

This is an Accepted Manuscript of a chapter published by Taylor & Francis Group in Law J, McKean C, Murphy C & Thordardottir E (eds.) *Managing children with developmental language disorder: theory and practice across Europe and beyond*. Abingdon: Routledge, pp. 497-509 on 18 Jun 2019, available online: <https://www.routledge.com/Managing-Children-with-Developmental-Language-Disorder-Theory-and-Practice/Law-McKean-Murphy-Thordardottir/p/book/9781138317246>

UK Vignette – Theory and practice for children with developmental language disorders

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1. History of language impairment/ developmental language disorder in the UK – first identified by whom – definitions, prevalence, key theoretical figures

The earliest references to developmental speech and language disorders (Wylie 1894; Kerr 1897) initially referred to it as ‘congenital word blindness’ (Hinshelwood 1895) ‘congenital semantic aphasia’ (Head, 1926), ‘aphasia in children’ (Ewing 1930) and ‘congenital auditory imperceptions/ word deafness’ (Worster Drought & Allen 1929). By the 1940s, the first schools for children with ‘developmental aphasia’ were starting to open. However, language disorder was not included in the UK 1944/45 Education Acts as a category of disability, although ‘speech defect’ was. By the nineteen sixties, there was a much greater awareness of a clinical ‘population’ (Renfrew & Murphy 1964; Ingram 1959) and a series of seminal texts were published (Rutter & Martin 1972; Yule & Rutter 1987). The focus was on symptom description and differential diagnosis although texts commonly included a chapter on speech and language therapy interventions. The terminology has continued to develop (Reilly et al. 2014). The terms currently recommended in the UK are *Developmental Language Disorders* (DLD), the consensus diagnostic term adopted by researchers and speech and language practitioners (Bishop et al. 2016) and *Speech, Language and Communication Needs* (SLCN), the educational category which includes any child with speech and language impairments.

Into the 1970s, causal theories postulated difficulties in auditory perceptual or linguistic processing with concomitant implications for therapeutic approaches (Wyke 1978), and specific clinical language assessments became available (e.g. Reynell 1969). By the 1990s the field had broadened out considerably in the UK with major contributions for example from Bishop with regard to the characterisation of receptive language disorders (Bishop 1979; Bishop 1998) and from Van der Lely in relation to modularity in specific grammatical disorder (van der Lely & Wexler, 1998) but also the increasingly widespread use of linguistic (Crystal & Varley 1998) and psycholinguistic (Chiat 2003) approaches to description and intervention.

The prevalence of developmental language disorder

Prevalence is affected by how a condition is defined, and as classifications have changed over time the numbers of children deemed to have difficulties have fluctuated (Law et al. 2017a). Early estimates tended to be comparatively low. For example, Rutter et al. (1970) reported 0.8 per 1000 for children with the most severe manifestations of developmental language disorder, although one of the earliest population estimates suggested five or six percent of children have marked difficulties at school entry with boys outnumbering girls by 2 or 3 to 1 (Morley 1965). The most recent estimate is much higher at 9% of children presenting with functional limitations (Norbury et al. 2016). Such average figures obscure a clear social gradient for the prevalence of developmentally immature language skills (McKean et al. 2018), which may be as high as 40% in the most disadvantaged populations (Locke et al. 2002; Law et al. 2011). Such difficulties lead to an increased risk for a number of adult outcomes (Law et al. 2009). One concern picked up in the Better Communication Research Programme (to follow) was a level of ‘ethnic disproportionality’ in terms of different ethnic groups, with low prevalence rates being associated with restricted access to services (Strand & Lindsay 2009; Dockrell et al. 2014).

Intervention and evidence based practice

Although speech and language therapy practice for the child with DLD was developing during the 1950s and 1960s there was relatively little in the way of high-quality published evidence of intervention efficacy coming from the UK. With the development of evidence based practice (EBP) in medicine in the 1970s and 1980s came the need to undertake new, and to synthesise existing, intervention research and to help ‘interpret’ what it meant for practitioners. The cornerstone of this process is the systematic review and meta-analysis and the first two UK reviews were Law et al. (1998) and the Cochrane Review (Law et al 2003). Over time the need for evidence led (Law et al. 2015) to the establishment of an interactive on-line database hosted by the Communication Trust (<http://www.thecommunicationtrust.org.uk/whatworks>) which now has over 18000 signed up members. Nevertheless it is important to acknowledge that, whilst practitioners would all sign up to an EBP approach, many work within the UK’s National Health Service where resource constraints have a major impact on the design of services. One dimension that has received relatively little attention is the costs and benefits of language interventions, although in one modelling study a potential economic return of £6.43 was identified for every £1 invested in intervention for primary school-aged children with language impairment (Marsh et al. 2010). Parents may have to be insistent in order to secure services for their children. The children’s charity AFASIC (<http://www.afasic.org.uk>) was set up in 1968 by a parent of a child with DLD (Browning 1972) and has performed the important task of informing parents about the resources available to meet their children’s needs and how to fight for their rights. The Communication Trust was developed after the Better Communication Research Programme (q.v.) and has also played a major role in producing ‘user friendly’ materials for parents and practitioners. Both charities continue to lobby for the needs of children with DLD. Parents often have rather different perspectives from those of professionals in terms of what their children need (Band et al. 2002; Roulstone et al. 2012a). Clearly they are central to the concept of the well informed service user so important to the principle of evidence based practice (Law et al. 2015).

