DLD Summary: International consensus on diagnosis for children with problems with language development

Dorothy V. M. Bishop
Department of Experimental Psychology,
University of Oxford
“What d’you do then?”

“I do research on specific language impairment.”

“What’s that?”

“I do research on autism.”

“Oh, my grandson’s got autism.”

“I do research on dyslexia.”

“Oh, they had a programme on the telly about it last week.”
NIH funding over time for neurodevelopmental disorders

Labels used for unexplained language problems

<table>
<thead>
<tr>
<th>Prefix</th>
<th>Descriptor</th>
<th>Noun</th>
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<tbody>
<tr>
<td>Specific</td>
<td>Language</td>
<td>Needs</td>
</tr>
<tr>
<td>Primary</td>
<td>Speech and Language</td>
<td>Difficulties</td>
</tr>
<tr>
<td>Developmental</td>
<td>Speech/Language</td>
<td>Problems</td>
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<tr>
<td>(no prefix)</td>
<td>Language Learning</td>
<td>Impairment</td>
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<tr>
<td></td>
<td>Speech, Language and Communication</td>
<td>Disability</td>
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<tr>
<td></td>
<td>Communication</td>
<td>Disorder</td>
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<td></td>
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<td>Delay</td>
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Of 168 possible combinations, 130 found at least once.
33 distinct terms were used 600 times or more during that period.
Hypothetical 8-yr-old: George

- Late to start to talk
- Didn’t speak in sentences until 4 years old
- Otherwise developed normally
- Weak vocabulary for his age
- Struggles with reading: has extra support
- Doesn’t always remember what his teacher says
- Teased for not understanding jokes
- Loves art and constructing things
- Parental concern; he is now reluctant to go to school
- Hates being singled out and made to feel different from others.
Educational psychology 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-year-old level
What should be done about George?

- Nothing
- Extra classroom support
- Referral to speech and language therapist
- Something else?
Would George benefit from any kind of label?

• Speech, Language and Communication Needs (SLCN)
• Specific Language Impairment (SLI)
• Social Communication Disorder
• Developmental dyslexia
• Something else
• None of the above
Questions about **impact** of label: Might labels do more harm than good?
## 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
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
Sternberg & Grigorenko
*Our Labeled Children* (1999)

- Schools have financial interest in identifying specific learning disabilities
- Teachers “let off the hook”
- “.. diagnosis as it now exists has provided some children who seem to be underachieving, based on their socioeconomic status, a way out”
- Notion that resources are denied to children whose parents don’t push for a label

- 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
• “To the extent that clinical economy depends on getting the right treatment to the right people, clinicians are, no matter what their philosophical bent or political point of view, categorisers. At a purely practical level this depends on a judgement being made that such and such a child belongs to the category of those who ‘need help’, whereas another child belongs to a (usually) larger category who do not.” (p. 117).

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.

Adult outcomes for school-aged children with language impairments

- Academic failure
- Psychiatric problems
- Unemployment
- Social impairment

Increased risk

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

Questions we need to be able to answer

- 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?

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

Natalie (Team Spirit)

Gina

Courtenay

Becky

Beth (Team Spirit)

Raising Awareness of Language Learning Impairments: 2012
Goals of RALLI campaign

- Raise awareness of language impairments through YouTube
- Sort out the mess in definitions and terminology
Goals of RALLI campaign

• Raise awareness of language impairments through YouTube

• Sort out the mess in definitions and terminology
CATALISE

Criteria and Terminology Applied to Language Impairments: Synthesising the Evidence

Dorothy Bishop, Maggie Snowling, Paul Thompson & Trisha Greenhalgh
What is the focus?

Seek consensus on how to identify children in need of extra, specialist help with language beyond what is usually available in the classroom.
What was the consensus?
The Bottom Line: Consensus on terminology
Why is it so hard to agree on labels?

1. Label misleading in implying a clearcut, homogenous condition
A model that is tidy but wrong!

NB. Brain diagram is schematic: location of regions not realistic!
Closer to the truth……

- Many-to-one mappings
- Same cause, different effect
- Same disorder, different cause
- Gene x environment interactions
- Gene x gene interactions
Implications for DLD

• It is NOT a coherent syndrome and there are no neat subtypes

• Many overlaps with other neurodevelopmental disorders

• Can seldom attribute the language disorder to a single cause
But, we still need a label!

