASAN 1	PRESTASI 2	KEPUASAN 2
1.				
2.				
3.				
4.				
5.				
SKOR: Jumlah skor = Jumlah skor prestasi atau kepuasan / bil. masalah (1-5)	SKOR PRESTASI 1 =	SKOR KEPUASAN 1 =	SKOR PRESTASI 2 =	SKOR KEPUASAN 2 =

LANGKAH 5: MENJUMLAHKAN SKOR PERUBAHAN

PERUBAHAN PRESTASI = Skor Prestasi 2 - Skor Prestasi 1 =

PERUBAHAN KEPUASAN = Skor Kepuasan 2 - Skor Prestasi 1 =

CATATAN DAN PEMERHATIAN TAMBAHAN:
Penilaian Permulaan:

Penilaian Semula:

Diterbitkan oleh CAOT Publications ACE

KEPENTINGAN

1	2	3	4	5	6	7	8	9	10
tidak penting sama sekali									amat penting

PRESTASI

1	2	3	4	5	6	7	8	9	10
tidak dapat melakukan									dapat melakukan dengan amat baik

KEPUASAN

1	2	3	4	5	6	7	8	9	10
tidak puas sama sekali									amat puas

APPENDIX U

THE VINELAND ADAPTIVE BEHAVIOUR SCALES, SECOND EDITION

(PARENT/CAREGIVER RATING FORM) IN THE MALAY LANGUAGE VERSION

Butiran individu:

Nama: _____ Telefon: _____

Kelulusan gred semasa atau tertinggi yang berjaya dilengkapkan (jika berkenaan): _____

Sekolah atau kemudahan lain (jika berkenaan): _____

Bahasa yang dituturkan di rumah: _____

Adakah individu mempunyai sebarang kekurangan? _____

Jantina (bulatkan): L P

	Tahun	Bulan	Hari
Tarikh ujian:	_____	_____	_____
Tarikh lahir:	_____	_____	_____
Umur kronologi:	_____	_____	_____

Buku Kecil Rekod

Skala Kelakuan Adaptif Vineland, Edisi Kedua

Borang Rating Ibu Bapa/Penjaga

Sara S. Sparrow, Domenic V. Cicchetti, dan David A. Balla
Kajian semula daripada Vineland Social Maturity Scale oleh Edgar A. Doll

Maklumat Responden:

Nama: _____ Jantina: _____

Hubungan dengan individu: _____ No. Tel.: _____

Nombor Produk 31013

Arahan:

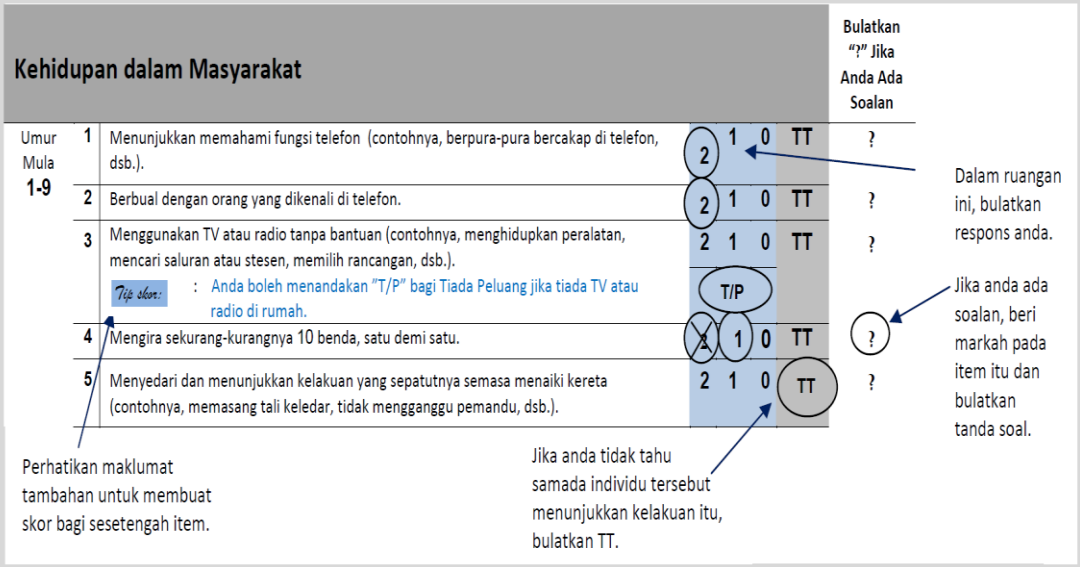
Buku kecil ini mengandungi frasa yang menerangkan banyak kelakuan berbeza yang ditunjukkan oleh seseorang di rumah, sekolah, tempat kerja atau tempat lain. Kelakuan tersebut berjulat antara yang sesuai untuk bayi dengan yang sesuai untuk orang dewasa. Sesetengahnya mungkin terlalu sukar bagi kanak-kanak yang lebih kecil, dan sesetengahnya mungkin terlalu mudah bagi kanak-kanak yang lebih besar atau orang dewasa. Oleh itu, kanak-kanak, remaja atau orang dewasa yang anda rating mungkin tidak akan menunjukkan semua kelakuan yang diterangkan dalam item.

Umur Mula

Bagi setiap bahagian, cari titik mula (**0-5**) bagi umur individu. Baca setiap frasa dan tandakan respons yang paling baik menerangkan kelakuan individu. Respons yang anda pilih hendaklah menggambarkan bagaimana kerap individu tersebut menunjukkan kelakuan tanpa bantuan, apabila kelakuan itu diperlukan. Tandakan markah anda dalam buku kecil ini dengan membulatkan satu pilihan respons bagi setiap item.

- Bulatkan "2" jika individu selalu menunjukkan kelakuan tanpa bantuan atau peringatan.
- Bulatkan "1" jika individu kadang-kadang menunjukkan kelakuan tanpa bantuan atau peringatan atau menunjukkan sedikit kelakuan tanpa bantuan atau peringatan.
- Bulatkan "0" jika individu tidak pernah menunjukkan kelakuan atau tidak pernah menunjukkannya tanpa bantuan atau peringatan.
- Jika anda tidak pernah melihat individu menunjukkan sesuatu kelakuan dan tidak tahu sama ada individu itu menunjukkannya, bulatkan "TT" yang bermaksud Tidak Tahu.
- Jika sesuatu item mempunyai Tip Skor, gunakan tip itu untuk membantu anda memutuskan pilihan respons yang mana patut dibulatkan.
- Jika sesuatu item mempunyai Tip Skor yang menyatakan anda boleh membulatkan "T/P" bagi Tiada Peluang, anda boleh membulatkan pilihan tersebut jika wajar, dan bukannya "2", "1", "0", atau "TT".
- Sesetengah bahagian tidak sesuai untuk kanak-kanak di bawah umur 3 tahun. Jika kanak-kanak yang anda rating itu lebih muda daripada umur pada titik mula yang pertama, jangan tandakan sebarang item dalam bahagian tersebut.

Berikut ialah satu contoh:



Bersambung dihalaman seterusnya

Jika anda ingin menukar respons, tandakan X di atas respons tersebut, dan bulatkan pilihan baru anda.

Jika anda ada soalan tentang sebarang item, **tandakan respons anda terlebih dahulu** yang paling baik menerangkan kelakuan individu, kemudian bulatkan tanda soal (?) di sebelah kanan pilihan respons.

Gunakan jadual berikut untuk membantu anda memilih respons yang paling baik menerangkan kelakuan individu yang anda rating.

RATING	**INDIVIDU:**
2 Selalu	Selalu menunjukkan kelakuan tanpa bantuan atau peringatan apabila diperlukan; atau Menunjukkan kelakuan pada umur yang lebih muda tetapi sekarang dia telah meninggalkan kelakuan itu.
1 Kadang-kadang atau sebahagian sahaja	Kadang-kadang menunjukkan kelakuan tanpa bantuan atau peringatan apabila ia diperlukan; atau Kadang-kadang melakukannya tanpa bantuan tetapi kadang-kadang memerlukan bantuan; atau Kadang-kadang melakukannya tanpa bantuan tetapi memerlukan peringatan; atau Menunjukkan sebahagian daripada kelakuan itu tanpa bantuan atau peringatan
0 Tidak pernah	Tidak pernah menunjukkan kelakuan tanpa bantuan atau peringatan; atau Tidak pernah menunjukkan kelakuan, kerana dia tidak mampu; atau Tidak pernah menunjukkan kelakuan, kerana dia terlalu muda; atau Tidak pernah menunjukkan kelakuan, kerana dia tidak dibenarkan; atau Tidak pernah menunjukkan kelakuan, kerana dia mempunyai ketidakupayaan fizikal yang menghalang kelakuan itu

Ingat untuk memberi respons dalam setiap bahagian bagi setiap item selepas titik mula umur individu tersebut.

Komunikasi

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau sebahagian sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu

Mendengar dan Memahami							**Bulatkan "?" Jika Anda Ada Soalan**
Umur Mula **0-4**	1	Alihkan mata dan kepala ke arah bunyi.	**2**	**1**	**0**	**TT**	?
	2	Lihat ke arah ibu bapa atau penjaga apabila mendengar suara mereka.	**2**	**1**	**0**	**TT**	?
	3	Memberi respons apabila nama ia disebut (contohnya, berpaling ke arah mereka yang menyebutnya, tersenyum, dsb.).	**2**	**1**	**0**	**TT**	?
	4	Menunjukkan memahami makna *tidak,* atau perkataan atau gerak badan yang bermakna *tidak* (contohnya, menghentikan aktiviti yang sedang dilakukan serta-merta).	**2**	**1**	**0**	**TT**	?
	5	Menunjukkan memahami makna *ya,* perkataan atau gerak badan yang bermakna *ya* (contohnya, meneruskan aktiviti, tersenyum, dsb.).	**2**	**1**	**0**	**TT**	?
	6	Mendengar cerita sekurang-kurangnya selama 5 minit (iaitu, duduk diam dan memberi tumpuan kepada tukang cerita atau pembaca).	**2**	**1**	**0**	**TT**	?
	7	Menunjukkan sekurang-kurangnya tiga bahagian badan utama apabila ditanya (contohnya, hidung, mulut, tangan, kaki, dsb.).	**2**	**1**	**0**	**TT**	?
Umur Mula **5+**	8	Menunjukkan objek yang biasa dilihat di dalam buku atau majalah apabila objek itu dinamakan (contohnya, anjing, kereta, cawan, kunci, dsb.).	**2**	**1**	**0**	**TT**	?
	9	Mendengar arahan.	**2**	**1**	**0**	**TT**	?
	10	Mengikut arahan bagi satu tindakan dan satu objek (contohnya, "Berikan saya buku"; "Tutup pintu itu"; dsb.).	**2**	**1**	**0**	**TT**	?
	11	Menunjukkan sekurang-kurangnya lima bahagian badan minor apabila ditanya (contohnya, jari, siku, gigi, jari kaki, dsb.).	**2**	**1**	**0**	**TT**	?
	12	Mengikut arahan bagi dua tindakan atau satu tindakan dengan dua objek (contohnya, "Berikan saya krayon dan kertas"; "Duduk dan makan hidangan tengah hari awak"; dsb.).	**2**	**1**	**0**	**TT**	?
	13	Mengikut arahan dalam bentuk "jika-maka" (contohnya, "Jika kamu mahu bermain di luar, maka simpanlah barang kamu"; dsb.).	**2**	**1**	**0**	**TT**	?
	14	Mendengar sebuah cerita sekurang-kurangnya selama 15 minit.	**2**	**1**	**0**	**TT**	?
	15	Mendengar sebuah cerita sekurang-kurangnya selama 30 minit.	**2**	**1**	**0**	**TT**	?
	16	Mengikut arahan dalam bentuk tiga bahagian (contohnya, "Berus gigi kamu, pakai baju, dan kemas katil"; dsb.).	**2**	**1**	**0**	**TT**	?
	17	Mengikut arahan atau arah yang didengari 5 minit sebelumnya.	**2**	**1**	**0**	**TT**	?
	18	Memahami kata-kata yang tidak membawa maksud perkataan demi perkataan (contohnya, "Kunci bibir kamu"; dsb.)	**2**	**1**	**0**	**TT**	?
	19	Mendengar sebuah ucapan bermaklumat sekurang-kurangnya selama 15 minit.	**2**	**1**	**0**	**TT**	?
	20	Mendengar sebuah ucapan bermaklumat sekurang-kurangnya selama 30 minit.	**2**	**1**	**0**	**TT**	?

Bercakap							**Bulatkan "?" Jika Anda Ada Soalan**
Umur Mula **0-4**	1	Menangis atau merungut apabila lapar atau basah.	**2**	**1**	**0**	**TT**	?
	2	Tersenyum apabila anda senyum padanya.	**2**	**1**	**0**	**TT**	?
	3	Membuat bunyi suka (contohnya, berdekut, ketawa, dsb.).	**2**	**1**	**0**	**TT**	?
	4	Membuat bunyi bayi tanpa sebarang perkataan (iaitu, mengagah).	**2**	**1**	**0**	**TT**	?
	5	Membuat bunyi atau gerak badan (contohnya, melambai tangan) untuk menarik perhatian ibu bapa atau penjaga.	**2**	**1**	**0**	**TT**	?
	6	Membuat bunyi atau gerak badan (contohnya, menggoyangkan kepala) jika ia hendak sesuatu aktiviti itu berhenti atau diteruskan.	**2**	**1**	**0**	**TT**	?

Komunikasi, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau sebahagian sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu

Bercakap, *sambungan*						Bulatkan "?" Jika Anda Ada Soalan
	7	Melambai selamat tinggal apabila seseorang melambai, atau ibu bapa atau penjaga menyuruhnya melambai.	2	1	0 TT	?
	8	Berkata "Da-da", "Ma-ma", atau nama lain yang merujuk kepada ibu bapa atau penjaga (termasuk nama atau nama gelaran ibu bapa atau penjaga).	2	1	0 TT	?
	9	Menunjukkan objek yang dia kehendaki yang tidak boleh dicapainya.	2	1	0 TT	?
	10	Menunjukkan atau membuat gerak badan untuk memberitahu pilihannya apabila diberi sesuatu pilihan (contohnya, "Kamu nak yang ini atau yang itu?", dsb.).	2	1	0 TT	?
	11	Mengulang atau cuba untuk mengulang perkataan yang biasa sebaik sahaja mendengarnya (contohnya, *bola, kereta, pergi,* dsb.).	2	1	0 TT	?
	12	Menamakan sekurang-kurangnya tiga objek (contohnya, botol, anjing, mainan kesukaan, dsb.).	2	1	0 TT	?
	13	Menyebut satu perkataan berbentuk permintaan (contohnya, *atas, lagi, keluar,* dsb.).	2	1	0 TT	?
	14	Menggunakan nama atau nama panggilan bagi abang, kakak atau kawan, atau menyebut nama mereka apabila ditanya.	2	1	0 TT	?
	15	Menjawab atau cuba untuk menjawab dengan perkataan apabila ditanya soalan.	2	1	0 TT	?
	16	Menamakan sekurang-kurangnya 10 benda.	2	1	0 TT	?
	17	Menyatakan nama atau nama panggilan sendiri (contohnya, Nuraisha, Adik Manja, dsb.) apabila ditanya.	2	1	0 TT	?
	18	Menggunakan frasa dengan kata nama dan kata kerja (contohnya, "Nurul tunggu"; "Pergi balik", dsb.).	2	1	0 TT	?
	19	Tanya soalan dengan menukar intonasi perkataan atau frasa yang mudah ("Saya punya?", "Saya pergi?"; dsb.); tatabahasa tidak penting.	2	1	0 TT	?
	20	Menyebut sekurang-kurangnya 50 perkataan yang boleh dikenali.	2	1	0 TT	?
	21	Menggunakan perkataan yang mudah untuk menerangkan sesuatu (contohnya, *kotor, cantik, besar, bising,* dsb.).	2	1	0 TT	?
	22	Menanyakan soalan yang bermula dengan *apa* atau *ke mana* (contohnya, "Apa itu?"; "Ke mana anjing pergi?"; dsb.).	2	1	0 TT	?
	23	Menggunakan perkataan negatif dalam ayat (contohnya, "Saya tak pergi"; "Saya tak nak minum ni"; dsb.).	2	1	0 TT	?
	24	Menceritakan pengalaman dalam ayat mudah (contohnya, "Comel main dengan saya"; "Aiman bacakan saya buku"; dsb.).	2	1	0 TT	?
Umur Mula **5-13**	25	Menyatakan umur yang betul apabila ditanya.	2	1	0 TT	?
	26	Menyebut sekurang-kurangnya 100 perkataan yang boleh dikenali.	2	1	0 TT	?
	27	Menggunakan perkataan *dalam*, *atas*, atau *bawah* dalam frasa atau ayat (contohnya, "Bola pergi bawah kerusi"; "Letak ia atas meja; dsb.).	2	1	0 TT	?
	28	Menggunakan perkataan *dan* dalam frasa atau ayat (contohnya, "Mak dan Ayah"; "Saya nak ais krim dan kek"; dsb.).	2	1	0 TT	?
	29	Menyebut nama dan nama penuh apabila ditanya.	2	1	0 TT	?
	30	Mengenal pasti dan menyatakan warna yang paling asas (iaitu, merah, biru, hijau, kuning, oren, ungu, coklat, dan hitam). *Tip skor:* Tandakan "2" jika individu menyatakan 6 hingga 8 warna; tandakan "1" jika individu menyatakan 2 hingga 5 warna; tandakan "0" jika individu menyatakan 0 warna atau hanya 1 warna.	2	1	0 TT	?
	31	Menanyakan soalan yang bermula dengan *siapa* atau *mengapa* (contohnya, "Siapa tu?"; " Mengapa saya mesti pergi?"; dsb.).	2	1	0 TT	?
	32	Menggunakan kata kerja semasa bagi perbuatan yang sedang berlaku (contohnya, "sedang menyanyi"; "sedang bermain"; dsb.).	2	1	0 TT	?