Population studies and a ‘public health’ approach

Although the ‘clinical’ approach has dominated much research and indeed provision in this area, a ‘whole population’ approach has become more common (Law et al.2013). The first example of this is the work of Morley in the 1950s with the Newcastle Thousand Families study (Morley 1972) but there have since been a range of studies drawing large scale population datasets (McKean et al. 2018). Intervention aimed at developing the whole population of children was expanded dramatically in England under a major government initiative called ‘Sure Start’ in the early 2000s. This included children’s language development as one of the key outcomes. The public health context is perhaps most coherently illustrated in the city wide intervention programme Stoke Speaks Out (www.stokespeaks.org). Speech and Language Therapists (SLTs) also focus on improving the communication environment for all children so that schools and nurseries become more ‘friendly’ for those with DLD and other disabilities

<https://www.thecommunicationtrust.org.uk/resources/resources/resources-for-practitioners/communication-friendly-checklists.aspx> ; <https://www.elklan.co.uk/information/cfs> .

Policy and legislation – how it has developed and what it means

The professional body

SLTs in the UK are represented by their professional body, the Royal College of Speech and Language Therapists (RCSLT: www.rcslt.org) with 17,000 members. Approximately two thirds of members work with children. RCSLT deals with professional standards and seeks to influence

government and other agencies on behalf of the profession and the clients they serve. It was founded in 1944 as the College of Speech Therapy, receiving a royal charter in 1995.

Service providers

As stated, the majority of SLT services for children with developmental language disorders are funded by the UK National Health Service (NHS) whose fundamental principle is that its services should be free at the point of use. Some NHS services are however contracted out to private providers, which are then commissioned by the NHS to provide interventions. Further, the four countries in the UK (England, Scotland, Wales and Northern Ireland) are ‘devolved’ with health, educational and social services becoming increasingly different across the different countries. Indeed, practice within the NHS, although evidence based, is tailored to localities, and most SLTs devise their own intervention plans, tailored to child goals, and follow locally agreed child ‘pathways’ through the service.

Child access to NHS SLT services may be by referral from professionals such as general practitioners, health visitors or school educational psychologists, or by direct referral from parents. Referral often results from parental concern, and may follow discussion with other professionals such as teachers or health visitors. It is common for speech and language therapy services to provide services within schools and early years settings, routinely based on agreed levels of service. Although most SLT services are provided by health services there is often a mixed model of funding with specific aspects of services being provided from a number of different sources. Services have developed considerably in recent years – especially for younger children – but, as with many publicly funded services, they expand and contract reflecting budgetary issues. In addition, there are some services provided by charitable organisations such as ICAN and a number of ostensibly private boarding schools for those with the most severe difficulties. There are also private SLT practices, more frequent within wealthy areas of the country – primarily the south east of England. Private practice offers a low percentage of SLT service.

Despite SLTs’ work in and with schools, an interesting tension has developed between health and education service providers. In part, this is based on epistemological differences between medical models using diagnosis and education models where intervention is targeted on an identified group of children or a whole child population. But under the surface there has also been a long running ‘border dispute’ in England and Wales between health and education providers as to which public body should fund services for children with DLD. Around the turn of the millennium the government departments for health and education in England commissioned a report to help resolve some of the issues involved, at least partly aiming to reduce the number of legal tribunals being pursued by parents unhappy with the provision offered their children (Law et al 2000). This has been resolved to some extent in recent years by explicit guidance in English legislation to the effect that responsibility for children with developmental language disorders may primarily be in health, especially in the preschool period, but ultimately educational services are responsible for all children in the classroom. There is also a presumption in law that children will attend mainstream school wherever possible. The introduction of new regulations outlined in the Children and Families Act 2014 and a new Code of Practice for children with special educational needs and disabilities (SEND) includes those with DLD and emphasises the need to involve families and the children themselves. There is now a *requirement* to consult with both children and families concerning the shape of services that they receive, and to involve children in decision-making about their own needs and wishes. This legislation, alongside studies of children’s perspectives (Roulstone et al, 2012a) has led to an increased focus on the achievement of functional communication outcomes for children and young people. With different legislation, similar issues have been considered in the other UK countries with similar outcomes.

