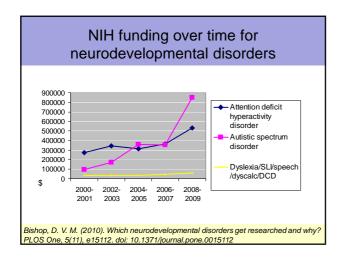


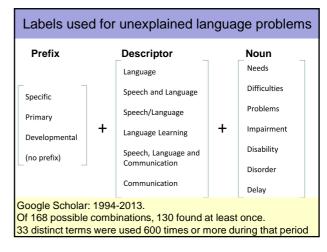
Amount of research (1985-2009) and prevalence of neurodevelopmental disorders /year Condition Tourette syndrome 83 0.5 Autistic spectrum disorder 643 0.7 Developmental dyscalculia 9 3.0 Attention deficit hyperactivity disorder 505 5.0 Developmental dyslexia 152 6.0 Developmental coordination disorder 16 6.5 Specific language impairment 46 7.4 Bishop, D. V. M. (2010). Which neurodevelopmental disorders get researched and why: PLOS One, 5(11), e15112. doi: 10.1371/journal.pone.0015112

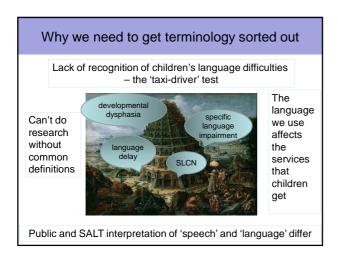
Research funding and frequency of neurodevelopmental disorders Condition 2000-2009 freq. % Tourette syndrome 252,709,203 0.5 Autistic spectrum disorder 2,613,298,181 0.7 Developmental dyscalculia 4,355,095 3.0 Attention deficit hyperactivity disorder 2,205,461,058 5.0 136.012.937 Developmental dyslexia 6.0 Developmental coordination disorder 4,093,060 6.5 Specific language impairment 125,035,522 7.4 *Frequency - best estimate from epidemiological studies Bishop, D. V. M. (2010). Which neurodevelopmental disorders get researched and why? PLOS One, 5(11), e15112. doi: 10.1371/journal.pone.0015112











Hypothetical 8-yr-old: George Late to start to talk Didn't speak in sentences until he was 4 years old. Otherwise developed normally

- Weak vocabulary for his age
 Struggles with reading
- Doesn't always remember what his teacher says
- · Teased for not understanding jokes
- Loves art
- Has become reluctant to go to school
- Hates being singled out and made to feel different from others.

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Psychological assessment

- Nonverbal IQ of 103
- Vocabulary and comprehension levels are lower, with scaled score equivalents of 85
- Poor scores on tests of verbal memory
- Reading ability is at a 7-yearold level



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What should be done about George?

- Nothing
- · Extra classroom support
- Individual speech and language therapy
- Something else?



Would George benefit from any kind of label?

- · Special Educational Needs
- Speech, Language and Communication Needs (SLCN)
- · Specific Language Impairment (SLI)
- · Social Communication Disorder
- · Something else
- None of the above



The key questions

- Who (if anyone) benefits from a label?
 - Could we do without labels?
 - What are their advantages/disadvantages?
 - What is purpose of labels? In clinic? In research?
- · Which children should be offered SALT services?
 - And what other options are there?
- · Who is currently excluded from services and who should be?

Would your answer to previous two questions be any different if George also had...

- · A score of 80 on a nonverbal IQ test
- · Attentional problems
- · Autistic features
- A known genetic condition such as Klinefelter's syndrome
- · A moderate unilateral hearing loss
- Polish-speaking parents with poor English
- · A chaotic and impoverished home background



A tale of two disorders

SPECIFIC LANGUAGE IMPAIRMENT

- Unexpected difficulty in learning to talk
- Not explained by lack of opportunity to learn
- Not explained by visual/hearing problems, low
- Not due to brain damage or known syndrome

(DEVELOPMENTAL DYSPHASIA) Prevalence 3-7%

DEVELOPMENTAL DYSLEXIA

- · Unexpected difficulty in learning to read
- · Not explained by lack of opportunity to learn
- Not explained by visual/hearing problems, low
- Not due to brain damage or known syndrome

(SPECIFIC READING DISABILITY) Prevalence 5-10%

For both SLI and dyslexia: Questions over validity as 'disorders'

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The Telegraph

6:47AM GMT 26 Feb 2014 Dyslexia may not exist, warn academics

Experts at Durham and Yale Universities are calling for the term 'dyslexia' to be abandoned because it is unscientific and lacks meaning



Elliott, J. G., & Grigorenko, E. L. (2014). The Dyslexia Debate. Cambridge: Cambridge

Public perception of diagnostic label

- · Explanatory force
- · Symptom complex
- · Aetiological basis
- · Qualitatively distinct from other disorders

Elliott and Grigorenko: None of these really bears scrutiny!