Komunikasi, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau sebahagian sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu

Bercakap, ***sambungan***				Bulatkan "?" Jika Anda Ada Soalan
	33	Menggunakan kata ganti milik dalam frasa atau ayat (contohnya, "Itu buku dia"; "Ini bola Siti"; dsb.).	**2 1 0 TT**	?
	34	Menggunakan kata ganti nama dalam frasa atau ayat; mesti menggunakan gender yang betul dan membentuk kata ganti nama tetapi ayat tidak perlu mengikut tatabahasa yang betul (contohnya, "Dia yg buat"; "Mereka pergi"; dsb.).	**2 1 0 TT**	?
	35	Menanyakan soalan yang bermula dengan *bila* (contohnya, "Bila makan malam?"; "Bila kita boleh balik?"; dsb.).	**2 1 0 TT**	?
	36	Menggunakan kata kerja kala lepas yang biasa (contohnya, *telah pergi, telah dimasak,* dsb.); mungkin menggunakan kata kerja kala lepas yang tidak biasa dengan tidak mengikut tatabahasa (contohnya, "Saya lari pergi"; dsb.).	**2 1 0 TT**	?
	37	Menggunakan *belakang* atau *depan* dalam frasa atau ayat (contohnya, "Saya berjalan di depan dia"; "Taufiq di belakang awak";, dsb.).	**2 1 0 TT**	?
	38	Membunyikan perkataan dengan jelas tanpa membunyikan penggantiannya (contohnya, tidak kata "wabbit" untuk "rabbit", "Thally" untuk "Sally", dsb.).	**2 1 0 TT**	?
	39	Memberitahu bahagian asas sesebuah cerita, cerita dongeng, atau jalan cerita di televisyen; tidak perlu memasukkan perincian sebenar atau menceritakannya mengikut turutan.	**2 1 0 TT**	?
Umur Mula **14+**	**40**	Menyatakan bulan dan hari bagi tarikh lahir apabila ditanya.	**2 1 0 TT**	?
	41	Mengatur nada suara, bunyi, dan irama yang sepatutnya (contohnya, tidak berterusan bercakap dengan kuat, terlalu perlahan, atau satu nada sahaja, dsb.).	**2 1 0 TT**	?
	42	Memberitahu pengalaman secara terperinci (contohya, memberitahu siapa yang terlibat, di mana aktiviti berlaku, dsb.).	**2 1 0 TT**	?
	43	Memberi arahan mudah (contohnya, bagaimana untuk bermain suatu permainan atau bagaimana untuk membuat sesuatu. *Tip skor:* Tandakan "2" jika arahan sangat jelas untuk diikuti, tandakan markah "1" jika individu memberikan arahan tetapi ia tidak cukup jelas untuk diikuti; tandakan "0" jika individu tidak pernah mencuba untuk memberi arahan.	**2 1 0 TT**	?
	44	Menggunakan *antara* dalam frasa atau ayat (contohnya, "Bola bergolek antara kereta; dsb.).	**2 1 0 TT**	?
	45	Menyebut nombor telefon sendiri apabila ditanya.	**2 1 0 TT**	?
	46	Mudah beralih dari pada satu topik kepada topik yang lain ketika perbualan.	**2 1 0 TT**	?
	47	Kekal dengan sesuatu topik dalam perbualan; dan tidak menyimpang daripada topik tersebut.	**2 1 0 TT**	?
	48	Menerangkan idea dengan lebih daripada satu cara (contohnya, "Ini sebuah buku yang bagus. Ia seronok dibaca dan ceritanya menarik, dsb.).	**2 1 0 TT**	?
	49	Terlibat dalam perbualan yang berlangsung selama 10 minit (contohnya, mengaitkan pengalaman, menyumbang idea, berkongsi perasaan, dsb.).	**2 1 0 TT**	?
	50	Menggunakan kata jamak yang tidak biasa dengan betul (contohnya, kanak-kanak, angsa-angsa, tikus-tikus, perempuan-perempuan, dsb.).	**2 1 0 TT**	?
	51	Menyebut alamat rumah yang lengkap (iaitu, jalan atau lorong, nombor apartmen, bandar dan negeri), dengan atau tanpa poskod, apabila ditanya.	**2 1 0 TT**	?
	52	Menerangkan matlamat jangka pendek dan apa yang perlu dilakukannya untuk mencapainya (contohnya, dengan berkata, "Saya akan mendapatkan A dalam ujian saya, oleh itu saya akan belajar bersungguh-sungguh", dsb.).	**2 1 0 TT**	?
	53	Memberikan arahan yang rumit kepada orang lain (contohnya, lokasi yang jauh, resepi yang banyak ramuan atau langkah-langkah untuk membuatnya, dsb.). *Tip skor:* Tandakan "2" jika arahan sangat jelas untuk diikuti; tandakan markah "1" jika individu memberikan arahan tetapi ia tidak cukup jelas untuk diikuti; tandakan "0" jika individu tidak pernah mencuba untuk memberikan arahan.	**2 1 0 TT**	?
	54	Menerangkan matlamat jangka panjang yang realistik yang boleh dilakukan dalam masa 6 bulan atau lebih (contohnya, dengan berkata, " Saya hendak membeli sebuah basikal, oleh itu saya akan mengasuh kanak-kanak dan membuat kerja suruhan untuk mendapatkan cukup duit untuk membelinya", dsb.).	**2 1 0 TT**	?

Komunikasi, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau sebahagian sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu

Membaca dan Menulis							Bulatkan "?" Jika Anda Ada Soalan
Umur Mula **3-13**	**1**	Kenal satu atau lebih huruf abjad sebagai huruf dan membezakannya dengan nombor.	**2**	**1**	**0**	**TT**	?
	2	Kenal nama sendiri dalam bentuk huruf bercetak.	**2**	**1**	**0**	**TT**	?
	3	Kenal sekurang-kurangnya 10 huruf abjad bercetak.	**2**	**1**	**0**	**TT**	?
	4	Mencetak atau menulis dengan menggunakan orientasi betul (contohnya, dalam bentuk bahasa Inggeris dari kiri ke kanan; dalam sesetengah bahasa dari kanan ke kiri atau atas ke bawah).	**2**	**1**	**0**	**TT**	?
	5	Menyalin nama sendiri.	**2**	**1**	**0**	**TT**	?
	6	Kenal semua cetakan huruf abjad, huruf besar dan huruf kecil.	**2**	**1**	**0**	**TT**	?
	7	Mencetak sekurang-kurangnya tiga perkataan mudah daripada contoh (contohnya, *cat, see, bee,* dsb.)	**2**	**1**	**0**	**TT**	?
	8	Mencetak atau menulis nama sendiri dan nama penuh dengan cara mengingat.	**2**	**1**	**0**	**TT**	?
	9	Membaca sekurang-kurangnya 10 perkataan dengan kuat.	**2**	**1**	**0**	**TT**	?
	10	Mencetak sekurang-kurangnya 10 perkataan mudah dengan cara mengingat (contohnya, *hat, ball, the,* dsb.)	**2**	**1**	**0**	**TT**	?
	11	Membaca cerita ringkas dengan kuat (iaitu, cerita yang mempunyai tiga hingga lima perkataan dalam satu ayat).	**2**	**1**	**0**	**TT**	?
	12	Mencetak ayat mudah yang mempunyai tiga atau empat perkataan; mungkin membuat sedikit kesilapan ejaan atau susunan ayat.	**2**	**1**	**0**	**TT**	?
	13	Mecetak lebih daripada 20 perkataan dengan cara mengingat; mungkin membuat sedikit kesilapan ejaan.	**2**	**1**	**0**	**TT**	?
Umur Mula **14+**	**14**	Membaca dan memahami sesuatu bahan sekurang kurangnya pada tahap gred dua.	**2**	**1**	**0**	**TT**	?
	15	Membuat senarai perkataan mengikut susunan abjad.	**2**	**1**	**0**	**TT**	?
	16	Menulis sepucuk surat ringkas sekurang-kurangnya tiga ayat panjangnya (contohnya, poskad, nota terima kasih, e-mel, dsb.).	**2**	**1**	**0**	**TT**	?
	17	Membaca dan memahami sesuatu bahan sekurang-kurangnya pada tahap gred empat.	**2**	**1**	**0**	**TT**	?
	18	Menulis laporan, kertas kerja, atau esei sekurang-kurangnya satu halaman panjangnya; boleh menggunakan komputer.	**2**	**1**	**0**	**TT**	?
	19	Menulis alamat penerima dan alamat balas yang lengkap pada surat atau pakej.	**2**	**1**	**0**	**TT**	?
	20	Membaca dan memahami sesuatu perkara sekurang-kurangnya pada tahap gred enam.	**2**	**1**	**0**	**TT**	?
	21	Mengedit atau membetulkan hasil penulisan sendiri sebelum dihantar (contohnya, menyemak tanda baca, ejaan, tatabahasa, dsb.).	**2**	**1**	**0**	**TT**	?
	22	Menulis surat yang lebih panjang sekurang-kurangnya mempunyai 10 ayat; boleh menggunakan komputer.	**2**	**1**	**0**	**TT**	?
	23	Membaca dan memahami sesuatu perkara sekurang-kurangnya pada tahap gred sembilan.	**2**	**1**	**0**	**TT**	?
	24	Membaca sekurang-kurang dua artikel surat khabar setiap minggu (versi bercetak atau elektronik).	**2**	**1**	**0**	**TT**	?
	25	Menulis surat perniagaan (contohnya, meminta maklumat, membuat aduan, membuat tempahan, dsb.); boleh menggunakan komputer.	**2**	**1**	**0**	**TT**	?

Kehidupan Seharian

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau sebahagian sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu

Mengurus Diri Sendiri							Bulatkan "?" Jika Anda Ada Soalan
Umur Mula **0-8**	**1**	Membuka mulut apabila disuapkan makanan.	**2**	**1**	**0**	**TT**	?
	2	Makan makanan pejal (contohnya, sayuran yang dimasak, daging cincang, dsb.).	**2**	**1**	**0**	**TT**	?
	3	Hisap atau kunyah sendiri makanan yang boleh dipegang (contohnya, keropok, biskut, roti bakar, dsb.).	**2**	**1**	**0**	**TT**	?
	4	Minum dengan menggunakan cawan atau gelas; mungkin tumpah.	**2**	**1**	**0**	**TT**	?
	5	Memberi tahu orang bila lampin atau seluarnya basah (contohnya, menunjuk-nunjuk, berbunyi, menarik lampin, dsb.)	**2**	**1**	**0**	**TT**	?
	6	Menyuap makanan dengan sudu; mungkin tumpah.	**2**	**1**	**0**	**TT**	?
	7	Menyedut minuman dengan menggunakan straw.	**2**	**1**	**0**	**TT**	?
	8	Membuka baju yang terbuka di bahagian depan (contohnya, baju kot atau baju panas); tidak perlu membuka butang atau zip.	**2**	**1**	**0**	**TT**	?
	9	Menarik ke atas pakaian yang bergetah dipinggang (contohnya, seluar dalam atau seluar panas ketat).	**2**	**1**	**0**	**TT**	?
	10	Makan sendiri dengan menggunakan garpu; mungkin tumpah.	**2**	**1**	**0**	**TT**	?
	11	Minum dengan menggunakan cawan atau gelas tanpa menumpahkannya.	**2**	**1**	**0**	**TT**	?
	12	Menyuap makan dengan menggunakan sudu tanpa menumpahkannya.	**2**	**1**	**0**	**TT**	?
	13	Membuang air kecil di tandas atau dibekas najis.	**2**	**1**	**0**	**TT**	?
	14	Memakai pakaian yang terbuka di bahagian depan (contohnya, baju kot atau baju panas); tanpa perlu mengancing zip atau mengenakan butang.	**2**	**1**	**0**	**TT**	?
	15	Memberitahu apabila hendak ke tandas.	**2**	**1**	**0**	**TT**	?
	16	Membuang air besar di tandas atau bekas najis.	**2**	**1**	**0**	**TT**	?
	17	Terlatih ke tandas pada waktu siang. *Tip skor:* Tandakan "2" jika individu menggunakan tandas tanpa bantuan dan tiada kemalangan; Tandakan "1" jika individu menggunakan tandas dengan bantuan, seperti mengelap, atau kadangkala Kemalangan; Tandakan "0" jika individu selalu memerlukan bantuan atau kerap beralaku kemalangan.	**2**	**1**	**0**	**TT**	?
	18	Menarik zip yang telah terkancing di sebelah bawahnya (contohnya, pada seluar, pada beg galas, dsb.).	**2**	**1**	**0**	**TT**	?
	19	Lap atau hembus hidung dengan menggunakan tisu atau sapu tangan.	**2**	**1**	**0**	**TT**	?
	20	Terlatih ke tandas pada waktu malam.	**2**	**1**	**0**	**TT**	?
	21	Menyarungkan kasut pada kaki yang betul; tidak perlu mengikat talinya.	**2**	**1**	**0**	**TT**	?
	22	Memasang butang katup.	**2**	**1**	**0**	**TT**	?
Umur Mula **9+**	**23**	Memegang sudu, garpu dan pisau dengan betul.	**2**	**1**	**0**	**TT**	?
	24	Membasuh dan mengeringkan muka dengan menggunakan sabun dan air.	**2**	**1**	**0**	**TT**	?
	25	Memberus gigi. *Tip skor:* Tandakan "2" jika individu memberus gigi tanpa bantuan, termasuk meletakkan ubat gigi pada berus gigi, dan tanpa perlu diberitahu supaya memberus giginya; tandakan "1" jika individu memerlukan bantuan untuk memberus atau meletak ubat gigi atau kerap memerlukan peringatan; tandakan "0" jika individu tidak pernah memberus gigi tanpa bantuan atau tanpa peringatan.	**2**	**1**	**0**	**TT**	?
	26	Mengenakan butang yang besar di bahagian hadapan pakaian, dengan memasukkannya ke dalam lubang butang yang betul.	**2**	**1**	**0**	**TT**	?
	27	Menutup mulut dan hidung apabila batuk dan bersin.	**2**	**1**	**0**	**TT**	?

Kehidupan Seharian, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau Sebahagian Sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu **T/P** = Tiada Peluang

Mengurus Diri Sendiri, ***sambungan***			Bulatkan "?" Jika Anda Ada Soalan
28	Mengenakan butang yang kecil di bahagian hadapan pakaian, dengan memasukkannya ke dalam lubang butang yang betul.	2 1 0 TT	?
29	Menyambung dan mengenakan zip yang tidak berkancing di sebelah bawahnya (contohnya, jaket, baju panas, dsb.).	2 1 0 TT	?
30	Membuka kepala paip dan menyelaraskan suhu untuk air panas atau air sejuk.	2 1 0 TT	?
31	Memakai pakaian yang sesuai pada ketika hujan atau sejuk (contohnya, baju hujan, kasut but, baju panas, dsb.).	2 1 0 TT	?
32	Mandi dan mengeringkan badan sendiri. *Tip skor:* Tandakan "2" jika iindividu mandi tanpa bantuan, termasuk membuka dan menutup air; tandakan jika individu memerlukan sebarang bantuan semasa mandi atau mengeringkan badan atau membuka dan menutup air; tandakan "0" jika individu tidak pernah mandi tanpa memerlukan bantuan atau peringatan.	2 1 0 TT	?
33	Mencari dan menggunakan tandas awam yang sesuai mengikut jantinanya.	2 1 0 TT	?
34	Membasuh dan mengeringkan rambut (dengan tuala atau alat pengering rambut).	2 1 0 TT	?
35	Merawat luka kecil (contohnya, membersihkan luka, membalut luka,dsb.).	2 1 0 TT	?
36	Memakan ubat seperti yang diarahkan (iaitu, mengikut arahan pada label ubat).	2 1 0 TT	?
37	Menggunakan termometer untuk mengambil suhu sendiri atau orang lain.	2 1 0 TT	?
38	Mendapatkan bantuan perubatan ketika kecemasan (contohnya, mengenal pasti tanda penyakit atau kecederaan serius, seperti sesak nafas, sakit dada, pendarahan yang tidak terkawal, dsb.). *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika individu tidak berada dalam rawatan kecemasan.	2 1 0 TT	?
39	Mengikut arahan prosedur jagaan kesihatan, diet khusus, atau rawatan perubatan. *Tip skor:* Anda boleh menandakan "T/P bagi Tiada Peluang jika individu tidak mempunyai masalah kesihatan yang memerlukan prosedur khas, diet atau rawatan.	2 1 0 TT	?
40	Sentiasa memastikan ubatannya mencukupi (yang dipreskripsi dan yang tidak dipreskripsi) dan diisi semula apabila diperlukan.	2 1 0 TT	?
41	Membuat temu janji bagi rawatan biasa dan pemeriksaan gigi.	2 1 0 TT	?

Mengurus Rumah			Bulatkan "?" Jika Anda Ada Soalan
Umur Mula **1-13**	1 Berhati-hati dengan benda panas (contohnya, dapur atau ketuhar, pembakaran terbuka ,dsb.).	2 1 0 TT	?
	2 Membantu tugas rumah yang mudah (contohnya, membuang habuk, mengutip pakaian atau mainan, memberi makan haiwan kesayangan, dsb.).	2 1 0 TT	?
	3 Membersihkan barang yang tidak mudah pecah di tempat sendiri di atas meja.	2 1 0 TT	?
	4 Membersihkan kawasan bekerja atau tempat bermain sendiri setelah selesai melakukan aktiviti (contohnya, melukis menggunakan jari, membina model, dsb.).	2 1 0 TT	?
	5 Menyimpan semula barang milik sendiri (contohnya, barang mainan, buku, majalah, dsb.).	2 1 0 TT	?
	6 Berhati-hati semasa menggunakan benda tajam (contohnya, gunting, pisau, dsb.).	2 1 0 TT	?
Umur Mula **14+**	7 Membersihkan barang yang boleh pecah di tempat sendiri di atas meja.	2 1 0 TT	?
	8 Menolong menyediakan makanan yang perlu diadun dan dimasak (contohnya, kek atau adunan biskut, makaroni dan keju, dsb.).	2 1 0 TT	?
	9 Menggunakan peralatan dapur yang mudah (contohnya, pembakar roti, pembuka tin, pembuka botol, dsb.).	2 1 0 TT	?