Screening

Population screening has been considered a solution to the identification of children with developmental language delays (as it is for many other conditions). In 1997, the UK Health Technology Assessment programme of the NHS commissioned a series of reviews of screening, including for speech and language, but concluded that the evidence was not strong enough to recommend formal universal screening. At the same time national guidance suggested that testing young children was not the most effective way of identifying children with DLD (Hall 1989; Elliman & Emond 2019), and the recommendation was therefore for routine observations by health visitors and parental guidance. However, in recognition of the importance of early identification and the potential to prevent costly downstream interventions, all UK children are now profiled or assessed between two and three years. The Ages and Stages Questionnaire (Squires et al, 2009) and the Early Years Foundation Stage Profile (<https://www.gov.uk/government/publications/early-years-foundation-stage-profile-2018-handbook>) or similar measures are used respectively in health and early years' settings. The data from the ASQ are routinely collected and analysed at a national level. Analysis of data from 28,530 children in England showed 9% of boys and 3% of girls falling below threshold in the communication domain (Gair 2017).

The Bercow Report

The most significant recent government initiative has been the Bercow review of services for children with speech, language and communication needs in England (Bercow 2008). The review was commissioned by the Department for Education to chart the quality and availability of support for children with identified language problems (Lindsay et al. 2008) using the broad term SLCN, which will include children with DLD. The government's response to Bercow's recommendations resulted in the establishment of the Communication Trust, the appointment of a Communication Champion for England and Wales, and the commissioning of the Better Communication Research Programme (BCRP) (Dockrell et al. 2014). The lasting effects of the Bercow review have recently been summarised in the report 'Bercow Ten Years On' based on a national survey of parents, practitioners and other interested parties (ICAN and RCSLT 2018). Overall much progress had been made, but five key themes emerged from the review (<https://www.bercow10yearson.com/findings/>):

- i) Communication is crucial** to children's life chances. Awareness amongst the public and decision makers is still not high enough. More than three quarters of parents and carers said information about SLCN was either not easily available or not available at all.
- ii) Strategic system-wide approaches to supporting SLCN are rare** - very often SLCN does not feature in national or local policies. Ninety-five percent of survey respondents felt that central Government's contribution to raising standards and improving outcomes for children and young people with SLCN is either not clear or in need of strengthening: fifty-three percent did not feel that the way children learn in schools supports their spoken language development.
- iii) Services can be inaccessible and inequitable.** Too often support for children's SLCN is planned and funded based on available resources, rather than what is needed, leading to an unacceptable level of variation across the country. Almost 40% of survey respondents felt that service commissioners' understanding of speech, language and communication required significant improvement. Only 15% of people said that the right level of speech and language therapy was available in their area.

iv) Support that makes a difference is based on the evidence of what works. However, service design and cuts frequently do not take account of the evidence we have. Only 15% of survey respondents felt that data were regularly collected and shared. The majority of NHS speech and language therapy services said their commissioner measured the performance of their service on outputs – such as the number of children seen – compared with around a third who were measured on the impact of their service.

v) Too many children with SLCN are being missed, and are not getting the vital support they need. Forty-eight percent of respondents thought the expertise of school and early years staff to identify and support children and young people's speech, language and communication was good or excellent. Yet half of parents said their child's needs were not picked up early enough. Just 12% of parents surveyed said their child's difficulties were identified by a professional.

2. Who delivers services and where?

The majority of public sector funded SLTs who work for the NHS are based in community health clinics or child development centres, and either see children within the clinical facility or provide 'outreach' to day care, nurseries and schools. Some children are initially assessed in the home, usually those with marked neurodevelopmental disorders such as cerebral palsy. Models of service delivery are complex, and there is limited research on the effectiveness or otherwise of commonly-used models (Ebbels et al. 2018).