Explanatory force

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Specific Language Impairment

What is specific language impairment? Specific language impairment (SLI) is a language disorder that delays the mastery of language skills in children who have no hearing loss or other developmental delays. SLI is also called developmental language disorder, language delay, or developmental dysphasia. It is one of the most common childhood learning disabilities, affecting approximately 7 to 8 percent of children in kindergarten. The impact of SLI persists into adulthood.

People assume (1), but (2) is true!

- He has difficulty reading because he has dyslexia
- 2. He is labelled as dyslexic **because** he has difficulty reading

cf. Erythema





Symptom complex

Distinctive symptoms?



Rutter and Yule (1975)

Data from epidemiological study on Isle of Wight

- No clustering of the developmental anomalies that are said to characterize dyslexia.
- "In short, there has been a complete failure to show that the signs of dyslexia constitute any meaningful pattern." p 194

Rutter, M., & Yule, W. (1975). The concept of specific reading retardation. *Journal of Child Psychology and Psychiatry*, 16(3), 181-197.

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Is IQ discrepancy meaningful?

Stanovich (1994)

· Same phonological core deficit in poor readers regardless of IQ



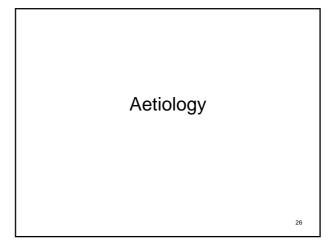
Reilly et al (2014)

- No justification for distinguishing language-impaired children on basis of mismatch between language and nonverbal IQ. Similar in:
- Response to intervention
- Aetiology

Prognosis generally better for those of high IQ

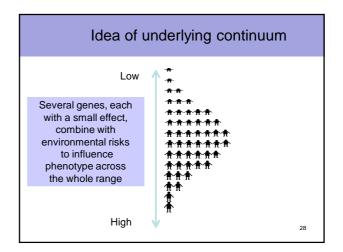
Stanovich, K. E. (1994). Annotation: does dyslexia exist? . Journal of Child Psychology

and Psychiatry, 35, 579-595.
Reilly, S., et al. (2014). SLI: a convenient label for whom? International Journal of Language and Communication Disorders.

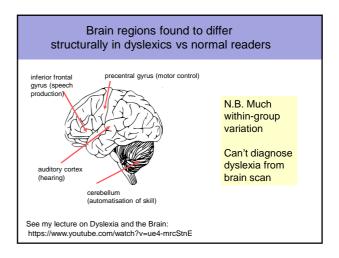


Genetic research: focus on underlying causes

- · Case of FOXP2 led to expectation that we might find clearcut genetic mutations to explain all severe language impairments
- · Not so! Language impairments behave like "complex multifactorial disorders"



Neuroscience

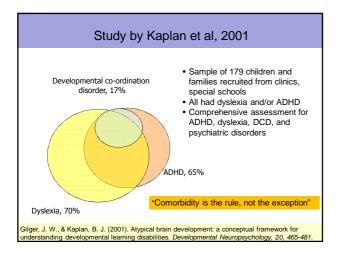


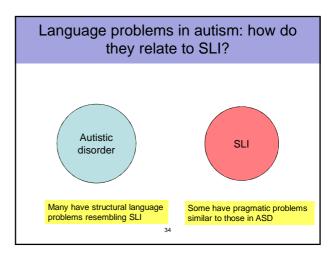
Bottom line: genes and brains

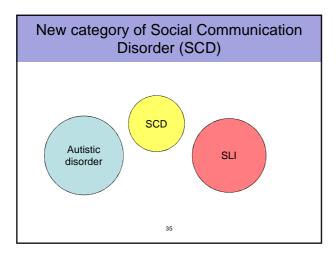
- Both SLI and dyslexia are complex and multifactorial
- Some evidence for effects of genes and brain differences in determining who has problems
- · But no single major causes identified
- Not possible to diagnose with genetic test or brain scan

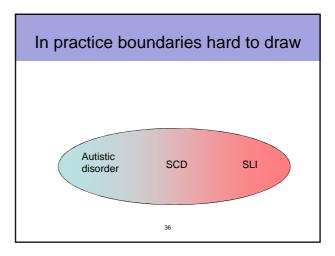
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Clearcut boundaries between disorders?









General issues for neurodevelopmental disorders SLI ASD dyslexia · Overlap at behavioural level · Also overlapping causes and neurobiology





- Neurologist: Developmental co-ordination disorder (DCD)
- · Paediatrician: ADHD



Should we abandon diagnostic labels?