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau Sebahagian Sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu **T/P** = Tiada Peluang

Mengurus Rumah, *sambungan*

			Bulatkan "?" Jika Anda Ada Soalan
10	Menggunakan ketuhar mikrogelombang untuk memanaskan, membakar, atau memasak makanan (iaitu, mengeset masa dan melaraskan kuasa, dsb.). *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika tiada ketuhar mikrogelombang di rumah.	**2 1 0 TT**	?
11	Meletakkan pakaian yang bersih pada tempat yang sepatutnya (contohnya, dalam laci atau almari, digantung, dsb.).	**2 1 0 TT**	?
12	Menggunakan peralatan (contohnya, penukul untuk mengetuk paku, skrudriver untuk menskru dan menanggalkan skru, dsb.).	**2 1 0 TT**	?
13	Membasuh pinggan mangkuk dengan tangan, atau meletakkannya ke dalam mesin cuci pinggan mangkuk dan memulakan basuhan.	**2 1 0 TT**	?
14	Menyapu, mengemop, atau memvakum lantai sebersih-bersihnya. *Tip skor:* Tandakan "2" jika individu mengemop, menyapu atau memvakum sangat baik dan kerja itu tidak perlu dilakukan semula; tandakan "1" jika individu tidak menyiapkan kerja itu secara konsisten dan baik; tandakan "0" jika individu tidak pernah mengemop, menyapu atau memvakum, atau tidak melakukan kerja itu dengan baik dan ia perlu dilakukan semula.	**2 1 0 TT**	?
15	Membersihkan meja dengan sempurna (contohnya, membuang sisa makanan dari pinggan mangkuk dan menyusun pinggan mangkuk secara bertindan, membuang benda yang tidak perlu, dsb.).	**2 1 0 TT**	?
16	Menggunakan barangan rumah dengan betul (contohnya, serbuk pencuci, pengilap perabot, pencuci kaca, dsb.).	**2 1 0 TT**	?
17	Menyediakan makanan asas yang tidak perlu diadun tetapi perlu dimasak (contohnya, nasi, sup, sayuran, dsb.).	**2 1 0 TT**	?
18	Membersihkan satu atau lebih bilik selain bilik tidur sendiri.	**2 1 0 TT**	?
19	Menggunakan pisau yang tajam untuk menyediakan makanan.	**2 1 0 TT**	?
20	Menggunakan dapur atau ketuhar untuk memanaskan, membakar, atau memasak (iaitu, menyalakan dan mematikan api dapur, mengawal suhu ketuhar, dsb.).	**2 1 0 TT**	?
21	Menyediakan makanan daripada bahan ramuan yang perlu disukat, diadun dan dimasak.	**2 1 0 TT**	?
22	Membasuh pakaian apabila perlu.	**2 1 0 TT**	?
23	Melakukan tugas penyelenggaraan apabila perlu (contohnya, menggantikan mentol lampu, menukar beg pembersih vakum, dsb.).	**2 1 0 TT**	?
24	Merancang dan menyediakan hidangan utama bagi hari tersebut.	**2 1 0 TT**	?

Kehidupan Dalam Masyarakat

Umur Mula			Bulatkan "?" Jika Anda Ada Soalan
1-9	**1**	Menunjukkan pemahaman mengenai fungsi telefon (contohnya, berpura-pura bercakap di telefon, dsb.).	**2 1 0 TT** ?
	2	Berbual dengan orang yang dikenali di telefon.	**2 1 0 TT** ?
	3	Menggendalikan TV atau radio tanpa bantuan (contohnya, menghidupkan peralatan, mencari saluran atau stesen, memilih rancangan, dsb.). *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika TV atau radio tiada di rumah.	**2 1 0 TT** ? **T/P**
	4	Mengira sekurang-kurangnya 10 benda, satu demi satu.	**2 1 0 TT** ?
	5	Berhati-hati dan menunjukkan kelakuan yang sepatutnya semasa menaiki kereta (contohnya memasang tali keledar, tidak mengganggu pemandu, dsb.).	**2 1 0 TT** ?
	6	Menunjukkan pemahaman mengenai fungsi wang (contohnya, dengan berkata "wang diperlukan untuk membeli barang di pasar raya"; dsb.).	**2 1 0 TT** ?
	7	Menggunakan laluan pejalan kaki (jika ada) atau bahu jalan apabila berjalan kaki atau menggunakan peralatan beroda (kasut roda, skuter, trisikal, dsb.).	**2 1 0 TT** ?

Kehidupan Seharian, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau Sebahagian Sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu **T/P** = Tiada Peluang

Kehidupan Dalam Masyarakat, sambungan				Bulatkan "?" Jika Anda Ada Soalan
	8	Menunjukkan pemahaman mengenai fungsi jam (contohnya, dengan berkata, "Jam memberitahu masa"; "Pukul berapa kita boleh pergi?"; dsb.)	2 1 0 TT	?
	9	Mematuhi peraturan di rumah (contohnya, tidak berlari di dalam rumah, tidak melompat di atas perabot, dsb.).	2 1 0 TT	?
	10	Menunjukkan kemahiran komputer yang perlu untuk bermain permainan komputer atau memulakan program komputer dengan komputer yang telah dihidupkan; tidak perlu menghidupkan komputer sendiri. *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika tiada komputer di rumah.	2 1 0 TT T/P	?
	11	Memanggil orang yang dihubungi melalui telefon atau memberitahu yang orang itu tiada.	2 1 0 TT	?
Umur Mula **10-15**	12	Kenal duit syiling apabila ditanya; tidak perlu tahu nilai duit siling tersebut.	2 1 0 TT	?
	13	Melihat kedua-dua belah hala jalan apabila melintas jalan.	2 1 0 TT	?
	14	Memberitahu hari apabila ditanya.	2 1 0 TT	?
	15	Menunjukkan pemahaman mengenai hak privasi bagi dirinya sendiri dan orang lain (contohnya, semasa menggunakan tandas atau menyalin pakaian, dsb.).	2 1 0 TT	?
	16	Menunjukkan pengetahuan mengenai nombor untuk dihubungi ketika kecemasan apabila ditanya.	2 1 0 TT	?
	17	Memberitahu masa dengan melihat jam digital.	2 1 0 TT	?
	18	Menyatakan nilai 1 sen, 5 sen, 10 sen, dan 20 sen.	2 1 0 TT	?
	19	Membezakan wang kertas bagi nilai yang berbeza (contohnya, merujuk wang RM1, RM5, dsb., dalam perbualan; dsb.).	2 1 0 TT	?
	20	Mematuhi lampu isyarat dan isyarat *Berjalan* dan *Berhenti.*	2 1 0 TT	?
	21	Menunjukkan tarikh hari bulan hari itu atau tarikh lain pada kalander jika ditanya.	2 1 0 TT	?
	22	Menunjukkan pemahaman bahawa sesetengah item lebih mahal daripada yang lain (contohnya, dengan berkata, "Saya mempunyai wang yang cukup untuk membeli gula-gula getah tetapi tak cukup untuk gula-gula"; "Pensel yang manakah yang murah?"; dsb.).	2 1 0 TT	?
Umur Mula **16+**	23	Memberitahu masa dalam selang setengah jam dengan melihat jam analog (contohnya, 1:30, 2:00, dsb.).	2 1 0 TT	?
	24	Membuat panggilan telefon kepada orang lain, dengan menggunakan telefon tetap atau telefon bimbit.	2 1 0 TT	?
	25	Menempah hidangan lengkap di restoran makanan segera. *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika individu tidak pernah makan di restoran makanan segera.	2 1 0 TT T/P	?
	26	Membawa atau menyimpan wang dengan selamat (contohnya, dalam dompet, beg duit, tali pinggang berpoket, dsb.).	2 1 0 TT	?
	27	Memberitahu masa dalam segmen lima minit dengan melihat jam analog (contohnya, 1:05, 1:10, dsb.).	2 1 0 TT	?
	28	Mematuhi masa keluar malam yang ditentukan oleh ibu bapa atau penjaga.	2 1 0 TT	?
	29	Melihat atau mendengar program bagi mendapatkan maklumat (contohnya, ramalan cuaca, berita, program pendidikan dsb.). *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika tiada TV atau radio di rumah.	2 1 0 TT T/P	?
	30	Mengira bayaran balik daripada sesuatu pembelian.	2 1 0 TT	?
	31	Menunjukkan kemahiran komputer yang perlu untuk melaksanakan tugas yang kompleks (contohnya, *word processing*, melayari Internet, memasang perisian, dsb.). *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika tiada komputer di rumah.	2 1 0 TT T/P	?
	32	Menilai kualiti dan harga apabila memilih item yang dibeli.	2 1 0 TT	?
	33	Mematuhi had masa rehat (contohnya, waktu makan tengah hari atau waktu minum, dsb.).	2 1 0 TT	?

Kehidupan Seharian, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau Sebahagian Sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu **T/P** = Tiada Peluang

Kehidupan Dalam Masyarakat, sambungan		Bulatkan "?" Jika Anda Ada Soalan
34	Mengembara sekurang-kurangnya 5 hingga 10 batu ke destinasi yang biasa (iaitu, berbasikal, menggunakan kenderaan awam, atau memandu sendiri).	2 1 0 TT ?
35	Menunjukkan pemahaman mengenai hak untuk mengadu atau melaporkan masalah yang munasabah apabila tidak berpuas hati dengan perkhidmatan atau sesuatu situasi.	2 1 0 TT ?
36	Memberitahu sekolah atau penyelia apabila dia akan datang lambat atau tidak dapat hadir.	2 1 0 TT ?
37	Menggunakan simpanan atau memeriksa akaun dengan bertanggungjawab (contohnya, menyimpan sebahagian wang dalam akaun, menyemak baki dengan teliti, dsb.).	2 1 0 TT ?
38	Mengembara sekurang-kurangnya 5 hingga 10 batu ke destinasi yang tidak biasa (iaitu, dengan berbasikal, menggunakan pengangkutan awam, atau memandu sendiri).	2 1 0 TT ?
39	Memperoleh wang hasil kerja sambilan (iaitu, sekurang-kurangnya 10 jam seminggu) dalam masa setahun. *Tip skor:* Jangan tandakan 1.	2 ~~1~~ 0 TT ?
40	Mencuba untuk menambah baik prestasi kerja selepas menerima kritikan membina daripada penyelia. *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika individu tidak mempunyai pekerjaan.	2 1 0 TT ?
41	Mengurus wang sendiri (contohnya, membayar hampir semua atau semuanya sekali pembelanjaan diri, menggunakan cek atau kiriman wang bagi membuat bayaran seperti yang dikehendaki, dsb.).	2 1 0 TT ?
42	Mempunyai pekerjaan sepenuh masa selama setahun. *Tip skor:* Jangan tandakan 1.	2 ~~1~~ 0 TT ?
43	Membuat belanjawan mengikut perbelanjaan bulanan (contohnya, utiliti, sewa, dsb.).	2 1 0 TT ?
44	Memohon dan menggunakan kad kredit peribadi dengan bertanggungjawab (contohnya, tidak melebihi had kredit, membuat pembayaran mengikut tempoh yang ditetapkan, dsb.).	2 1 0 TT ?

Kemahiran sosial dan Perhubungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau sebahagian sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu

Hubungan Dengan Orang Lain							**Bulatkan "?" Jika Anda Ada Soalan**
Umur Mula **0-4**	**1**	Memandang wajah ibu bapa atau penjaga.	**2**	**1**	**0**	**TT**	?
	2	Memandang (iaitu, mengikuti dengan pergerakan mata) seseorang yang bergerak dari katil bayi atau katil selama 5 saat atau lebih.	**2**	**1**	**0**	**TT**	?
	3	Menunjukkan dua atau lebih emosi (contohnya, ketawa, menangis, menjerit, dsb.).	**2**	**1**	**0**	**TT**	?
	4	Tersenyum atau membuat bunyi apabila didekati oleh orang yang dikenali.	**2**	**1**	**0**	**TT**	?
	5	Membuat atau mencuba membuat hubungan sosial (contohnya, tersenyum, membuat bising, dsb.).	**2**	**1**	**0**	**TT**	?
	6	Menjangkau kearah orang yang dikenali apabila orang itu menghulurkan tangan ke arahnya.	**2**	**1**	**0**	**TT**	?
	7	Menunjukkan kecenderungan lebih suka kepada orang dan benda tertentu (contohnya, tersenyum, cuba menjangkau atau bergerak ke arah orang atau benda itu, dsb.).	**2**	**1**	**0**	**TT**	?
	8	Menunjukkan kasih sayang terhadap orang yang dikenali (contohnya, menyentuh, memeluk, mencium, mendakap, dsb.).	**2**	**1**	**0**	**TT**	?
	9	Meniru atau cuba meniru ekspresi muka ibu bapa atau penjaga (contohnya, tersenyum, berkerut, dsb.).	**2**	**1**	**0**	**TT**	?
	10	Bergerak mencari ibu bapa atau penjaga atau orang lain yang dikenali yang berada berdekatan.	**2**	**1**	**0**	**TT**	?
	11	Menunjukkan minat terhadap kanak-kanak yang sama umur, selain daripada adik-beradik sendiri (contohnya, memandang mereka, tersenyum pada mereka, dsb.).	**2**	**1**	**0**	**TT**	?
Umur Mula **5-15**	**12**	Meniru pergerakan mudah (contohnya, bertepuk tangan, melambai selamat tinggal, dsb.).	**2**	**1**	**0**	**TT**	?
	13	Menggunakan aksi untuk menunjukkan kegembiraan atau kebimbangan terhadap orang lain (contohannya, memeluk, menepuk lengan, memegang tangan, dsb.).	**2**	**1**	**0**	**TT**	?
	14	Menunjukkan keinginan untuk menggembirakan orang lain (contohnya, berkongsi makanan ringan atau permainan, cuba membantu walaupun tidak mampu, dsb.).	**2**	**1**	**0**	**TT**	?
	15	Menunjukkan kelakuan mencari hubungan dengan orang lain yang sama umur (contohnya, dengan berkata, "Awak nak main?" atau memimpin tangan seorang kanak-kanak lain, dsb.).	**2**	**1**	**0**	**TT**	?
	16	Meniru tindakan yang agak rumit ketika tindaakan tersebut sedang dilakukan oleh orang lain (contohnya, bercukur, memakai alat solek, menukul paku, dsb.).	**2**	**1**	**0**	**TT**	?
	17	Menjawab apabila orang dewasa yang dikenali membuat teguran ringkas (contohnya, jika ditanya, "Apa khabar?" jawabnya "Saya sihat", jika diberitahu, "Awak kelihatan cantik,", jawabnya, "Terima kasih"; dsb.).	**2**	**1**	**0**	**TT**	?
	18	Mengulang frasa yang pernah didengar daripada seorang dewasa (contohnya, "Sayang, saya dah balik"; "Tak boleh makan pencuci mulut selagi awak tak bersihkan pinggan awak"; dsb.).	**2**	**1**	**0**	**TT**	?
	19	Menggunakan perkataan untuk menyatakan emosi sendiri (contohnya, "Saya gembira"; "Saya takut"; dsb.).	**2**	**1**	**0**	**TT**	?
	20	Mempunyai kawan baik atau menunjukkan kecenderungan memilih siapa kawan yang ia lebih suka (atau jantina yang lain) berbanding kawan lain.	**2**	**1**	**0**	**TT**	?
	21	Meniru tindakan yang agak rumit selepas beberapa jam melihat seseorang melakukannya (contohnya, bercukur, memakai alat solek, menukul paku, dsb.).	**2**	**1**	**0**	**TT**	?
	22	Menggunakan perkataan untuk menyatakan kegembiraan atau kebimbangan kepada yang lain (contohnya, dengan berkata "Yeah! Awak menang"; "Awak tidak apa-apa ke?"; dsb.).	**2**	**1**	**0**	**TT**	?
	23	Bertindak apabila orang lain memerlukan bantuan (contohnya, membuka pintu, mengambil benda yang jatuh, dsb.).	**2**	**1**	**0**	**TT**	?
	24	Mengetahui perkara yang seseorang itu suka dan tidak suka (contohnya, dengan berkata, "Chow suka bola sepak"; Suzana tak suka makan piza"; dsb.).	**2**	**1**	**0**	**TT**	?
	25	Menunjukkan tahap emosi yang sama yang dialami oleh orang lain di sekelilingnya (contohnya, tidak mengheboh-hebohkan atau berkelakuan berlebih-lebihan terhadap sesuatu situasi, dsb.).	**2**	**1**	**0**	**TT**	?
	26	Berada dalam jarak kedudukan yang selesa antara orang lain dalam situasi sosial (contohnya, tidak berada terlalu dekat dengan orang lain ketika bercakap, dsb.).	**2**	**1**	**0**	**TT**	?

Kemahiran sosial dan Perhubungan, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau sebahagian sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu

Hubungan Dengan Orang Lain, sambungan						Bulatkan "?" Jika Anda Ada Soalan
	27	Bercakap dengan seseorang tentang minat yang sama (contohnya, sukan, rancangan TV, percutian, dsb.).	2	1	0 TT	?
	28	Memulakan teguran ringkas apabila berjumpa dengan orang yang ia kenali (contohnya, dengan berkata, "Apa khabar?"; "Bagaimana sekarang?"; dsb.).	2	1	0 TT	?
	29	Kerap berjumpa dengan kawan.	2	1	0 TT	?
	30	Memilih untuk tidak berkata sesuatu yang memalukan atau kata-kata kesat atau bertanyakan soalan yang biadab ketika berada dikalangan orang ramai.	2	1	0 TT	?
	31	Mewujudkan hubungan persahabatan yang sewajarnya (contohnya, tidak mengharapkan agar dia merupakan satu-satunya kawan kepada seseorang atau mengharapkan kawannya sentiasa dapat meluangkan masa bersamanya, dsb.).	2	1	0 TT	?
	32	Memahami bahawa orang lain tidak tahu apa yang ia fikirkan melainkan ia menyatakannya.	2	1	0 TT	?
	33	Berhati-hati apabila memperkatakan sesuatu yang bersifat peribadi.	2	1	0 TT	?
	34	Bekerjasama dengan orang lain untuk merancang atau melibatkan diri dalam aktiviti (contohnya, parti hari jadi, acara sukan, dsb.).	2	1	0 TT	?
	35	Menunjukkan yang ia memahami isyarat atau bahasa kiasan dalam perbualan (contohnya, tahu bahawa menguap itu boleh membawa maksud, "Saya bosan," atau cepat menukar tajuk yang sedang diperkatakan mungkin bermaksud, "Saya tak mahu bercakap tentang perkara itu"; dsb.).	2	1	0 TT	?
	36	Memulakan perbualan dengan bercakap tentang perkara yang menarik perhatian orang lain (contohnya, "Zana beritahu saya yang awak suka komputer"; dsb.).	2	1	0 TT	?
	37	Melibatkan diri dalam temujanji berkumpulan.	2	1	0 TT	?
	38	Melibatkan diri dalam temujanji secara individu.	2	1	0 TT	?