School-based services are probably the most common location of intervention for DLD in the UK (Roulstone et al. 2012b). Each of the four devolved nations of the UK has school curriculum policies that develop listening and talking, and legislation to ensure that each child's special educational/additional support needs are met, with educational services provided to support language disorders. SLTs often contribute to this support in schools, working with educational staff to advise them of general good language practices; to suggest interventions that may be delivered by educational staff, or to work with and support educational staff who are delivering interventions. Many SLT services also employ clinical support workers as SLT assistants to deliver intervention tasks with children. SLTs at times also work personally with individual or small groups of children. Language units or classes, where children spend time in separate groups, are mainly offered to children with the more severe difficulties. SLTs also work on developing 'communication friendly' environments where the whole communication environment rather than the needs of the individual child are the focus.

3. What do people do with children with DLD

Evidence-based interventions, such as those from the Communication Trust's 'What Works' data base and from SpechBITE (<http://speechbite.com>) are available. Approaches include developing parent- or staff-child interaction, direct language teaching, and supporting pragmatics. Widely-used named interventions with some supporting evidence include the Hanen Programmes, used to promote parent/child interaction; Colourful Semantics; the Strathclyde Language Intervention Programme; Shape Coding and the Nuffield Early Language Intervention (NELI) programme. But there are also a great many less formally evaluated programmes such as the Derbyshire Language Scheme, Boosting Language Auditory Skills and Talking (Blast); ICAN's Early Language Development Programme (ELDP); Talk Boost and Early Talk Boost which are widely used by practitioners across the country. Further, while such programmes often have formal procedures which are key to their delivery, they are often adapted by practitioners and combined in an eclectic mix, rather than being used as discrete entities (Roulstone et al. 2016, p. 218). This aims to individualise the intervention to fit the particular profile of the child (Roulstone 2012b; Joffe & Pring 2008), but makes evaluating intervention outcomes very difficult.

Investigations of practice suggest that interventions often include training of key adults in children's lives in terms of their understanding of the nature of DLD, their role in intervention, and particular strategies that are helpful. With pre-school children, the engagement of parents is seen as central to the success of interventions but challenging in some social contexts. (Roulstone et al 2015; Klatte & Roulstone, 2016).

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4. Looking to the future – what would make a difference?

Definitions matter

We recommend that researchers and practitioners adopt the terminology and approach proposed by the CATALISE initiative (Bishop et al. 2016) to ensure that children with language learning difficulties are described in a consistent fashion, thereby allowing greater equity in service delivery and comparability across studies. This applies both to the use of the term ‘developmental language disorder’ for the most marked cases, and to the need to capture not only test scores but also how children are functioning more generally at school and at home. Improved public awareness of DLD would lead to significant progress.

Comorbidity

There is a need within an educational context for a better understanding of the relationship between oral language skills and other aspects such as social development and literacy. All too often, these are perceived as discrete where the evidence suggests that this is clearly not the case. Children with social-emotional and mental health difficulties are at very high risk of having language difficulties, and vice versa. The strength and pattern of these associations appear to vary as children develop (Lindsay and Dockrell, 2012).

Language and social risk

We need to know more about how social disadvantage and language development interrelate and to find means of clearly identifying those most in need of support with oral language skill, whilst also developing interventions with the capacity to increase children’s abilities to optimise their language skills, and thereby access the curriculum. On the one hand this is a matter of supporting enriched childcare and preschool provision from at least age two onwards, but it also requires developing the science of intervention with these children to determine who stands to benefit most from which approach.

Identification and screening

Children’s language development should be viewed as a public health wellbeing indicator, similar to obesity (Marmot 2010; Law et al. 2017b), rather than just an individual or ‘clinical’ concern. This is reflected in the UK introduction of universal speech and language screening to identify children who may benefit from further intervention discussed above (although see Law et al. 1998; Nelson et al. 2006). Public and professional awareness is key, as is the need to adopt a life course approach to understand the meaning of the risks associated with early difficulties.

Approaches and interventions

We need more good quality descriptions and evaluations of complex interventions which include clear theories of change/logic models and behaviour change taxonomies (Stringer et al. in preparation) and a better understanding of the ecological/social validity of interventions, and how valid they are for children from diverse social and cultural backgrounds. It is important that SLTs investigate parents’ beliefs and understandings about DLD as part of their initial assessments and ongoing interactions with families (Marshall et al, 2017).

Conclusions

As the ‘Bercow Ten Years On’ report has shown, there has been considerable progress over recent years in the service offered to the child with DLD in the UK. Professional understanding of the needs of these children is much more sophisticated than it was fifty years ago and services have developed considerably. The emphasis on working with the child in the most appropriate context

(usually schools and early years settings) is now universally recognised. However, there remains much that needs to be done in bringing together ‘practice’ in the clinic or school with external evidence. Research has been underfunded in this area and this creates challenges for evidence based decision making. Resources are key, but it is how we use those resources which will determine what happens in the next fifty years.

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