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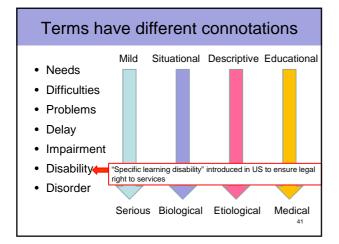
Tension between education and medicine Education

- · General dislike of medical labels
- · Prefer 'needs' or 'problems' to 'disability' or 'disorder'
- Focus on social rather than biological causes

Medicine

- Diagnostic labels
 - International Classification of Diseases (ICD10)
 - DSM5
- Emphasise neurobiological origins/genetics

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For dyslexia (and SLI?):

Questions about impact of label: Suggestions that it may do more harm than good

Arguments against labelling as disorder

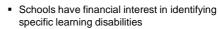
- Focus on what is wrong with the child; may ignore aspects of environment
- Can be excuse for what is really consequence of bad teaching



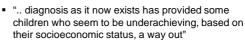
- · Parents/teachers take no responsibility
- · Child feels failure inevitable, stops trying
- Labelling leads to stigmatisation, social disadvantage and exclusion

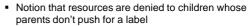
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Sternberg & Grigorenko Our Labeled Children (1999)









- Implication seems to be that life will be fairer if we do away with labels
- · Runs risk that no children will get adequate services!
- · May be better to retain labels but ensure they are used fairly

Two things we can all agree on?

 There are children who have difficulties with oral or written language that are serious enough to affect everyday life and academic outcomes and are not just a consequence of poor schooling/parenting



 We should do our best to help these children overcome these difficulties: doing nothing is not an option

Bishop, D. V. M. (2014). Ten questions about terminology for children with unexplained language problems. *International Journal of Language and Communication Disorders.* (To be published Open Access in summer 2014)

Adult outcomes for school-aged children with language impairments Academic Psychiatric problems

Increased risk

Unemployment

Social

N.B. Outcomes very varied; may depend on severity and language profile. Comprehension problems seem to have worst prognosis:

Clegg J, Hollis C, Mawhood L, Rutter M (2005). "Developmental language disorders—a follow-up in later adult life. Cognitive, language and psychosocial outcomes". *J Child Psychol Psychiatry* **46** (2): 128–49.

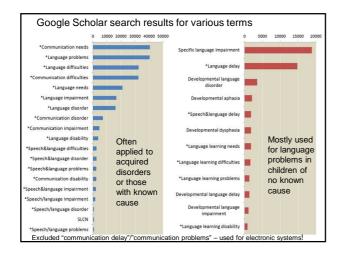
Questions we need to be able to answer

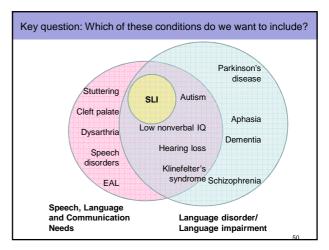
Can only answer these if we have common criteria for identifying problems and common language for referring to them

- Which children should get extra help?
- Audit: how many SALTs do we need?
- Is rate of language problems increasing/decreasing over time?
- How do different countries/region compare?
- What causes children's language problems?

Children's language impairments:

Current situation - inconsistency and confusion





Specific language impairment (SLI)

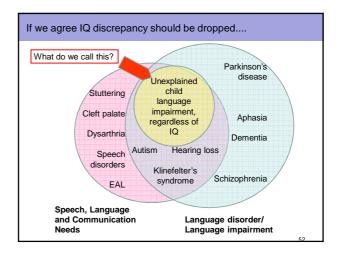
Advantages

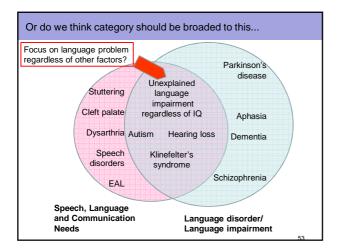
 Most common term in academic settings, though less widely used in clinical and educational practice in UK.

Disadvantages

Too exclusive: 'Specific' often taken to mean that child (a) has a substantial discrepancy between language and nonverbal ability and

- (b) has no other difficulties
 - this excludes many children from services
- Research on genetics and intervention does NOT support distinguishing children with and without verbalnonverbal discrepancy





SLI is too narrow: Three possible solutions

- a) Retain the term but use it less stringently, so specific just used to mean 'idiopathic', cf. ASHA (2008) :
- Nonverbal IQ broadly within normal limits
- Does not require absence of other neurodevelopmental problems
- b) Drop 'specific' and just use Language Impairment Preferred option of Reilly, Tomblin and others. PROBLEM: too general – poor internet search term; need specifier indicating child; loses distinction between language impairment of unknown cause and of known cause
- c) Use another term such as Language Delay, Primary Language Impairment, Developmental Language Disorder, Language Learning Impairment

Three terms that were not popular with commentators:

- · Language delay
- Developmental dysphasia
- · Primary language impairment

Language delay

Widely used, but NOT recommended Different meanings for different people!