Bermain dan Menggunakan Masa Lapang						Bulatkan "?" Jika Anda Ada Soalan
Umur Mula **0-7**	1	Memberi respons apabila ibu bapa atau penjaga bergurau (contohnya, tersenyum, ketawa, bertepuk tangan, dsb.).	2	1	0 TT	?
	2	Menunjukkan minat untuk meneroka sesuatu tempat yang ia berada (contohnya, memandang atau bergerak sekeliling, menyentuh benda atau orang, dsb.).	2	1	0 TT	?
	3	Bermain permainan interaksi yang mudah dengan orang lain (contohnya, bermain ba ba cak, tepuk amai-amai, dsb.).	2	1	0 TT	?
	4	Bermain berdekatan kanak-kanak lain, setiap orang membuat perkara yang berbeza.	2	1	0 TT	?
	5	Memilih untuk bermain dengan kanak-kanak lain (contohnya, tidak terasing daripada kumpulan atau menjauhi orang lain).	2	1	0 TT	?
	6	Bermain bersama-sama dengan seorang kanak-kanak atau lebih selama 5 minit.	2	1	0 TT	?
	7	Bermain bersama-sama dengan lebih daripada seorang kanak-kanak selama lebih daripada 5 minit.	2	1	0 TT	?
	8	Terus bermain dengan kanak-kanak lain dengan hanya sedikit sungutan apabila ibu bapa atau penjaga meninggalkannya.	2	1	0 TT	?
	9	Berkongsi barang mainan atau barang miliknya apabila diminta.	2	1	0 TT	?
Umur Mula **8-15**	10	Bermain dengan orang lain dengan pengawasan yang minimum.	2	1	0 TT	?
	11	Menggunakan peralatan rumah yang biasa atau benda lain untuk membuat sesuatu aktiviti seperti sebenar (contohnya, berpura-pura bahawa sebuah blok seolah-olah sebuah kereta, sebuah kotak seolah-olah sebuah rumah, dsb.).	2	1	0 TT	?
	12	Melindungi diri dengan beredar daripada seseorang yang memusnahkan benda atau menyebabkan kecederaan (contohnya, mereka yang suka menggigit, memukul, membaling benda, menarik rambut, dsb.).	2	1	0 TT	?
	13	Bermain aktiviti macam sebenar yang mudah dengan orang lain (contohnya, bermain merias diri, memakai pakaian seperti seorang wira, dsb.).	2	1	0 TT	?

Kemahiran sosial dan Perhubungan, sambungan

Pilihan Respons: 2 = Selalu, 1 = Kadang-kadang atau sebahagian sahaja, 0 = Tidak pernah, TT = Tidak Tahu

Bermain dan Menggunakan Masa Lapang, *bersambung*						Bulatkan "?" Jika Anda Ada Soalan
	14	Mencari orang lain untuk bermain atau sebagai teman (contohnya, menjemput orang lain ke rumah, pergi ke rumah orang lain, bermain dengan orang lain di padang permainan, dsb.).	2	1	0	TT	?
	15	Menunggu giliran apabila diminta semasa bermain suatu permainan atau sukan.	2	1	0	TT	?
	16	Bermain permainan berkumpulan tak rasmi di luar rumah (contohnya, main kejar-kejar, lompat tali, dsb.).	2	1	0	TT	?
	17	Berkongsi barang permainan atau milik sendiri tanpa perlu diminta.	2	1	0	TT	?
	18	Mengikut peraturan dalam permainan mudah (lari berganti-ganti, permainan elektronik, dsb.).	2	1	0	TT	?
	19	Mengikut giliran tanpa perlu disuruh.	2	1	0	TT	?
	20	Bermain kad atau permainan papan yang mudah yang bergantung pada nasib (contohnya, Dam Ular, dsb.).	2	1	0	TT	?
	21	Keluar dengan kawan-kawan disiang hari dengan pengawasan orang dewasa (contohnya, pergi membeli-belah, ke taman, pusat komuniti, dsb.).	2	1	0	TT	?
Umur Mula **16+**	22	Meminta izin sebelum menggunakan sesuatu barang kepunyaan orang lain atau yang sedang digunakan oleh orang lain.	2	1	0	TT	?
	23	Tidak melibatkan diri dalam sesuatu kumpulan apabila ada isyarat tanpa suara yang menunjukkan bahawa ia tidak diterima ke dalam kumpulan itu.	2	1	0	TT	?
	24	Bermain permainan mudah yang memerlukannya menyimpan markah (contohnya, menendang bola, mengutip bola jaring, dsb.).	2	1	0	TT	?
	25	Menunjukkan semangat kesukanan yang baik (iaitu, mematuhi peraturan, tidak terlalu agresif, mengucapkan tahniah kepada pasukan yang menang, dan tidak marah apabila kalah).	2	1	0	TT	?
	26	Bermain lebih daripada satu permainan papan, kad atau elektronik yang memerlukan kemahiran dan membuat keputusan (contohnya, *Monopoly™, Cribbage*, dsb.).	2	1	0	TT	?
	27	Keluar dengan kawan-kawan pada sebelah malam dengan pengawasan orang dewasa (contohnya, ke konsert, mendengar ceramah, acara sukan, menonton wayang, dsb.).	2	1	0	TT	?
	28	Mematuhi peraturan dalam permainan atau sukan yang sukar (contohnya, bola sepak, bola tampar, dsb.).	2	1	0	TT	?
	29	Keluar dengan kawan-kawan disiang hari tanpa pengawasan orang dewasa (contohnya, pergi ke pusat beli-belah, taman, pusat komuniti, dsb.).	2	1	0	TT	?
	30	Merancang aktiviti yang menyeronokkan yang perlu menguruskan lebih daripada dua perkara (contohnya, rombongan ke pantai atau taman yang perlu menguruskan pengangkutan, makanan, peralatan rekreasi, dsb.).	2	1	0	TT	?
	31	Keluar dengan kawan-kawan pada sebelah malam tanpa pengawasan orang dewasa (contohnya, ke konsert, mendengar ceramah, acara sukan, menonton wayang, dsb.).	2	1	0	TT	?

Kemahiran sosial dan Perhubungan, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau sebahagian sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu

Penyesuaian							**Bulatkan "?" Jika Anda Ada Soalan**
Umur Mula **1+**	**1**	Mudah berubah daripada satu aktiviti di rumah kepada aktiviti yang lain.	**2**	**1**	**0**	**TT**	?
	2	Mengucapkan "terima kasih" apabila diberikan sesuatu.	**2**	**1**	**0**	**TT**	?
	3	Menukar kelakuan bergantung kepada berapa rapat ia mengenali seseorang itu (contohnya, berkelakuan berbeza dengan anggota keluarga berbanding dengan orang yang tidak dikenali, dsb.).	**2**	**1**	**0**	**TT**	?
	4	Mengunyah dengan mulut tertutup.	**2**	**1**	**0**	**TT**	?
	5	Berkata "tolonglah" apabila meminta sesuatu.	**2**	**1**	**0**	**TT**	?
	6	Mengakhiri perbualan dengan sewajarnya (contohnya, berkata, "Selamat Tinggal"; "Jumpa Lagi"; dsb.).	**2**	**1**	**0**	**TT**	?
	7	Membersihkan atau mengelap muka dan tangan ketika atau selepas makan.	**2**	**1**	**0**	**TT**	?
	8	Memberi respons sepatutnya terhadap perubahan rutin yang munasabah (contohnya, tidak mengadu, dsb.).	**2**	**1**	**0**	**TT**	?
	9	Memohon maaf apabila ia melakukan kesalahan yang tidak disengajakan (contohnya, terlanggar seseorang, dsb.).	**2**	**1**	**0**	**TT**	?
	10	Tidak mencemuh, mengusik atau membuli orang.	**2**	**1**	**0**	**TT**	?
	11	Bertindak sepatutnya apabila diperkenalkan kepada orang yang tidak dikenali (contohnya, mengangguk, tersenyum, bersalam, menegur mereka, dsb.).	**2**	**1**	**0**	**TT**	?
	12	Menukar nada suara bergantung pada lokasi atau situasi (contohnya, dalam perpustakaan, semasa menonton wayang atau bermain, dsb.).	**2**	**1**	**0**	**TT**	?
	13	Memohon maaf apabila ia melukakan perasaan seseorang.	**2**	**1**	**0**	**TT**	?
	14	Tidak bercakap ketika makanan berada di dalam mulut.	**2**	**1**	**0**	**TT**	?
	15	Bercakap dengan orang lain tanpa mengganggunya atau berlaku biadap.	**2**	**1**	**0**	**TT**	?
	16	Menerima cadangan atau penyelesaian yang membantu daripada orang lain.	**2**	**1**	**0**	**TT**	?
	17	Mengawal perasaan marah atau tergores hati apabila rancangan bertukar atas alasan yang tidak boleh dielakkan (contohnya, cuaca buruk, kereta rosak, dsb.).	**2**	**1**	**0**	**TT**	?
	18	Menyimpan rahsia atau kepercayaan selama lebih dari sehari.	**2**	**1**	**0**	**TT**	?
	19	Memohon maaf apabila ia membuat kesalahan atau kesilapan secara tidak sengaja ketka membuat pertimbangan (contohnya, apabila secara tidak sengaja telah tidak melibatkan seseorang dalam permainan, dsb.).	**2**	**1**	**0**	**TT**	?
	20	Menunjukkan memahami bahawa usikan manja antara keluarga dan kawan-kawan boleh merupakan satu bentuk gurauan atau kemesraan.	**2**	**1**	**0**	**TT**	?
	21	Memberitahu ibu bapa atau penjaga tentang rancangannya (contohnya, pukul berapa ia akan pergi atau balik, ke mana ia akan pergi, dsb.).	**2**	**1**	**0**	**TT**	?
	22	Memilih untuk mengelak daripada aktiviti berbahaya atau berisiko (contohnya, melompat dari tempat tinggi, menumpangkan pengembara, memandu secara berbahaya, dsb.).	**2**	**1**	**0**	**TT**	?
	23	Mengawal perasaan marah atau tergores hati apabila kehendaknya tidak dapat dituruti (contohnya, apabila tidak dibenarkan menonton televisyen atau menghadiri parti; apabila cadangannya ditolak oleh kawan atau penyelia; dsb.).	**2**	**1**	**0**	**TT**	?
	24	Mengikut apa yang telah diatur (contohnya, jika berjanji untuk menemui seseorang, berjumpalah dengan orang itu, dsb.).	**2**	**1**	**0**	**TT**	?
	25	Menamatkan atau menjauhi hubungan atau situasi yang melukakan hati atau berbahaya (contohnya, dibuli atau dipersendakan, diambil kesempatan dari segi seks atau kewangan, dsb.).	**2**	**1**	**0**	**TT**	?
	26	Mengawal perasaan marah atau tergores hati disebabkan kritikan yang membina (contohnya, membaiki kelakuan yang buruk, membincangkan markah atau gred ujian, kajian semula prestasi, dsb.).	**2**	**1**	**0**	**TT**	?
	27	Menyimpan rahsia atau kepercayaan selama mana yang dikehendaki.	**2**	**1**	**0**	**TT**	?
	28	Memikirkan apa yang boleh berlaku sebelum membuat keputusan (contohnya, tidak bertindak mengikut gerak hati, memikirkan maklumat yang penting, dsb.).	**2**	**1**	**0**	**TT**	?
	29	Menyedari potensi bahaya dan berhati-hati apabila bertemu dengan situasi sosial berisiko (contohnya, parti minuman liar, bilik sembang Internet, iklan peribadi, dsb.).	**2**	**1**	**0**	**TT**	?
	30	Menunjukkan hormat kepada teman sekerja (contohnya, tidak mengganggu orang lain yang sedang bekerja, hadir mesyuarat tepat pada masanya, dsb.).	**2**	**1**	**0**	**TT**	?

Aktiviti Fizikal

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau Sebahagian Sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu **T/P** = Tiada Peluang

Menggunakan Otot Besar							**Bulatkan "?" Jika Anda Ada Soalan**
Umur Mula **0-1**	**1**	Menegakkan kepala sekurang-kurangnya selama 15 saat apabila didokong secara menegak oleh ibu bapa atau penjaga.	**2**	**1**	**0**	**TT**	?
	2	Duduk dengan sokongan (contohnya, di atas kerusi, dengan bantal, dsb.) sekurang-kurangnya selama 1 minit.	**2**	**1**	**0**	**TT**	?
	3	Duduk tanpa sokongan selama sekurang-kurangnya 1 minit.	**2**	**1**	**0**	**TT**	?
	4	Merayap atau bergerak dengan perutnya di atas lantai.	**2**	**1**	**0**	**TT**	?
	5	Duduk tanpa sokongan sekurang-kurangnya selama 10 minit.	**2**	**1**	**0**	**TT**	?
	6	Mengangkat dirinya untuk duduk dan duduk tanpa sokongan sekurang-kurangnya selama 1 minit.	**2**	**1**	**0**	**TT**	?
	7	Merangkak sekurang-kurangnya 5 kaki jauhnya dengan menggunakan tangan dan lutut, tanpa perut mencecah lantai.	**2**	**1**	**0**	**TT**	?
	8	Bangun untuk berdiri.	**2**	**1**	**0**	**TT**	?
	9	Merangkak menaiki tangga.	**2**	**1**	**0**	**TT**	?
	10	Melangkah sekurang-kurangnya dua langkah.	**2**	**1**	**0**	**TT**	?
	11	Berdiri sendiri selama 1 hingga 3 minit.	**2**	**1**	**0**	**TT**	?
	12	Menggolekkan bola semasa duduk.	**2**	**1**	**0**	**TT**	?
	13	Memanjat naik dan turun objek yang rendah (contohnya, kerusi, bangku tangga, cerun, dsb.)	**2**	**1**	**0**	**TT**	?
	14	Merangkak menuruni tangga.	**2**	**1**	**0**	**TT**	?
	15	Berdiri sekurang-kurangnya selama 5 minit.	**2**	**1**	**0**	**TT**	?
Umur Mula **2-4**	**16**	Berjalan menyeberang bilik; mungkin terhuyung-hayang dan kadangkala jatuh.	**2**	**1**	**0**	**TT**	?
	17	Membaling bola.	**2**	**1**	**0**	**TT**	?
	18	Berjalan sekeliling ruang; tidak perlu memegang atau berpaut pada sesuatu benda.	**2**	**1**	**0**	**TT**	?
	19	Memanjat naik dan turun kerusi orang dewasa.	**2**	**1**	**0**	**TT**	?
	20	Berlari tanpa terjatuh; mungkin kekok dan tidak ada kordinasi.	**2**	**1**	**0**	**TT**	?
	21	Berjalan menaiki tangga; meletakkan kedua-dua belah kaki pada setiap anak tangga; mungkin memegang susur tangga.	**2**	**1**	**0**	**TT**	?
	22	Menendang bola.	**2**	**1**	**0**	**TT**	?
	23	Berlari dengan lancar tanpa terjatuh.	**2**	**1**	**0**	**TT**	?
	24	Berjalan menuruni tangga, menghadap ke depan, meletakkan kedua-dua belah kaki pada setiap anak tangga; mungkin memegang susur tangga.	**2**	**1**	**0**	**TT**	?
	25	Melompat dengan kedua-dua belah kaki tidak menyentuh lantai.	**2**	**1**	**0**	**TT**	?
Umur Mula **5-6**	**26**	Membaling bola pelbagai saiz ke arah tertentu.	**2**	**1**	**0**	**TT**	?
	27	Menangkap bola bersaiz bola pantai dengan kedua-dua belah tangan dari jarak 2 atau 3 kaki.	**2**	**1**	**0**	**TT**	?
	28	Menaiki tangga dengan menukar-nukar kaki; mungkin memegang susur tangga.	**2**	**1**	**0**	**TT**	?
	29	Mengayuh basikal roda tiga atau mainan lain yang beroda tiga sekurang-kurangnya sejauh 6 kaki. *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika individu tidak mempunyai basikal roda tiga atau mainan beroda tiga. Walau bagaimanapun, jika individu mempunyai kenderaan sedemikian tetapi tidak menunggangnya atas apa sebab sekalipun, termasuk ibu bapa atau penjaga tidak fikir yang ia bersedia untuk menunggangnya, tandakan "0".	**2**	**1**	**0**	**TT** **T/P**	?
	30	Melompat atau meloncat ke depan sekurang-kurangnya sebanyak tiga kali.	**2**	**1**	**0**	**TT**	?
	31	Meloncat sebelah kaki sekurang-kurangnya sekali tanpa terjatuh; mungkin memegang sesuatu untuk menyeimbangkan badan.	**2**	**1**	**0**	**TT**	?

