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Editorial Perspective: Speaking up for developmental language disorder – the top 10 priorities for research

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Developmental language disorder (DLD) is one of the most common neurodevelopmental conditions, yet is also one of the least recognised and poorly funded in terms of both service provision and research (Bishop, 2010; McGregor, 2020). Prevalence studies suggest DLD affects around 7% of children at school entry (Norbury et al., 2016), and longitudinal studies highlight its stable trajectory (e.g. McKean et al., 2017) and lifelong impact (Clegg, Hollis, Mawhood, & Rutter, 2005). As well as facing significant difficulties with communication, children and young people with DLD are at risk of experiencing a range of associated challenges with education and employment (Conti-Ramsden, Durkin, Toseeb, Botting, & Pickles, 2018), quality of life (Eadie et al., 2018) and mental health and well-being (Yew & O’Kearney, 2013).

The wide-ranging and serious effects of DLD are well recognised in parts of the research community; for example, the Journal of Child Psychology and Psychiatry (JCPP) has a rich history of publishing seminal papers and has previously curated a special issue on the topic (Norbury & Sonuga-Barke, 2017). Nevertheless, DLD remains chronically understudied. Bishop (2010) analysed the number of papers published relative to prevalence and impact across 35 developmental conditions over a 15-year period. A clear pattern emerged in which rare disorders with a known genetic or acquired aetiology, with more severe outcomes, tended to be more extensively researched than more common conditions. In stark contrast, where multifactorial causation is suspected, severity and prevalence were not consistent predictors of research activity. While ADHD and autism spectrum disorder fell within the range of predicted research for a given prevalence and severity, the number of publications for developmental language disorder was 16 times lower than ADHD. It was also notable that there were three times as many

studies on developmental dyslexia as on DLD, even though these conditions are similar in terms of rated severity and prevalence. Even after a decade of campaigning this pattern remains; between 2010 and 2020, 0.16 papers per 100 were published on DLD (McGregor, 2020).

At current levels of research investment and publication, our understanding of DLD will take many decades to improve, affecting the life-chances of further generations of children and young people. In their introduction to the JCPP’s special issue on DLD, the editors (Norbury & Sonuga-Barke, 2017) highlight the amount, variety and coherence of the research required, suggesting the next 25 years require a clear, co-ordinated and scaled-up research agenda to deliver maximum impact for individuals with DLD, focusing on three broad areas: (1) large-scale randomised controlled trials to explore language change and response to treatment; (2) intervention studies exploring the impact of improved language on communication and other outcomes, including mental health, education and psychosocial adjustment; and (3) longitudinal research, to develop our understanding of DLD in older children and adults. This provides a useful summary from leading researchers in the field, but for research to have real world impact, it is vital for the voices of all key stakeholders to be heard and for research agendas to be shaped in partnership with those with most at stake: in this case people with DLD, their families and carers, and the professionals who support them. To that end, the Royal College of Speech and Language Therapists (RCSLT) ran a research priority-setting partnership (PSP), concluding in 2019, which drew from James Lind Alliance (JLA) methodology (see Figure 1 for overview) and included all principal stakeholders, with adaptations made to the communication demands of priority-setting activities to ensure all involved could play an equal part.

An initial survey identified clinical questions that speech and language therapists felt most urgently needed answering. A subsequent literature search verified which of these questions had not yet been addressed in systematic reviews, randomised controlled trials or clinical guidelines based on this level of evidence, and allowed any further areas of uncertainty to be established. Grouping of these uncertainty areas resulted in 11 broad topics: raising awareness; identification (relating to initial referral to speech and language therapy or screening for DLD); assessment and diagnosis (relating to the ways in which DLD is formally assessed and distinguished from other communication difficulties); intervention; service provision (primary-aged); service provision (secondary-aged); service provision (adults); multi-disciplinary working; bilingualism; lifelong impact; and technology.

Speech and language therapists supported children and young people with DLD and their caregivers to prioritise these topics using a specially designed protocol (see Chadd, Kulkarni, & Longhurst, 2020, for further details) that enabled adaptation of activities and materials to suit each individual's unique communication needs. Professionals working in DLD then identified the specific research required within the prioritised broad topics across two, multi-stakeholder workshops. The majority of these professionals were SLTs in clinical practice, but representatives from psychology, education, academia and charities/service-user organisations also took part. This resulted in a longlist of 60 research areas, which were then prioritised via online surveys, including an adapted survey for children and young people with DLD and their care-givers. Data from the earlier prioritisation task by children and young people with DLD and their care-givers were also incorporated via a novel weighting process (Chadd et al., 2020). Over 500 professionals and 43 children and young people with DLD, and their families or carers contributed to this process, through which the top 10 research priorities for DLD were identified (see Box 1).