• We need a term to indicate the child has problems that might benefit from involvement of a speech-language therapist

• We need a way to group children for research purposes

• We also need a label that can be used by the general public

“We need a label with some authority. Once again, I really do have to go back to the suggestion of dysphasia, on analogy with dyslexia and dyspraxia. Terms like this have the advantage of sounding like real conditions (which is why parents will fight so hard for a 'diagnosis' of dyslexia). People sit up and take notice of it.”

Panel member
Diagnosing DLD
Starting point

Child with language difficulties that:
• impair social and/or educational functioning
• with indicators of poor prognosis

Language disorder
Child with language difficulties that:
- impair social and/or educational functioning
- with indicators of poor prognosis

Language disorder

Developmental language disorder (DLD)

Language disorder associated with X*

Important!
Not exclusionary factors.
Child eligible for assessment/intervention

*includes genetic syndromes, a sensorineural hearing loss, neurological disease, ASD or Intellectual Disability
Language Disorder is a subset of broader category of SLCN

![Diagram showing Language Disorder as a subset of Speech, Language, and Communication Needs]
DLD is a subset of Language Disorder

- Developmental Language Disorder
- Language Disorder
- Speech, Language and Communication Needs
This definition very broad: need additional information

Nature of language impairments
- Phonology
- Syntax
- Semantics
- Word finding
- Pragmatics/language use
- Verbal learning & memory

Decided against subtypes – too many children don’t fit neatly!

Risk factors
- Family history
- Poverty
- Low level of parental education
- Neglect or abuse
- Prenatal/perinatal problems
- Male

Co-occurring disorders
- Attention
- Motor skills
- Literacy
- Speech
- Executive function
- Adaptive behaviour
- Behaviour
Common questions

1. What about children with ‘language delay’?

- The term ‘language delay’ was rejected by the CATALISE panel: The ‘delay’ vs ’disorder’ distinction has been around for a very long time but there is remarkably little evidence to support it.

- Back in 1987 I found that children with a ‘spikey’ profile had milder problems and better prognosis than those with a ‘flat’ profile – yet the former group often get better access to therapy.

- In addition, it is sometimes argued that a distinctive profile of ‘language delay’ is caused by poor environment, but comparisons of children from deprived/non-deprived backgrounds don’t support this.

2. What about younger children who would not meet criteria for ‘disorder’?

They weren’t the focus of CATALISE, as we were concerned with those requiring Tier 3 specialist provision.

We don’t recommend using ‘disorder’ except for more persistent problems.

This group would come under the umbrella of SLCN; they could be referred to as having ‘language difficulties’ or ‘needs’.
Common questions

3. Will services get flooded with low IQ children who were previously excluded because their problems were not ‘specific’?

Population survey of children in Surrey by Norbury:

- 4.8% with DLD and average range IQ (85 upwards)
- 2.8% with DLD and low average IQ (70-84)
- 2.34% with language disorder + associated condition

- No differences between those with average and low-average NVIQ scores in severity of language deficit, social, emotional, and behavioural problems or educational attainment.
- In contrast, children with language impairments associated with known medical diagnosis and/or intellectual disability displayed more severe deficits on multiple measures.
Access to services: a key issue

- Rational response requires speech-language therapy (SLT) profession to examine what it has to offer by way of effective intervention.

- Evidence base is still very weak, so decisions often based on habitual practice, assumption that intervention works, or local pressures.

- Urgent need for more multicentre intervention research: won’t get funding unless can demonstrate impact of SLT.

- Need outcome measures that assess impact on child and family social and educational functioning: many language disorders won’t be ‘cured’ but can be managed to make a big difference (cf. autism, hearing impairment).
Conclusion

Remember! Not a single, homogenous condition, and no label is perfect.

Hope is that we can agree to go with the consensus and so move forward to raise awareness, improve services to children, and do much-needed research.

http://www.slideshare.net/deevybishop/ijlcd-winter-lecture-20167-references