Aktiviti Fizikal, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau Sebahagian Sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu **T/P** = Tiada Peluang

Menggunakan Otot Besar, *sambungan*			Bulatkan "?" Jika Anda Ada Soalan
32	Memanjat naik dan turun objek yang tinggi (contohnya, *jungle gym*, tangga cerun 4 kaki, dsb.).	2 1 0 TT	?
33	Berjalan menuruni tangga, dengan menukar-nukar kaki; mungkin memegang susur tangga.	2 1 0 TT	?
34	Berlari dengan lancar, dengan menukar kelajuan dan arah.	2 1 0 TT	?
35	Menunggang basikal dengan roda latihan sekurang-kurangnya sejauh 10 kaki.	2 1 0 TT	?
	Tip skor: Anda boleh menandakan "T/P" bagi Tiada Peluang jika individu tidak mempunyai basikal. Walau bagaimanapun, jika individu mempunyai basikal tetapi tidak menunggangnya atas apa sebab sekalipun, termasuk ibu bapa atau penjaga tidak fikir ia bersedia untuk menunggangnya, tandakan "0".	T/P	
36	Menangkap bola bersaiz bola pantai (dari jarak sekurang kurangnya sejauh 6 kaki) dengan kedua-dua belah tangan.	2 1 0 TT	?
37	Meloncat sebelah kaki ke depan dengan mudah.	2 1 0 TT	?
38	Lompat langkau (skip) sekurang-kurangnya 5 kaki.	2 1 0 TT	?
39	Menangkap bola bersaiz bola tenis atau besbal (dari jarak sekurang-kurangnya sejauh 10 kaki), bergerak untuk menangkapnya jika perlu.	2 1 0 TT	?
40	Menunggang basikal tanpa roda latihan tanpa terjatuh.	2 1 0 TT	?
	Tip skor: Anda boleh menandakan "T/P" bagi Tiada Peluang jika individu tidak mempunyai basikal. Walau bagaimanapun, jika individu mempunyai basikal tetapi tidak menunggangnya atas apa sebab sekalipun, termasuk ibu bapa atau penjaga tidak fikir yang ia bersedia menunggangnya, tandakan "0".	T/P	

	Menggunakan Otot Kecil		Bulatkan "?" Jika Anda Ada Soalan
Umur Mula **0-4**	1 Mencapai mainan atau objek.	2 1 0 TT	?
	2 Mengambil objek kecil (tidak lebih daripada 2 inci panjang pada mana-mana bahagian); mungkin menggunakan kedua-dua belah tangan.	2 1 0 TT	?
	3 Memindahkan objek dari sebelah tangan ke sebelah tangan yang satu lagi.	2 1 0 TT	?
	4 Memicit mainan atau objek bagi menghasilkan bunyinya.	2 1 0 TT	?
	5 Mengambil objek kecil dengan ibu jari dan jari-jari.	2 1 0 TT	?
	6 Memindahkan objek (contohnya, blok atau penyepit baju) dari sebuah bekas.	2 1 0 TT	?
	7 Memasukkan objek (contohnya, blok atau penyepit baju) ke dalam sebuah bekas.	2 1 0 TT	?
	8 Membalikkan muka surat daripada buku bermuka surat keras, kain atau kertas, sehelai demi sehelai.	2 1 0 TT	?
	9 Menyusun secara bertindan sekurang-kurangnya empat blok kecil atau objek kecil yang lain; susunan mesti tidak jatuh.	2 1 0 TT	?
	10 Membuka pintu dengan memusing tombol pintu.	2 1 0 TT	?
Umur Mula **5-6**	11 Membuka bungkusan objek kecil (contohnya, gula-gula getah atau coklat).	2 1 0 TT	?
	12 Menyiapkan susun suai yang mudah sekurang-kurangnya sebanyak dua keping atau dua bentuk.	2 1 0 TT	?
	13 Menyelak buku atau majalah sehelai demi sehelai.	2 1 0 TT	?
	14 Menggunakan pergerakan memusing-musing tangan (contohnya, memusing mainan, membuka atau menutup tutup balang, dsb.).	2 1 0 TT	?
	15 Memegang pensel dengan betul (bukan menggenggamnya) untuk menulis atau melukis.	2 1 0 TT	?
	16 Mewarna bentuk mudah; mungkin mewarna di luar garisan.	2 1 0 TT	?
	17 Membina struktur tiga dimensi (contohnya, rumah, jambatan, kenderaan, dsb.) dengan sekurang-kurangnya lima blok kecil.	2 1 0 TT	?
	18 Membuka dan menutup gunting dengan sebelah tangan.	2 1 0 TT	?

Aktiviti Fizikal, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang atau Sebahagian Sahaja, **0** = Tidak pernah, **TT** = Tidak Tahu **T/P** = Tiada Peluang

Menggunakan Otot Kecil, ***sambungan***			Bulatkan "?" Jika Anda Ada Soalan
19	Gam atau menampal dua atau lebih kepingan bersama-sama (contohnya, untuk kerja seni atau projek sains, dsb.).	**2 1 0 TT**	?
20	Menggunakan pita pelekat untuk melekatkan benda (contohnya, halaman yang koyak, kerja seni dsb.).	**2 1 0 TT**	?
21	Melukis lebih daripada satu bentuk yang boleh dikenali (contohnya, orang, rumah, pokok, dsb.). *Tip skor:* Tandakan "2" jika iindividu melukis dua atau lebih bentuk yang boleh dikenali; tandakan "1" jika individu melukis satu bentuk yang boleh dikenali; tandakan "0" jika individu tidak melukis apa-apa bentuk yang boleh dikenali.	**2 1 0 TT**	?
22	Membuat huruf atau nombor yang dikenali.	**2 1 0 TT**	?
23	Melukis bulatan dengan tangan sambil melihat contoh.	**2 1 0 TT**	?
24	Menggunakan gunting untuk memotong kertas mengikut garisan yang lurus.	**2 1 0 TT**	?
25	Mewarna bentuk yang mudah; mewarna di dalam garisan.	**2 1 0 TT**	?
26	Memotong bentuk yang mudah (contohnya, bulatan, segi empat tepat, segi empat sama, dsb.).	**2 1 0 TT**	?
27	Menggunakan pemadam tanpa mengoyakkan kertas.	**2 1 0 TT**	?
28	Melukis segi empat dengan tangan dengan melihat contoh.	**2 1 0 TT**	?
29	Melukis segi tiga dengan tangan dengan melihat contoh.	**2 1 0 TT**	?
30	Membuat ikatan.	**2 1 0 TT**	?
31	Membuat garisan lurus dengan menggunakan pembaris atau sesuatu yg mempunyai tepi yang lurus.	**2 1 0 TT**	?
32	Membuka *dead-bolt*, kunci atau kunci kombinasi yang perlu diputar. *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika tiada *dead bolt*, kunci atau kunci kombinasi di rumah.	**2 1 0 TT** **T/P**	?
33	Memotong bentuk yang rumit (contohnya, bintang, haiwan, huruf abjad, dsb.).	**2 1 0 TT**	?
34	Menggunakan kekunci, mesin taip, atau skrin sentuh untuk menaip nama atau perkataan pendek; boleh melihat kekunci. *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika tiada komputer di rumah.	**2 1 0 TT** **T/P**	?
35	Membuat ikatan kupu-kupu yang kemas.	**2 1 0 TT**	?
36	Menggunakan kekunci untuk menaip sehingga 10 baris; boleh melihat kekunci. *Tip skor:* Anda boleh menandakan "T/P" bagi Tiada Peluang jika tiada komputer di rumah.	**2 1 0 TT** **T/P**	?

Masalah Kelakuan Bahagian 1

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang, **0** = Tidak pernah

Seksyen A						**Bulatkan "?" Jika Anda Ada Soalan**
Umur Mula **3+**	**1**	Terlalu bergantung (iaitu, terlalu berharap pada penjaga, guru, atau adik-beradik).	**0**	**1**	**2**	?
	2	Menjauhi orang lain dan lebih suka bersendirian.	**0**	**1**	**2**	?
	3	Menghadapi masalah makan (contohnya, makan terlalu cepat atau terlalu perlahan, mengumpul makanan, terlebih makan, enggan makan, dsb.).	**0**	**1**	**2**	?
	4	Menghadapi masalah tidur (contohnya, berjalan semasa tidur, kerap mengalami mimpi ngeri, tidur berlebihan atau kurang daripada biasa bagi umurnya).	**0**	**1**	**2**	?
	5	Enggan pergi ke sekolah atau bekerja kerana takut, perasaan tersisih atau terasing, dsb.	**0**	**1**	**2**	?
	6	Terlalu cemas atau gementar.	**0**	**1**	**2**	?
	7	Menangis atau ketawa terlalu mudah.	**0**	**1**	**2**	?
	8	Mempunyai hubungan mata yang kurang (iaitu, tidak memandang atau menghadap kearah orang tersebut yang dilawan bercakap).	**0**	**1**	**2**	?
	9	Bersedih kerana sebab yang tidak jelas.	**0**	**1**	**2**	?
	10	Mengelak interaksi sosial.	**0**	**1**	**2**	?
	11	Kurang tenaga atau kurang minat dalam hidup.	**0**	**1**	**2**	?

Seksyen B						**Bulatkan "?" Jika Anda Ada Soalan**
Umur Mula **3+**	**1**	Bertindak mengikut gerak hati (iaitu, bertindak tanpa berfikir).	**0**	**1**	**2**	?
	2	Berperangai panas baran.	**0**	**1**	**2**	?
	3	Tidak taat secara sengaja dan melawan orang atasan.	**0**	**1**	**2**	?
	4	Mencemuh, mengusik atau membuli.	**0**	**1**	**2**	?
	5	Tidak bertimbang rasa atau tidak sensitif terhadap orang lain.	**0**	**1**	**2**	?
	6	Menipu, memperdaya atau mencuri.	**0**	**1**	**2**	?
	7	Agresif secara fizikal (contohnya, memukul, menendang, menggigit, dsb.).	**0**	**1**	**2**	?
	8	Degil atau muram.	**0**	**1**	**2**	?
	9	Berkata perkara yang memalukan atau menanyakan soalan yang memalukan dalam khalayak ramai (contohnya, "Awak gemuk," atau "Apakah benda merah besar atas hidung awak tu?").	**0**	**1**	**2**	?
	10	Berkelakuan yang tidak sewajarnya apabila mendesak orang lain.	**0**	**1**	**2**	?

Seksyen C						**Bulatkan "?" Jika Anda Ada Soalan**
Umur Mula **3+**	**1**	Menghisap ibu jari atau jari-jari.	**0**	**1**	**2**	?
	2	Kencing malam atau mesti memakai lampin semasa tidur.	**0**	**1**	**2**	?
	3	Bertindak terlalu mesra dengan orang asing (contohnya, memegang tangan, memeluk, duduk di atas pahanya, dsb.).	**0**	**1**	**2**	?
	4	Menggigit kuku-kukunya.	**0**	**1**	**2**	?
	5	Mengalami tik (iaitu, mengelip mata di luar kawalan, menyentap-nyentap, menggoyang-goyangkan kepala, dsb.).	**0**	**1**	**2**	?

Masalah Kelakuan Bahagian 1, sambungan

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang, **0** = Tidak pernah

Seksyen C, *sambungan*			Bulatkan "?" Jika Anda Ada Soalan
6	Mengasah gigi disiang hari atau malam.	0 1 2	?
7	Menghadapi kesukaran untuk menumpukan perhatian.	0 1 2	?
8	Lebih aktif atau gelisah berbanding orang lain yang sama umur.	0 1 2	?
9	Menggunakan harta sekolah atau tempat kerja (contohnya, telefon, capaian Internet, bekalan pejabat, dsb.) bagi tujuan peribadi yang tidak sah.	0 1 2	?
10	Menyumpah.	0 1 2	?
11	Melarikan diri (iaitu, hilang dalam masa 24 jam atau lebih).	0 1 2	?
12	Kaki ponteng sekolah atau kerja.	0 1 2	?
13	Tidak peduli atau tidak memberikan perhatian kepada orang lain di sekelilingnya.	0 1 2	?
14	Menggunakan wang atau hadiah untuk "membeli" kasih sayang.	0 1 2	?
15	Mengambil minuman keras atau dadah semasa sekolah atau sewaktu bekerja.	0 1 2	?

Masalah Kelakuan Bahagian 2

Pilihan Respons: **2** = Selalu, **1** = Kadang-kadang, **0** = Tidak pernah, **T** = Teruk, **S** = Sederhana

Seksyen D				Bulatkan "?" Jika Anda Ada Soalan
Umur Mula **3+**	1	Membuat kelakuan seks yang tak sepatutnya (contohnya, mendedahkan diri sendiri, melancap di khalayak ramai, membuat cubaan seksual yang kurang sopan, dsb.).	0 1 2 T S	?
	2	Terlalu memikirkan sesuatu objek atau aktiviti (contohnya, kerap mengulang perkataan atau frasa, terlalu asyik terhadap sesuatu objek mekanikal, dsb.).	0 1 2 T S	?
	3	Menyatakan pemikiran yang tidak dapat diterima akal (contohnya, bercakap tentang suara yang didengar, mengalami delusi, dsb.).	0 1 2 T S	?
	4	Mempunyai tabiat atau cara yang pelik (contohnya, membuat bising yang berulang-ulang, pergerakan tangan yang pelik, dsb.).	0 1 2 T S	?
	5	Lebih suka objek daripada manusia secara konsisten (contohnya, menumpukan lebih perhatian kepada objek daripada manusia, dsb.).	0 1 2 T S	?
	6	Menunjukkan kelakuan yang menyebabkan kecederaan kepada diri sendiri (contohnya, mengetuk kepala, memukul atau menggigit diri sendiri, mencakar kulit, dsb.).	0 1 2 T S	?
	7	Merosakkan hak milik sendiri atau orang lain dengan sengaja.	0 1 2 T S	?
	8	Menggunakan kata-kata yang pelik (contohnya, berbual seorang diri di khalayak ramai, bercakap dengan menggunakan frasa atau ayat yang tiada makna, mengulang-ulang perkataan atau frasa yang sama, dsb.).	0 1 2 T S	?
	9	Tidak sedar apa yang berlaku di sekelilingnya (contohnya, seperti berada dalam "kekaburan", renungan kosong, dsb.).	0 1 2 T S	?
	10	Bergoyang ke depan dan ke belakang berulang kali.	0 1 2 T S	?
	11	Ketakutan yang luar biasa terhadap bunyi, objek atau keadaan biasa.	0 1 2 T S	?
	12	Mengingat maklumat ganjil secara terperinci beberapa tahun kemudian.	0 1 2 T S	?
	13	Tidak mampu menamatkan sekolah atau hari bekerja biasa kerana kesakitan atau keletihan yang kronik.	0 1 2 T S	?
	14	Tidak mampu menamatkan sekolah atau hari bekerja biasa kerana simptom-simptom psikologi.	0 1 2 T S	?

Individu:_____ Tarikh:_____ Umur:_____ Borang: ____ Tinjauan Temu Duga
____ Rating Ibu bapa/Penjaga

VINELAND-II RINGKASAN MARKAH

SUBDOMAIN/ DOMAIN	Markah Mentah	Markah Skala-v Jadual B.1	Markah Standard Domain Jadual B.2	___% Sela Keyakinan Jadual C.1/C.2	Pangkat Persentil Jadual C.3	Paras Adaptif Jadual C.4	Persama-an Umur Jadual C.5	Stanine Jadual C.3	KEKUATAN dan KELEMAHAN: Markah Tolak Median*	KEKUATAN dan KELEMAHAN: S(kekuatan atau W(kelemah-an)
Reseptif				±						
Ekspresif				±						
Bertulis				±						
Komunikasi	Jumlah:_____			±						
Peribadi				±						
Domestik				±						
Komuniti				±						
Kemahiran Kehidupan Harian	Jumlah:_____			±						
Hubungan Interperorangan				±						
Bermain dan Masa Lapang				±						
Kemahiran Kendalian				±						
Sosialisasi	Jumlah:_____			±						
Kasar				±						
Halus				±						
Kemahiran Motor	Jumlah:_____			±						

Jumlah Markah Standard Domain =

	Markah Standard Jadual B.2	___% Sela Keyakinan Jadual C.1/C.2	Pangkat Persentil Jadual C.3	Paras Adaptif Jadual C.4		Stanine Jadual C.3
Komposit Kelakuan Adaptif		±				

	Markah Mentah	Markah Skala-v Jadual B.3	___% Sela Keyakinan Jadual C.6	Paras Jadual C.7
Indeks Kelakuan Maladaptif			±	
Dalaman			±	
Luaran			±	

Item-item Kritikal Kelakuan Maladaptif

Item (Bulatkan semua item markah 2 atau 1, dan tandakan keterukannya.)

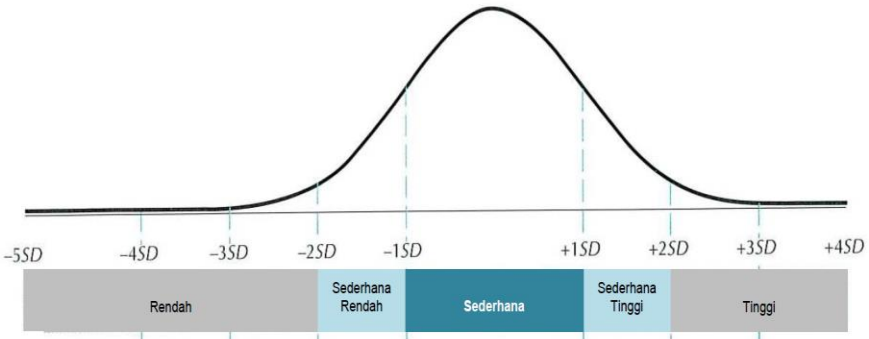
1 S M 2 S M 3 S M 4 S M 5 S M 6 S M 7 S M 8 S M 9 S M 10 S M 11 S M 12 S M 13 S M 14 S M

* Bagi arahan tentang bagaimana untuk menentukan markah median, lihat Bab 3 Manual Borang Tinjauan Vineland-II.