There is clear alignment between these multi-stakeholder priorities and the three broad research areas suggested by Norbury and Sonuga-Barke (2017). Developing effective interventions with meaningful outcomes, the second of Norbury & Sonuga-Barke's themes, is a focus across most of the priorities (1, 2, 3, 4, 6, 8 and 9). Developing our understanding of DLD in older children and adults, also emerges as an explicit priority (6 & 10). This system-wide prioritisation partnership suggests one further research priority – developing understanding of and support for children and young people with DLD amongst professionals working in education – the topic of the final two priorities (5 & 7). Taken together, this focus on genuine impact, on holistic outcomes, across a life course perspective, and supported by more integrated working, also

Box 1 Top 10 research priorities in DLD¹ (descending priority)

1. Outcomes for individuals with DLD across settings (e.g. special educational or mainstream schools), in relation to curriculum access, language development and social skills.
2. Specific characteristics of evidence based DLD interventions which facilitate progress towards the speech, language and communication-related goals of an individual with DLD.
3. Relative effectiveness of face-to-face versus indirect approaches to intervention for individuals with DLD
4. Identify and/or develop and evaluate effective interventions targeting receptive language for individuals with DLD.
5. Impact of including speech, language and communication needs (SLCN)/ developmental language disorder (DLD) in teacher training course curricula on referral rates and level of support for children with DLD.
6. Impact of SLT interventions for adolescents and adults with DLD, on wider functional outcomes (e.g. quality of life, access to the curriculum, social inclusion and mental health).
7. Implementation of SLT recommendations in the classroom by teaching staff: confidence levels, capacity, capability and levels of success.
8. Identify and/or develop and evaluate effective ways of teaching self-help strategies to children and young people with DLD.
9. Impact of targeted vocabulary interventions on curriculum access for individuals with DLD.
10. Impact of teacher training (on specific strategies/ language support) on academic attainment in adolescents with DLD in secondary schools.

resonates with the World Health Organisation's definition and priorities for health and health services (WHO, 2021).

What next?

Research takes time, research funding is limited, and we cannot afford research resources to be wasted. Hence, these priorities matter. They provide a voice for children and young people with DLD and those working with them, and they show clear alignment with previous assessments of the evidence

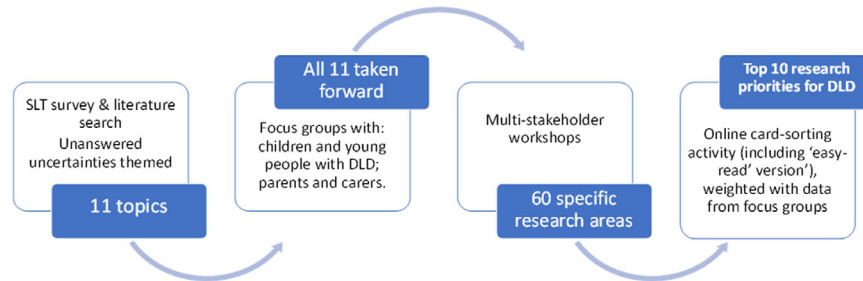


Figure 1 Overview of research priority-setting process

(Norbury & Sonuga-Barke, 2017). It is crucial that we draw from these priorities, especially now, following the disruption caused by COVID-19. Fully understanding the impact of the pandemic and the associated lockdowns will take time, but early evidence suggests a disproportionate negative impact on all aspects of development, including communication and mental health outcomes, for children and young people with DLD and other special educational needs (Ofsted, 2021). What was already an alarming dearth in research attention paid to people with DLD has therefore become even more consequential, but with the prospect of increased pressure on research funding and therefore reduced research capacity. As a result, we call on the research community to focus efforts on the areas that matter most to those with a stake in the outcome of that research, be they practitioners, families or children and young people with DLD. The DLD research priorities identified here provide this focus. They are a call to arms. Children and

young people with DLD, their families and carers, and the people working with them have told us what matters most and where answers are urgently needed. It is now time to listen. Their priorities must be the priorities for research funders; their questions should be the questions that shape the research agenda for the coming decades so the next generation of children with DLD have the best chance to live fulfilling, and healthy lives.

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Key points

- DLD is a common, but under-served and under-researched developmental condition.
- Disorders of language increase risk for adverse mental health outcome.
- This editorial perspective highlights 10 Research Priorities identified by the Royal College of Speech and Language Therapists through consultation with researchers and stakeholders, including young people with lived experience of DLD.
- These priorities highlight the need for increased funding to investigate optimal treatment approaches, involving joint working with other clinical professions, and assessing the impact of improved language on other developmental outcomes, including quality of life and mental health.

Note

¹Since the list was first published, minor changes have been made to the wording of priorities to reflect terminology currently used.

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