- Sometimes as a rather general term to indicate the child has language difficulties – in which case 'delay' is a misleading in implying language will ultimately develop
- Sometimes to contrast with 'disorder' and to deny services!
- Main criterion can be whether language profile is uneven flat profile seen as 'delay' and spiky as 'disorder'.
- But research evidence does not support this distinction and in fact finds worse prognosis for 'delay'. No evidence that 'delay' has social origins

Developmental dysphasia/aphasia

- Advantages
 - Sounds 'neurological', parallel with dyslexia, and so taken seriously
- Disadvantages
 - Sounds as if there's a known neurological basis, when there isn't
 - Implies sharp divide with normality
- · Current status
 - Not much used in UK or US, but still quite often used in mainland Europe

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Primary language impairment

- · Not widely used: 362 hits on Google scholar search
- Used by Boyle et al (2007) to refer to language difficulties that are not secondary to another condition, without requiring a discrepancy with nonverbal ability

PROBLEMS

- · People may think 'primary' refers to school-aged
- People may interpret to mean language is the child's primary problem – subtly different meaning from 'not secondary to other condition'
- Not always easy to judge if a language problem is secondary to another problem
- Potential for confusion with 'pragmatic language impairment

Developmental language disorder

- Advantages
 - Descriptive, without implying anything about causes
 - This term will be used in ICD-11 (and also fairly compatible with DSM5 'language disorder')
- Disadvantages
 - Objections to 'disorder'; too medical, disease focused; implies qualitative rather than quantitative differences between children
 - Affected children grow up: 'developmental' may be seen as inappropriate for teenagers/adults

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Language Learning Impairment

Adopted for RALLI

Advantages

- Avoids 'specific', 'primary' and 'developmental', but more narrow than 'language impairment'
- · Focus on learning
- Could be applied to any child where language learning impaired, regardless of other factors
- Would imply dynamic assessment of learning potential should be used

Disadvantages

 Not widely used; break with the past, though some overlap with SLI

Remaining problem

- · All of these solutions focus just on language
- We know that language problems commonly cooccur with other areas of difficulty

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A more radical alternative

- Broad category of 'neurodevelopmental disability' for those in need for services
- 'Disability' emphasises impact on individual
- 'Neurodevelopmental' emphasises biological basis: not just poor teaching
- Supplemented with assessment to establish profile of difficulties/strengths on different dimensions, and determine which services to prioritise

Advantages

- · Avoids need for multiple diagnoses
- · Encourages multidisciplinary assessment

Disadvantages

- Difficult to overturn use of labels such as dyslexia/autism, which would be incorporated in this category
- Less of a link between language impairment and SALT provision

Lessons from dyslexia.

The importance of a good 'meme'

Alan Kamhi (2004)

"Why is it more desirable to have dyslexia than to have a reading disability?

Why does no one other than speech-language pathologists and related professionals seem to know what a language disorder is?

Why is Asperger's syndrome, a relatively new disorder, already familiar to many people?"

Kamhi, A. G. (2004). A meme's eye view of speech-language pathology. Language Speech and Hearing Services in Schools, 35(2), 105-111.

Memes: What Are They?

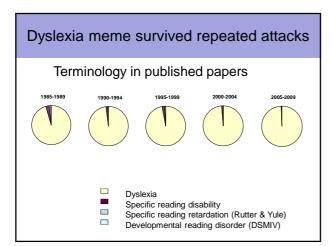
"Examples of memes are tunes, ideas, catch-phrases, clothes fashions, ways of making pots or of building arches. Just as genes propagate themselves in the gene pool by leaping from body to body via sperms or eggs, so memes propagate themselves in the meme pool by leaping from brain to brain via a process which, in the broad sense, can be called imitation."

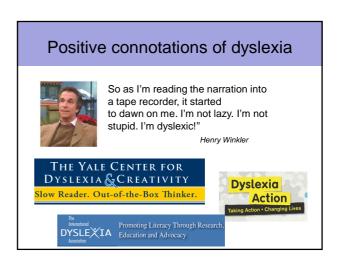


R. Dawkins

Successful meme

- Easy to understand, remember, and communicate to others
- Popularity of a meme does not depend on whether it is useful, true, or potentially harmful
 - In fact, dyslexia meme may be effective because it implies a distinct medical cause, when it is really just redescription
- Meme survival may be influenced by whether confers advantage to the person communicating





Conclusion

GOAL: Find an agreed way of identifying and talking about children who need services

WHILE

Minimising negative impact of labels:

- Misunderstanding
- Denial of services
 - Stigmatisation

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