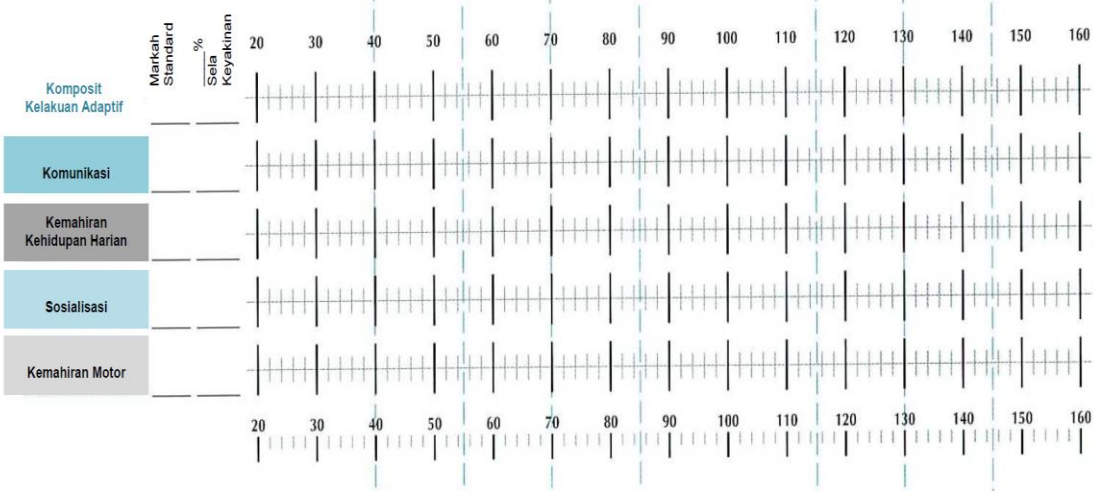
Domain kekuatan/kelemahan
S = Markah Standard – Median ≥ 10
W = Markah Standard – Median ≤ -10

Subdomain kekuatan/kelemahan
S = Markah Skala-v – Median ≥ 2
W = Markah Skala-v – Median ≤ -2

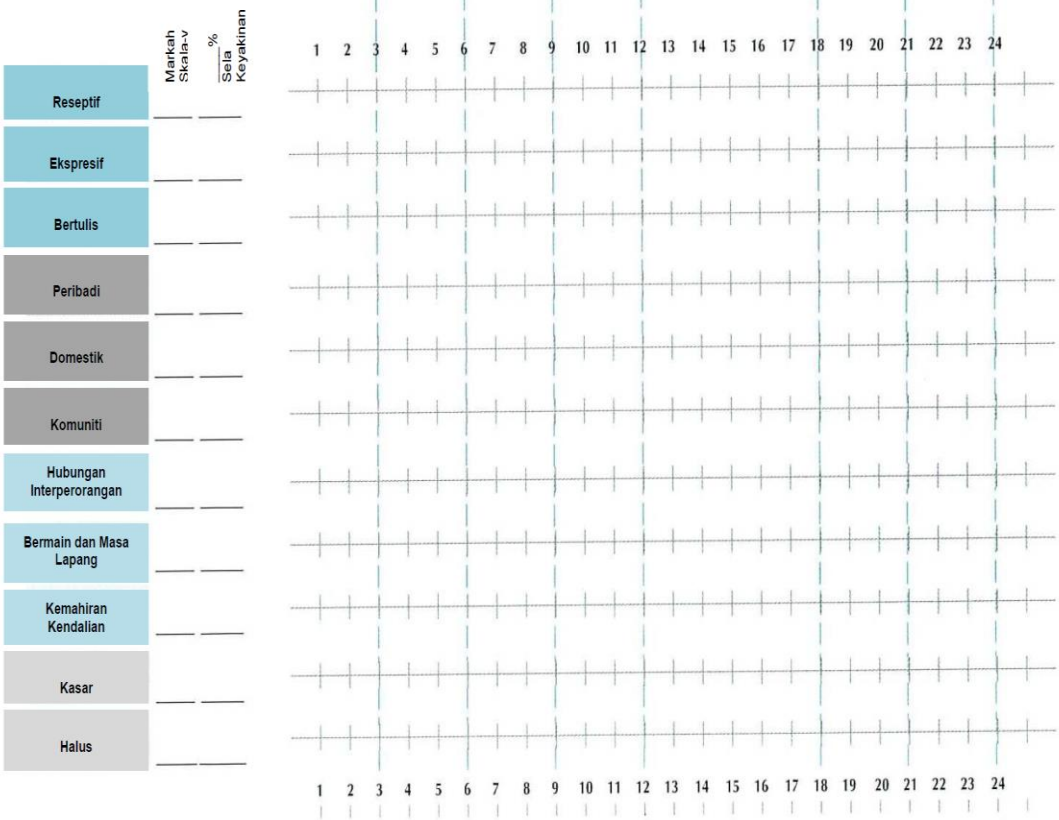
VINELAND-II PROFIL MARKAH



Profile Markah Domain



Profile Markah Subdomain



VINELAND-II PERBANDINGAN CARA BERPASANGAN

Perbandingan Domain	Markah Standard	<, >, atau =	Markah Standard		Perbezaan Markah Standard	Aras Keertian Statistik (.05 atau .01) Jadual D.1	Kekerapan perbezaan (Nilai Lampau 16, 10, 5, atau 1%) Jadual D.2
Komunikasi				Kemahiran Kehidupan Harian			
Komunikasi				Sosialisasi			
Kemahiran kehidupan Harian				Sosialisasi			
Komunikasi				Kemahiran Motor			
Sosialisasi				Kemahiran Motor			
Kemahiran Kehidupan Harian				Kemahiran Motor			

Perbandingan Subdomain	Markah skala-v	<, >, atau =	Markah skala-v		Perbezaan Markah Skala-v	Aras Keertian Statistik (.05 atau 0.1) Jadual D.3 atau D.5	Kekerapan perbezaan (Nilai Lampau 16, 10,5 atau 1%) Jadual D.4
Komunikasi							
Reseptif				Ekspresif			
Reseptif				Bertulis			
Ekspresif				Bertulis			
Kemahiran Kehidupan Harian							
Peribadi				Domestik			
Peribadi				Komuniti			
Domestik				Komuniti			
Sosialisasi							
Hubungan Interperorangan				Bermain dan Masa Lapang			
Hubungan Interperorangan				Kemahiran Kendalian			
Bermain dan Masa Lapang				Kemahiran Kendalian			
Kemahiran Motor							
Kasar				Halus			

Perbandingan Subdomain Merentas Domain Terpilih	Markah Skala-v	<, >, atau =	Markah Skala-v		Perbezaan Markah Skala-v	Aras Keertian Statistik (.05 atau .01) Jadual D.3 atau D.5	Kekerapan perbezaan (Nilai Lampau 16, 10,5 atau 1%) Jadual D.4
Ekspresif				Hubungan Interperorangan			
Ekspresif				Kemahiran Kendalian			
Halus				Bertulis			
Halus				Domestik			
Halus				Peribadi			

Vineland-II

Skala Kelakuan Adaptif Vineland, Edisi Kedua

Laporan Markah Borang Rating Ibu Bapa/Penjaga

Individu:_____

Umur Kronologi:_____-_____-_____ Tarikh Penilaian:_____-_____-_____

Gred (jika berkenaan):_____ Gred Tertinggi Yang Dilengkapkan:_____

Responden:_____ Pemeriksa:_____

Data daripada Ujian Lain: Kecerdasan:_____ Pencapaian:_____

Kelakuan Adaptif:_____ Lain-lain:_____

Domain:

Komunikasi	Kemahiran Kehidupan Harian	Sosialisasi	Kemahiran Motor
Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang*+ ☐ Jumlah bagi 2s dan 1s + ☐	Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang*+ ☐ Jumlah T/P + ☐ Jumlah bagi 2s dan 1s + ☐	Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang*+ ☐ Jumlah bagi 2s dan 1s + ☐	Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang* + ☐ Jumlah T/P + ☐ Jumlah bagi 2s dan 1s + ☐
Markah Mentah Reseptif = ☐ JUMLAH	**Markah Mentah Peribadi** = ☐ JUMLAH	**Markah Mentah Hubungan Interperorangan** = ☐ JUMLAH	**Markah Mentah Kasar** = ☐ JUMLAH
Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang*+ ☐ Jumlah bagi 2s dan 1s + ☐	Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang*+ ☐ Jumlah T/P + ☐ Jumlah bagi 2s dan 1s + ☐	Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang*+ ☐ Jumlah bagi 2s dan 1s + ☐	Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang* + ☐ Jumlah T/P + ☐ Jumlah bagi 2s dan 1s + ☐
Markah Mentah Ekspresif = ☐ JUMLAH	**Markah Mentah Domestik** = ☐ JUMLAH	**Markah Mentah Bermain dan Masa lapang** = ☐ JUMLAH	**Markah Mentah Halus** = ☐ JUMLAH
Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang*+ ☐ Jumlah bagi 2s dan 1s + ☐	Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang*+ ☐ Jumlah T/P + ☐ Jumlah bagi 2s dan 1s + ☐	Item Sebelum Basal ☐ x 2 = ☐ **Item Basal Menerusi Item Siling** TT dan/atau Jumlah Hilang*+ ☐ Jumlah bagi 2s dan 1s + ☐	**Masalah Kelakuan** Seksyen A Jumlah bagi 2s dan 1s ☐ Seksyen B Jumlah bagi 2s dan 1s ☐ Seksyen C Jumlah bagi 2s dan 1s ☐
Markah Mentah Bertulis = ☐ JUMLAH	**Markah Mentah Komuniti** = ☐ JUMLAH	**Markah Mentah Kemahiran Kendalian** = ☐ JUMLAH	**Markah Mentah Masalah Kelakuan** = ☐ JUMLAH

**Jika jumlah TT dan/atau yang Hilang lebih besar daripada 2, jangan tandakan subdomain.*

PEARSON

A0987654

APPENDIX V

THE APPLICATION LETTER TO COLLECT DATA

Application Letter to NASOM

Puan Masne Kadar
Pensyarah Program Terapi Carakerja,
Fakulti Sains Kesihatan Bersekutu (FSKB)
Universiti Kebangsaan Malaysia (UKM)
Jalan Raja Muda Abdul Aziz
43000 Kuala Lumpur

15 Mei 2010

Kepada

Pn. Liew Yoon Loy
Pengarah Executive NASOM
Pusat Pendidikan Autisme Kuala Lumpur
No. 4, Jalan Chon Chin Mooi
Off Jalan Pahang, 53200
Kuala Lumpur

Memohon Kebenaran Untuk Menjalankan Kajian di Pusat Pendidikan Autisme Kuala Lumpur (NASOM)

Saya, Masne Binti Kadar merupakan pensyarah di Program Terapi Carakerja, Fakulti Sains Kesihatan Bersekutu (FSKB), Universiti Kebangsaan Malaysia (UKM) yang kini sedang didalam bercuti belajar secara sepenuh masa di Monash University, Australia didalam pengajian peringkat PhD.

2) Berkaitan dengan perkara di atas, saya ingin memohon kebenaran dari pihak puan bagi menjalankan kajian saya yang bertajuk 'Adaptive Skills in Children with Autistic Spectrum Disorders (ASD)' ditempat puan.

3) Kajian yang akan saya jalankan ini akan melibatkan temuduga dan soal-selidik ke atas ibubapa/penjaga kepada kanak-kanak Autistic Spectrum Disorders (ASD) yang menghadiri pusat rawatan puan. Segala maklumat penerangan berkaitan proses kajian ini saya sertakan bersama-sama surat permohonan ini bagi makluman dan penerangan pihak puan, iaitu:

1) Explanatory Statement (Parents/caregivers of children with Autistic Spectrum Disorders – Questionnaire), and

2) Explanatory Statement (Parents/caregivers of children with Autistic Spectrum Disorders – Semi-structured interview).

4) Bahan/peralatan yang akan saya gunakan didalam kajian ini ialah:

i) The Vineland Adaptive Behaviour Scales (Second edition) (The Vineland-II) yang akan digunakan didalam soal-selidik, dan
ii) The Canadian Occupational Performance Measure (COPM) yang akan digunakan didalam proses temuduga.

5) Untuk maklumat puan, kajian ini tidak akan melibatkan proses atau prosedur yang invasive ke atas kanak-kanak tersebut.

Oleh yang demikian, saya amat berharap agar puan dapat mempertimbangkan permohonan saya ini dan segala perhatian puan saya dahului dengan ucapan ribuan terima kasih.

Sekiranya puan mempunyai sebarang pertanyaan, saya boleh dihubungi melalui nombor talipon 010-4000758 atau fax 03-26878199.

Sekian, terima kasih.

Yang benar,

……..
Masne Kadar
Calon PhD
Monash University, Australia.

Application Letter to UKMMC

Puan Masne Kadar
Pensyarah Program Terapi Carakerja,
Fakulti Sains Kesihatan Bersekutu (FSKB)
Universiti Kebangsaan Malaysia (UKM)
Jalan Raja Muda Abdul Aziz
43000 Kuala Lumpur

15 Mei 2010

Kepada

Pn. Rohana Mukahar
Ketua Unit Terapi Carakerja
Pusat Perubatan Universiti Kebangsaan Malaysia (PPUKM)
Jalan Yaacob Latif
56000, Cheras,
Kuala Lumpur

Memohon Kebenaran Untuk Menjalankan Kajian di Unit Terapi Carakerja, PPUKM

Saya, Masne Binti Kadar merupakan pensyarah di Program Terapi Carakerja, Fakulti Sains Kesihatan Bersekutu (FSKB), Universiti Kebangsaan Malaysia (UKM) yang kini sedang didalam bercuti belajar secara sepenuh masa di Monash University, Australia didalam pengajian peringkat PhD.

2) Berkaitan dengan perkara di atas, saya ingin memohon kebenaran dari pihak puan bagi menjalankan kajian saya yang bertajuk 'Adaptive Skills in Children with Autistic Spectrum Disorders (ASD)' ditempat puan.

3) Kajian yang akan saya jalankan ini akan melibatkan temuduga dan soal-selidik ke atas ibubapa/penjaga kepada kanak-kanak Autistic Spectrum Disorders (ASD) yang menghadiri pusat rawatan puan. Segala maklumat penerangan berkaitan proses kajian ini saya sertakan bersama-sama surat permohonan ini bagi makluman dan penerangan pihak puan, iaitu:

3) Explanatory Statement (Parents/caregivers of children with Autistic Spectrum Disorders – Questionnaire), and
4) Explanatory Statement (Parents/caregivers of children with Autistic Spectrum Disorders – Semi-structured interview).

5) Bahan/peralatan yang akan saya gunakan didalam kajian ini ialah:

iii) The Vineland Adaptive Behaviour Scales (Second edition) (The Vineland-II) yang akan digunakan didalam soal-selidik, dan

iv) The Canadian Occupational Performance Measure (COPM) yang akan digunakan didalam proses temuduga.

5) Untuk maklumat puan, kajian ini tidak akan melibatkan proses atau prosedur yang invasive ke atas kanak-kanak tersebut.

Oleh yang demikian, saya amat berharap agar puan dapat mempertimbangkan permohonan saya ini dan segala perhatian puan saya dahului dengan ucapan ribuan terima kasih.

Sekiranya puan mempunyai sebarang pertanyaan, saya boleh dihubungi melalui nombor talipon 010-4000758 atau fax 03-26878199.

Sekian, terima kasih.

Yang benar,

……..
Masne Kadar
Calon PhD
Monash University, Australia.

APPENDIX W

THE EXPLANATORY STATEMENT

MONASH University
Medicine, Nursing and Health Sciences

Explanatory Statement

(Parents/caregivers of children with Autistic Spectrum Disorders - Questionnaire)

Title: Adaptive skills in children with Autistic Spectrum Disorders: Parents'/caregivers' perspective.

This information sheet is for you to keep.
My name is Masne Kadar and I am conducting a survey project towards a PhD degree in collaboration with Dr. Rachael McDonald and Dr. Primrose Lentin, Senior Lecturers in the Department of Occupational Therapy, Monash University. This survey is about the adaptive skills abilities of children with Autistic Spectrum Disorders (ASD). In this survey, parents/caregivers of children with ASD will be asked to complete a questionnaire regarding the adaptive skills abilities of their children with ASD. This involves your observation on your child's abilities in daily living skills.

The aim of the research

The study aims are:

1) To determine the levels of adaptive skills in children with ASD in Peninsular Malaysia as measured on Vineland-II.
2) To investigate the areas of difficulties in adaptive skills in children with ASD in Peninsular Malaysia as measured on Vineland-II.
3) To investigate the difficulties in areas of occupational performance in children with ASD from parents' or caregivers' perspectives.
4) To determine the priorities for occupational therapy intervention for children with ASD and their families in Peninsular Malaysia.
5) To explore the relationship between adaptive skills and identified difficulties in occupational performance in children with ASD in Peninsular Malaysia.
6) To explore the relationship between adaptive skills and priorities in occupational performance in children with ASD in Peninsular Malaysia.

The overall purpose of the study is to find out what children can and cannot do in their daily lives as well as to find out your goals and priorities for occupational therapy services. We can use this information to improve services for you and your child in the future.

Possible benefits

There are no direct benefits to yourself or your child from the survey. However, we hope that from you and your child participation in this survey will provide valuable information in understanding the needs of children with ASD and also their families. Through this information, it is hope that children with ASD and their families will be able to receive more suitable occupational therapy intervention in the future.

What does the research involve?

The survey deals with gathering information regarding the daily skills of children with ASD. Parents/caregivers will be asked to complete a questionnaire of The Vineland Adaptive Behaviour Scale-Second edition (Vineland-II) (Parent/caregiver rating form). The Vineland-II is a questionnaire which measures your child's abilities in performing the daily living activities in self care and communication, such as eating, brushing teeth, playing games and writing.

How much time will the research take?

The Vineland-II will take about 10 to 20 minutes to complete.

Inconvenience/discomfort

The questionnaire may make you feel uncomfortable, because they are asking about what you feel about your child's level of adaptive skills. However, there are no physical/psychological inconveniences or discomfort beyond normal everyday life anticipated from participating in this survey.
If you feel distressed, and you find you need to talk about this, you may want to:

- Talk with your General Practitioner or your family doctor.

- Contact the: 1) Counselling Unit,
  Ministry of Woman, Family and Community Development (KPWKM), Malaysia
  [redacted]
  KPWKM, through its Department of Women Development (JPW), has formalised a counselling unit to provide counselling services for individuals and families in distress.

  2) Selangor Counselling Centre,
  [redacted]
  This is a social service that is providing counselling services to public in helping them to manage their crisis. Various types of counselling are available either through phone calls or face to face appointment.

Can I withdraw from the research?

Participation in the survey is voluntary, and you are under no obligation to consent to take part. If you do consent to participate, you may withdraw at any time without negative consequences. You do not have to answer any questions in the survey which you feel too personal or intrusive. It will not be possible to withdraw once the information you provide has been analysed.

Confidentiality

Any information you share in this research is confidential. Once data is collected, it will be coded in numerical order, and thus become unidentified.

Storage of data

Storage of the data collected during the study will adhere to Monash University regulations and will be kept at Monash University premises in a locked cupboard/filing cabinet for 5 years and on a password protected computer which is only accessible to the researchers. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Use of data for other purposes

The collected data in this research project will not be used for other purposes.

Result

If you would like to be informed of the aggregate research finding, please contact Mrs. Masne Kadar on [redacted]

Contact details

If you would like to contact the researchers about any aspect of this study, please contact the Chief investigator:	If you have a complaint concerning the manner in which this research is being conducted, please contact:
Dr. Rachael McDonald, PhD Senior Lecturer Department of Occupational Therapy Faculty of medicine, Nursing and Health Sciences Monash University – Peninsula Campus PO Box 527, Frankston, Victoria, 3199, Australia [redacted] Or Masne Kadar, PhD Candidate Department of Occupational Therapy Faculty of medicine, Nursing and Health Sciences Monash University – Peninsula Campus PO Box 527, Frankston, Victoria, 3199, Australia [redacted]	Executive Officer Monash University Human Research Ethics Committee (MUHREC) Building 3e Room 111 Research Office Monash University VIC 3800 [redacted] Local contact person for participants in Malaysia; Puan Rohana Mukahar Head of Occupational Therapy Department Universiti Kebangsaan Malaysia Medical Centre (UKMMC) Jalan Yaacob Latif, 56000 Cheras, Kuala Lumpur MALAYSIA [redacted]

Dr. Rachael McDonald **Senior Lecturer**	**Dr. Primrose Lentin** **Senior Lecturer**	**Mrs. Masne Kadar** **PhD Candidate**

MONASH University
Medicine, Nursing and Health Sciences

Kenyataan Penerangan

(Ibu bapa/pengasuh kanak-kanak yang mengalami Gangguan Spektrum Autistik – Soal selidik)

Tajuk: Kemahiran adaptasi pada kanak-kanak yang mengalami Gangguan Spektrum Autistik: Perspektif Ibu bapa/Penjaga

Lembaran maklumat ini adalah untuk simpanan anda.

Nama saya Masne Kadar dan saya sedang menjalankan satu projek kaji selidik untuk ijazah Kedoktoran bersama dengan Dr Rachael McDonald dan Dr Primrose Lentin, kedua-duanya Pensyarah Kanan Jabatan Pemulihan Carakerja, Monash University. Kajian ini adalah tentang keupayaan kemahiran adaptasi bagi kanak-kanak yang mengalami Gangguan Spektrum Autistik (ASD). Dalam kajian ini, ibu bapa/penjaga kanak-kanak ASD akan diminta melengkapkan soal selidik berhubung dengan keupayaan kemahiran adaptasi anak ASD mereka, melalui satu temu bual. Ini melibatkan pemerhatian anda tentang keupayaan anak anda dalam kemahiran hidup seharian.

Tujuan penyelidikan

Tujuan kajian adalah:

1) Untuk menentukan tahap kemahiran adaptasi kanak-kanak ASD di Semenanjung Malaysia seperti yang diukur pada Vineland-II.
2) Untuk mengkaji bidang kesukaran dalam kemahiran adaptasi kanak-kanak ASD di Semenanjung Malaysia seperti yang diukur pada Vineland-II.
3) Untuk menyiasat kesukaran dalam bidang prestasi carakerja pada kanak-kanak ASD dari perspektif ibu bapa atau penjaga
4) Untuk menentukan keutamaan dalam intervensi pemulihan carakerja untuk kanak-kanak ASD dan keluarga mereka di Semenanjung Malaysia.
5) Untuk meneliti hubungan antara kemahiran adaptasi dengan kesukaran yang dikenal pasti dalam prestasi carakerja pada kanak-kanak ASD di Semenanjung Malaysia.
6) Untuk meneliti hubungan antara kemahiran adaptasi dengan keutamaan dalam prestasi carakerja pada kanak-kanak ASD di Semenanjung Malaysia.

Tujuan keseluruhan kajian ini adalah untuk mengetahui apa yang boleh dan tidak boleh dilakukan oleh kanak-kanak dalam kehidupan seharian mereka, selain mengetahui matlamat dan keutamaan anda untuk perkhidmatan pemulihan carakerja. Kami boleh menggunakan maklumat ini untuk menambahbaikkan perkhidmatan untuk anda dan anak anda pada masa hadapan.

Manfaat yang mungkin ada

Kajian ini tidak memberikan manfaat secara langsung kepada diri anda atau anak anda. Walau bagaimanapun, kami berharap bahawa penyertaan anda dan anak anda dalam kajian ini dapat memberikan maklumat yang berguna dalam memahami keperluan kanak-kanak ASD dan juga keluarga mereka. Melalui maklumat ini, diharapkan agar kanak-kanak ASD dan keluarga mereka berupaya menerima intervensi pemulihan carakerja yang lebih sesuai pada masa hadapan.

Apakah yang terlibat dalam penyelidikan ini?

Kajian melibatkan pengumpulan maklumat berkaitan dengan kemahiran harian kanak-kanak ASD. Ibu bapa/penjaga akan diminta untuk melengkapkan soal selidik *The Vineland Adaptive Behaviour Scale* – Edisi Kedua (Vineland-II) (Borang penilaian Ibu bapa/Penjaga). Vineland-II ialah soal selidik yang mengukur keupayaan anak anda melakukan aktiviti kehidupan seharian dalam jagaan diri dan komunikasi seperti makan, memberus gigi, bermain dan menulis.

Berapa lamakah masa yang diambil untuk menjalankan penyelidikan?

Kira-kira 10-20 minit diperlukan untuk melengkapkan soal selidik Vineland-II.

Kesulitan/rasa tidak selesa

Semasa mengisi soal selidik ini anda mungkin berasa tidak selesa, kerana kami meminta pendapat anda tentang tahap kemahiran adaptasi anak anda. Walau bagaimanapun, tiada sebarang ketidakselesaan mahupun kesulitan yang di luar kehidupan seharian biasa dijangka daripada penyertaan anda dalam kajian ini.

Jika anda berasa tertekan, dan anda rasa anda perlu berbincang tentang hal ini, anda boleh:

- Berbincang dengan Pengamal Perubatan Umum atau doktor keluarga anda
- Hubungi: 1) Unit Kaunseling
  Kementerian Pembangunan Wanita, Keluarga dan Masyarakat (KPWKM), Malaysia
  [redacted]
  KPWKM, melalui Jabatan Pembangunan Wanita (JPW) telah menubuhkan unit kaunseling rasmi untuk menyediakan perkhidmatan kaunseling kepada individu dan keluarga yang menghadapi tekanan.

  2) Pusat Kaunseling Selangor
  [redacted]

Ini adalah khidmat masyarakat yang menyediakan perkhidmatan kaunseling kepada orang awam untuk membantu mereka menangani krisis. Terdapat pelbagai jenis kaunseling sama ada melalui panggilan telefon atau secara temu janji bersemuka.

Bolehkah saya menarik diri daripada penyelidikan ini?

Penyertaan dalam kajian ini adalah secara sukarela, dan anda tidak diwajibkan untuk bersetuju mengambil bahagian. Akan tetapi, jika anda bersetuju untuk mengambil bahagian, anda boleh menarik diri pada bila-bila masa tanpa sebarang akibat buruk. Anda tidak perlu menjawab apa-apa soalan yang anda rasa terlalu peribadi atau mengganggu. Sebaik sahaja maklumat yang anda berikan itu telah dianalisis, ia tidak mungkin dapat ditarik balik.

Kerahsiaan

Sebarang maklumat yang anda kongsi bersama dalam penyelidikan ini adalah rahsia. Sebaik sahaja data dikumpulkan, ia akan dikod dalam turutan berangka, oleh itu, data tidak dapat dikenal pasti.

Penyimpanan data

Penyimpanan data yang dikumpulkan sepanjang kajian akan mematuhi peraturan Monash University, dan akan disimpan di premis Monash University di dalam kabinet/almari fail berkunci selama 5 tahun dan di dalam komputer yang dilindungi dengan kata laluan, yang dapat diakses oleh penyelidik sahaja. Satu laporan tentang kajian mungkin dihantar untuk penerbitan tetapi setiap peserta tidak dapat dikenal pasti dalam laporan tersebut.

Penggunaan data untuk tujuan lain

Data yang dikumpulkan dalam projek penyelidikan ini tidak akan digunakan untuk tujuan lain.

Keputusan

Jika anda ingin dimaklumkan tentang dapatan penyelidikan secara keseluruhannya, sila hubungi Puan Masne Kadar di talian [redacted]

Maklumat pegawai yang dapat dihubungi

Jika anda ingin menghubungi penyelidik tentang apa jua aspek kajian ini, sila hubungi Ketua Penyelidik:	Jika anda mempunyai aduan berkaitan dengan cara penyelidikan ini dijalankan, sila hubungi:
Dr. Rachael McDonald, PhD Pensyarah Kanan Jabatan Pemulihan Carakerja Fakulti Sains Perubatan, Kejururawatan dan Kesihatan Monash University – Peninsula Campus Peti Surat 527, Frankston, Victoria, 3199, Australia [redacted] Atau Masne Kadar, Calon PhD Jabatan Pemulihan Carakerja Fakulti Sains Perubatan, Kejururawatan dan Kesihatan Monash University – Peninsula Campus Peti Surat 527, Frankston, Victoria, 3199, Australia [redacted]	Pegawai Eksekutif Jawatankuasa Etika Penyelidikan Manusia (MUHREC) Monash University Bangunan 3e Bilik 111 Pejabat Penyelidikan Monash University VIC 3800 [redacted] Pegawai setempat untuk dihubungi bagi peserta di Malaysia: Puan Rohana Mukahar Ketua Jabatan Pemulihan Carakerja Pusat Perubatan Universiti Kebangsaan Malaysia Jalan Yaacob Latif, 56000 Cheras, Kuala Lumpur [redacted]

Terima kasih

Dr Rachael McDonald Pensyarah Kanan	Dr Primrose LentinPuan Pensyarah Kanan	Masne Kadar Calon PhD

MONASH University
Medicine, Nursing and Health Sciences

Explanatory Statement

(Parents/caregivers of children with Autistic Spectrum Disorders – Semi-structured interview)

Title: Adaptive skills in children with Autistic Spectrum Disorders: Parents'/caregivers' perspective.

This information sheet is for you to keep.

My name is Masne Kadar and I am conducting a study towards a PhD degree in collaboration with Dr. Rachael McDonald and Dr. Primrose Lentin, Senior Lecturers in the Department of Occupational Therapy, Monash University. This study is about the adaptive skills abilities of children with Autistic Spectrum Disorders (ASD). In this study, parents/caregivers of children with ASD will be asked questions regarding the adaptive skills abilities of their children with ASD in an interview. This involves your opinion on your child's abilities in daily living skills.

The aim of the research

The study aims are:

7) To determine the levels of adaptive skills in children with ASD in Peninsular Malaysia as measured on Vineland-II.
8) To investigate the areas of difficulties in adaptive skills in children with ASD in Peninsular Malaysia as measured on Vineland-II.
9) To investigate the difficulties in areas of occupational performance in children with ASD from parents' or caregivers' perspectives.
10) To determine the priorities for occupational therapy intervention for children with ASD and their families in Peninsular Malaysia.
11) To explore the relationship between adaptive skills and identified difficulties in occupational performance in children with ASD in Peninsular Malaysia.
12) To explore the relationship between adaptive skills and priorities in occupational performance in children with ASD in Peninsular Malaysia.

The overall purpose of the study is to find out what children can and cannot do in their daily lives as well as to find out your goals and priorities for occupational therapy services. We can use this information to improve services for you and your child in the future.

Possible benefits

There are no direct benefits to yourself or your child from the study. However, we hope that from you and your child participation in this study will provide valuable information in understanding the needs of children with ASD and also their families. Through this information, it is hope that children with ASD and their families will be able to receive more suitable occupational therapy intervention in the future.

What does the research involve?

The study deals with gathering information regarding the daily skills of children with ASD. Parents/caregivers will be asked questions based on the Canadian Occupational Performance Measure (COPM). The COPM is a semi-structured interview which measures your child's abilities in performing daily living activities in self care, leisure and productivity, such as eating, brushing teeth, playing games and writing.

How much time will the research take?

The interview will take about 30-60 minutes or more depending on the amount of information that you are willing to provide.

Inconvenience/discomfort

The interview may make you feel uncomfortable, because we are asking about what you feel about your child's level of adaptive skills. However, there are no physical/psychological inconveniences or discomfort beyond normal everyday life anticipated from participating in this project.

If you feel distressed, and you find you need to talk about this, you may want to:

- Talk with your General Practitioner or your family doctor.
- Contact the:
  1) Counselling Unit,
  Ministry of Woman, Family and Community Development (KPWKM), Malaysia
  [redacted]
  KPWKM, through its Department of Women Development (JPW), has formalised a counselling unit to provide counselling services for individuals and families in distress.
  2) Selangor Counselling Centre,
  [redacted]
  This is a social service that is providing counselling services to public in helping them to manage their crisis. Various types of counselling are available either through phone calls or face to face appointment.

Can I withdraw from the research?

Participation in the study is voluntary, and you are under no obligation to consent to take part. If you do consent to participate, you may withdraw at any time without negative consequences. You do not have to answer any questions which you feel too personal or intrusive. It will not be possible to withdraw once the information you provide has been analysed.

Confidentiality

Any information you share in this study is confidential. Once data is collected, it will be coded in numerical order, and thus become unidentified.

Storage of data

Storage of the data collected during the study will adhere to Monash University regulations and will be kept at Monash University premises in a locked cupboard/filing cabinet for 5 years and on a password protected computer which is only accessible to the researchers. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Use of data for other purposes

The collected data in this research project will not be used for other purposes.

Result

If you would like to be informed of the aggregate research finding, please contact Mrs. Masne Kadar [redacted]

Contact details

If you would like to contact the researchers about any aspect of this study, please contact the Chief investigator:	If you have a complaint concerning the manner in which this study is being conducted, please contact:
Dr. Rachael McDonald, PhD Senior Lecturer Department of Occupational Therapy Faculty of medicine, Nursing and Health Sciences Monash University – Peninsula Campus PO Box 527, Frankston, Victoria, 3199, Australia [redacted] Or Masne Kadar, PhD Candidate Department of Occupational Therapy Faculty of medicine, Nursing and Health Sciences Monash University – Peninsula Campus PO Box 527, Frankston, Victoria, 3199, Australia [redacted]	Executive Officer Monash University Human Research Ethics Committee (MUHREC) Building 3e Room 111 Research Office Monash University VIC 3800 [redacted] Local contact person for Participants in Malaysia; Puan Rohana Mukahar Head of Occupational Therapy Department Universiti Kebangsaan Malaysia Medical Centre (UKMMC) Jalan Yaacob Latif, 56000 Cheras, Kuala Lumpur MALAYSIA [redacted]

Thank you

Dr. Rachael McDonald **Senior Lecturer**	**Dr. Primrose Lentin** **Senior Lecturer**	**Mrs. Masne Kadar** **PhD Candidate**

MONASH University
Medicine, Nursing and Health Sciences

Kenyataan Penerangan

(Ibu bapa/pengasuh kanak-kanak yang mengalami Gangguan Spektrum Autistik – Temu bual separa berstruktur)

Tajuk: Kemahiran adaptasi pada kanak-kanak yang mengalami Gangguan Spektrum Autistik: Perspektif Ibu bapa/Penjaga

Lembaran maklumat ini adalah untuk simpanan anda.

Nama saya Masne Kadar dan saya sedang menjalankan satu projek kaji selidik untuk ijazah Kedoktoran bersama dengan Dr Rachael McDonald dan Dr Primrose Lentin, kedua-duanya Pensyarah Kanan Jabatan Pemulihan Carakerja, Monash University. Kajian ini adalah tentang keupayaan kemahiran adaptasi bagi kanak-kanak yang mengalami Gangguan Spektrum Autistik (ASD). Dalam kajian ini, ibu bapa/penjaga kanak-kanak ASD akan ditanya beberapa soalan berhubung dengan keupayaan kemahiran adaptasi anak ASD mereka, melalui satu temu bual. Ini melibatkan pandangan anda tentang keupayaan anak anda dalam kemahiran hidup seharian.

Tujuan penyelidikan

Tujuan kajian adalah:

7) Untuk menentukan tahap kemahiran adaptasi kanak-kanak ASD di Semenanjung Malaysia seperti yang diukur pada Vineland-II.
8) Untuk mengkaji bidang kesukaran dalam kemahiran adaptasi kanak-kanak ASD di Semenanjung Malaysia seperti yang diukur pada Vineland-II.
9) Untuk menyiasat kesukaran dalam bidang prestasi carakerja pada kanak-kanak ASD dari perspektif ibu bapa atau penjaga.
10) Untuk menentukan keutamaan dalam intervensi pemulihan carakerja untuk kanak-kanak ASD dan keluarga mereka di Semenanjung Malaysia.
11) Untuk meneliti hubungan antara kemahiran adaptasi dengan kesukaran yang dikenal pasti dalam prestasi carakerja pada kanak-kanak ASD di Semenanjung Malaysia.
12) Untuk meneliti hubungan antara kemahiran adaptasi dengan keutamaan dalam prestasi carakerja pada kanak-kanak ASD di Semenanjung Malaysia.

Tujuan keseluruhan kajian ini adalah untuk mengetahui apa yang boleh dan tidak boleh dilakukan oleh kanak-kanak dalam kehidupan seharian mereka, selain mengetahui matlamat dan keutamaan anda untuk perkhidmatan pemulihan carakerja. Kami boleh menggunakan maklumat ini untuk menambahbaikkan perkhidmatan untuk anda dan anak anda pada masa hadapan.

Manfaat yang mungkin ada

Kajian ini tidak memberikan manfaat secara langsung kepada diri anda atau anak anda. Walau bagaimanapun, kami berharap bahawa penyertaan anda dan anak anda dalam kajian ini dapat memberikan maklumat yang berguna dalam memahami keperluan kanak-kanak ASD dan juga keluarga mereka. Melalui maklumat ini, diharapkan agar kanak-kanak ASD dan keluarga mereka berupaya menerima intervensi pemulihan carakerja yang lebih sesuai pada masa hadapan.

Apakah yang terlibat dalam penyelidikan ini?

Kajian melibatkan pengumpulan maklumat berkaitan dengan kemahiran harian kanak-kanak ASD. Ibu bapa/penjaga akan ditanya soalan berdasarkan Ukuran Prestasi Pekerjaan Kanada (COPM). COPM merupakan temu bual separa berstruktur yang mengukur keupayaan anak anda melakukan aktiviti kehidupan seharian dalam jagaan diri, aktiviti pada waktu lapang dan produktiviti, seperti makan, memberus gigi, bermain dan menulis.

Berapa lamakah masa yang diambil untuk menjalankan penyelidikan?

Temu bual akan mengambil masa kira-kira 30-60 minit atau lebih bergantung pada jumlah maklumat yang anda bersedia berikan.

Kesulitan/rasa tidak selesa

Temu bual mungkin menyebabkan anda berasa tidak selesa, kerana kami bertanya pendapat anda tentang tahap kemahiran adaptasi anak anda. Walau bagaimanapun, tiada sebarang ketidakselesaan mahupun kesulitan yang di luar kehidupan seharian biasa dijangka daripada penyertaan anda dalam projek ini.

Jika anda berasa tertekan, dan anda rasa anda perlu berbincang tentang hal ini, anda boleh:

- Berbincang dengan Pengamal Perubatan Umum atau doktor keluarga anda
- Hubungi: 1) Unit Kaunseling
  Kementerian Pembangunan Wanita, Keluarga dan Masyarakat (KPWKM), Malaysia
  [redacted]
  atau [redacted]
  KPWKM, melalui Jabatan Pembangunan Wanita (JPW) telah menubuhkan unit kaunseling rasmi untuk menyediakan perkhidmatan kaunseling kepada individu dan keluarga yang menghadapi tekanan.
  2) Pusat Kaunseling Selangor
  [redacted]
  Ini adalah khidmat masyarakat yang menyediakan perkhidmatan kaunseling kepada orang awam untuk

membantu mereka menangani krisis. Terdapat pelbagai jenis kaunseling sama ada melalui panggilan telefon atau secara temu janji bersemuka.

Bolehkah saya menarik diri daripada penyelidikan ini?

Penyertaan dalam kajian ini adalah secara sukarela, dan anda tidak diwajibkan untuk bersetuju mengambil bahagian. Akan tetapi, jika anda bersetuju untuk mengambil bahagian, anda boleh menarik diri pada bila-bila masa tanpa sebarang akibat buruk. Anda tidak perlu menjawab apa-apa soalan yang anda rasa terlalu peribadi atau mengganggu. Sebaik sahaja maklumat yang anda berikan itu telah dianalisis, ia tidak mungkin dapat ditarik balik.

Kerahsiaan

Sebarang maklumat yang anda kongsi bersama dalam kajian ini adalah rahsia. Sebaik sahaja data dikumpulkan, ia akan dikod dalam turutan berangka, oleh itu, data tidak dapat dikenal pasti.

Penyimpanan data

Penyimpanan data yang dikumpulkan sepanjang kajian akan mematuhi peraturan Monash University, dan akan disimpan di premis Monash University di dalam kabinet/almari fail berkunci selama 5 tahun dan di dalam komputer yang dilindungi dengan kata laluan, yang dapat diakses oleh penyelidik sahaja. Satu laporan tentang kajian mungkin dihantar untuk penerbitan tetapi setiap peserta tidak dapat dikenal pasti dalam laporan tersebut.

Penggunaan data untuk tujuan lain

Data yang dikumpulkan dalam projek penyelidikan ini tidak akan digunakan untuk tujuan lain.

Keputusan

Jika anda ingin dimaklumkan tentang dapatan penyelidikan secara keseluruhannya, sila hubungi Puan Masne Kadar di talian [redacted]

Maklumat pegawai yang dapat dihubungi

Jika anda ingin menghubungi penyelidik tentang apa jua aspek kajian ini, sila hubungi Ketua Penyelidik:	Jika anda mempunyai aduan berkaitan dengan cara kajian ini dijalankan, sila hubungi:
Dr. Rachael McDonald, PhD Pensyarah Kanan Jabatan Pemulihan Carakerja Fakulti Sains Perubatan, Kejururawatan dan Kesihatan Monash University – Peninsula Campus Peti Surat 527, Frankston, Victoria, 3199, Australia [redacted] Atau Masne Kadar, Calon PhD Jabatan Pemulihan Carakerja Fakulti Sains Perubatan, Kejururawatan dan Kesihatan Monash University – Peninsula Campus Peti Surat 527, Frankston, Victoria, 3199, Australia [redacted]	Pegawai Eksekutif Jawatankuasa Etika Penyelidikan Manusia (MUHREC) Monash University Bangunan 3e Bilik 111 Pejabat Penyelidikan Monash University VIC 3800 [redacted] Pegawai setempat untuk dihubungi bagi Peserta di Malaysia: Puan Rohana Mukahar Ketua Jabatan Pemulihan Carakerja Pusat Perubatan Universiti Kebangsaan Malaysia Jalan Yaacob Latif, 56000 Cheras, Kuala Lumpur MALAYSIA [redacted]

Terima kasih

Dr Rachael McDonald	Dr Primrose LentinPuan	Masne Kadar
Pensyarah Kanan	Pensyarah Kanan	Calon PhD

APPENDIX X

THE PERMISSION LETTER TO COLLECT DATA

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19 Aug 2010 13:42 HP LASERJET FAX p.1

19. Aug. 2010 12:44 No. 0235 P. 3

Mrs. Masne Kadar
Program Terapi Carakerja
Fakulti Sains Kesihatan Bersekutu (FSKB)
Universiti Kebangsaan Malaysia (UKM)
Jalan Raja Muda Abdul Aziz
43000 Kuala Lumpur
Tel (HP): 010-4000758
Fax: 03-26878199

Dear Mrs. Masne Kadar,

Study On "Adaptive Skills in Children with Autistic Spectrum Disorders: Parents'/Caregivers' Perspective"

Thank you for your request to recruit participants from NASOM (PUSAT PENDIDIKAN AUTISME KUALA LUMPUR) for the above-named study.

I have read and understood the Explanatory Statement regarding the study.

I hereby give/~~refuse~~ to give permission for this study to be conducted at my centre.

Yours Sincerely,

.....[redacted].....
Pn.
Pengarah Executive NASOM
PUSAT PENDIDIKAN AUTISME KUALA LUMPUR
No 4 Jalan Chan Chin Mooi,
Off Jalan Pahang, 53200 Kuala Lumpur

UNIVERSITI KEBANGSAAN MALAYSIA
National University of Malaysia

PUSAT PERUBATAN UKM • UKM MEDICAL CENTRE
Jabatan Perkhidmatan Pemulihan Perubatan (JPPP) . Medical Rehabilitation Services Department

Occupational Therapy Department

28th May 2010

Mrs. Masne Kadar
Level 4, Building G,
Department of Occupational Therapy,
Monash University (Peninsula Campus),
McMahon Roads, Frankston, 3199
Victoria, AUSTRALIA.

Dear Mrs Masne Kadar,

Permission Letter for Survey On "Adaptive skills in children with Autistic Spectrum Disorders: Parents'/caregivers' perspective."

Thank you for your request to recruit participants from Occupational Therapy Department, Universiti Kebangsaan Malaysia Medical Centre for the above-named research.

I have read and understood the Explanatory Statement regarding the research and hereby give permission for this research to be conducted at Occupational Therapy Department.

Yours Sincerely,

[redacted]

Mrs. Rohana Mukahar
Head of Occupational Therapy Department,
Universiti Kebangsaan Malaysia Medical Centre

APPENDIX Y

THE HUMAN ETHICS CERTIFICATE OF APPROVAL FROM MUHREC

MONASH University

Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

Date:	**1 September 2010**
Project Number:	**CF10/1520 - 2010000818**
Project Title:	**Adaptive skills in children with Autistic Spectrum Disorders: Parents'/caregivers' perspective**
Chief Investigator:	**Dr Rachael McDonald**
Approved:	**From: 1 September 2010 To: 1 September 2015**

Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to MUHREC before any data collection can occur at the specified organisation. **Failure to provide permission letters to MUHREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

[redacted]

Professor Ben Canny
Chair, MUHREC

cc: Dr Primrose Ann Lentin, Mrs Masne Kadar

Postal – Monash University, Vic 3800, Australia
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APPENDIX Z

THE ETHICAL APPROVAL FROM MEDICAL RESEARCH AND INDUSTRY

SECRETARIAT, UKM

UNIVERSITI KEBANGSAAN MALAYSIA
The National University of Malaysia

UKM

Pusat Perubatan UKM | *UKM Medical Research*

Sekretariat Penyelidikan Perubatan & Industri

UKM 1.5.3.5/244/SPP/NN-102-2010
/ 5 November 2010

Datin Ruhani Ibrahim
Program Terapi Carakerja
Fakulti Sains Kesihatan Bersekutu
UKM, Kuala Lumpur

Saudari,

Kelulusan Etika Menjalankan Penyelidikan di UKM

Dengan segala hormatnya, merujuk kepada perkara di atas.

Sukacita dimaklumkan permohonan untuk kelulusan etika bagi penyelidikan bertajuk **"Adaptive Skills in Children with Autistic Spectrum Disorders: Parents'/Caregivers' Perspective"** telah diluluskan.

Sekian, terima kasih.

Yang benar,

Profesor Mad[redacted] Dr Fuad Ismail
Pengerusi
Jawatankuasa [redacted]dikan
Universiti Keb[redacted]aysia

DITERIMA
18 NOV 2010
PUSAT MEL
JABATAN PENTADBIRAN AM
PPUKM

s.k. → Timbalan Dekan (Penyelidikan & Antarabangsa)
Fakulti Sains Kesihatan Bersekutu

Puan Masne Kadar
Program Terapi Carakerja
Fakulti Sains Kesihatan Bersekutu
UKM, Kuala Lumpur

→ Fail NN-102-2010

→ Fail Edaran

FI//Kandili/NN-102-2010

19 NOV 2010

Sekretariat Penyelidikan Perubatan & Industri, Pusat Perubatan Universiti Kebangsaan Malaysia,
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Telefon: +603-9145 5046/5048 Faksimili: +603-91725339. Laman web: http://www.ppukm.ukm.my

APPENDIX AA

THE CONSENT FORM FOR THE QUESTIONNAIRE

MONASH University
Medicine, Nursing and Health Sciences

Consent Form – Parents/caregivers of children with Autistic Spectrum Disorders (Questionnaire)

NOTE : Signed written consent will remain with the Monash University researcher for their record.

Title: Adaptive skills in children with Autistic Spectrum Disorders: Parents'/caregivers' perspective.

I agree to take part in the research project specified above. I have read the Explanatory Statement, which I keep for my records. I understand that agreeing to take part means that:

I agree to complete the Vineland Adaptive Behavior Scale-Second edition (Vineland-II) (Parent/caregiver rating form) asking me about the adaptive skills of my child.	☐ Yes	☐ No

and

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

and

I understand that any data that the researcher extracts from the questionnaire for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

and

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

and

I understand that data from the questionnaire will be kept in a secure storage and accessible to the researcher. I also understand that the data will be destroyed after a 5 year period unless I consent to it being used in future research.

Participant's name:

Signature:

Date:

MONASH University
Medicine, Nursing and Health Sciences

Borang Persetujuan – Ibu bapa/pengasuh kanak-kanak yang mengalami Gangguan Spektrum Autistik (Soal selidik)

NOTA: Persetujuan bertulis yang telah ditandatangani akan disimpan oleh penyelidik Monash University untuk rekod mereka.

Tajuk: Kemahiran adaptasi pada kanak-kanak yang mengalami Gangguan Spektrum Autistik: Perspektif Ibu bapa/penjaga

Saya bersetuju untuk mengambil bahagian dalam projek penyelidikan yang diterangkan di atas. Saya telah membaca Kenyataan Penerangan tersebut dan telah disimpan sebagai rekod saya. Saya faham bahawa dengan bersetuju untuk mengambil bahagian, ini bermakna:

Saya bersetuju untuk melengkapkan *Vineland Adaptive Behavior Scale* - Edisi Kedua (Vineland-II) (Borang penilaian ibu bapa/penjaga) yang bertanyakan tentang kemahiran adaptasi anak saya. Ya ☐ Tidak ☐

dan

saya memahami bahawa penyertaan saya adalah secara sukarela, dan saya boleh memilih untuk tidak mengambil bahagian dalam sebahagian atau keseluruhan projek, dan saya boleh menarik diri pada mana-mana peringkat projek ini tanpa dikenakan hukuman atau mengalami apa-apa kerugian, dalam apa jua cara.

dan

saya memahami bahawa apa-apa data yang diambil oleh penyelidik daripada soal selidik ini untuk digunakan dalam laporan atau dapatan yang diterbitkan, tidak akan, di bawah apa jua keadaan, mengandungi nama atau ciri-ciri pengenalan diri.

dan

saya memahami bahawa apa-apa maklumat yang saya berikan adalah rahsia, dan tiada apa-apa maklumat yang dapat mengenal pasti mana-mana individu akan didedahkan dalam apa jua laporan tentang projek, atau kepada mana-mana pihak lain.

dan

saya memahami bahawa data daripada soal selidik itu akan disimpan di satu tempat yang selamat dan hanya dapat diakses oleh penyelidik. Saya juga memahami bahawa data akan dimusnahkan selepas tempoh lima tahun, melainkan saya bersetuju data tersebut digunakan dalam penyelidikan pada masa hadapan.

Nama Peserta:

Tandatangan:

Tarikh:

APPENDIX AB

THE CONSENT FORM FOR THE SEMI-STRUCTURED INTERVIEW

MONASH University
Medicine, Nursing and Health Sciences

Consent Form – Parents/caregivers of children with Autistic Spectrum Disorders (Semi-structured interview)

NOTE : Signed written consent will remain with the Monash University researcher for their record.

Title: Adaptive skills in children with Autistic Spectrum Disorders: Parents'/caregivers' perspective.

I agree to take part in the research project specified above. I have read the Explanatory Statement, which I keep for my records. I understand that agreeing to take part means that:

I agree to be interviewed by the researcher. ☐ Yes ☐ No

I agree to allow the interview to be audio-taped. ☐ Yes ☐ No

and
I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

and
I understand that any data that the researcher extracts from the interview for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

and
I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

and
I understand that data from the interview will be kept in a secure storage and accessible to the researcher. I also understand that the data will be destroyed after a 5 year period unless I consent to it being used in future research.

Participant's name:

Signature:

Date:

MONASH University
Medicine, Nursing and Health Sciences

Borang Persetujuan – Ibu bapa/pengasuh kanak-kanak yang mengalami Gangguan Spektrum Autistik (Temu bual separa berstruktur)

NOTA: Persetujuan bertulis yang telah ditandatangani akan disimpan oleh penyelidik Monash University untuk rekod mereka.

Tajuk: Kemahiran adaptasi pada kanak-kanak yang mengalami Gangguan Spektrum Autistik: Perspektif Ibu bapa/penjaga

Saya bersetuju untuk mengambil bahagian dalam projek penyelidikan yang diterangkan di atas. Saya telah membaca Kenyataan Penerangan tersebut dan telah disimpan sebagai rekod saya. Saya faham bahawa dengan bersetuju untuk mengambil bahagian, ini bermakna:

Saya bersetuju untuk ditemu bual oleh penyelidik. Ya ☐ Tidak ☐

Saya bersetuju untuk membenarkan temu bual dirakam. Ya ☐ Tidak ☐

dan
saya memahami bahawa penyertaan saya adalah secara sukarela, dan saya boleh memilih untuk tidak mengambil bahagian dalam sebahagian atau keseluruhan projek, dan saya boleh menarik diri pada mana-mana peringkat projek ini tanpa dikenakan hukuman atau mengalami apa-apa kerugian, dalam apa jua cara.

dan
saya memahami bahawa apa-apa data yang diambil oleh penyelidik daripada soal selidik ini untuk digunakan dalam laporan atau dapatan yang diterbitkan, tidak akan, di bawah apa jua keadaan, mengandungi nama atau ciri-ciri pengenalan diri.

dan
saya memahami bahawa apa-apa maklumat yang saya berikan adalah rahsia, dan tiada apa-apa maklumat yang dapat mengenal pasti mana-mana individu akan didedahkan dalam apa jua laporan tentang projek, atau kepada mana-mana pihak lain.

dan
saya memahami bahawa data daripada temu bual itu akan disimpan di satu tempat yang selamat dan hanya dapat diakses oleh penyelidik. Saya juga memahami bahawa data akan dimusnahkan selepas tempoh lima tahun, melainkan saya bersetuju data tersebut digunakan dalam penyelidikan pada masa hadapan.

Nama Peserta:

Tandatangan:

Tarikh:

APPENDIX AC

DETAILED OCCUPATIONAL PERFORMANCE PROBLEMS FOR EACH OF THE TOP FOUR IDENTIFIED CATEGORIES LISTED IN THE COPM

The occupational performance issues identified in the top four categories of issues experienced by the greatest numbers of the children with ASD listed in the COPM

Detailed occupational performance issues	
Issues	Number of responses
Issues in communication (N*=31) (N=31)	
1) Verbal communication	
- Completely cannot talk yet	16
- Unable to pronounce word/s clearly/difficult to understand what the child is saying	2
2) Non-verbal communication	
- Unable to indicate own needs, example, by pointing to desire item/s	13
Issues in personal care activities (N*=42) (N=30)	
1) Toileting	14
2) Dressing	
- Cannot dress independently	13
- Does not like new clothes	1
3) Eating	
- Cannot eat independently	4
- Selective eaters	2
4) Washing oneself (Including bathing and washing/cleaning part of body)	4
5) Caring for own safety	4
Issues in socialisation (N*25) (N=24)	
1) Making and playing with friends	23
2) Sharing	2
Issues in activities related to academic skills at school and/or at home (N*=27) (N=22)	
1) Performing basic academic skills (Reading/writing/counting)	13
2) Low concentration span	9
3) Following verbal instructions	4
4) Holding pencils properly	1

Note. N*= represent the number of issues, N= represent the number of children with ASD