



The Association  
for Child and Adolescent  
Mental Health

# THE BRIDGE

November 2018

## Neuro development issue

Routine screening is needed to identify  
language problems in children with ADHD

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children's early language development

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## Editorial

*Guest Editor, Dr Mark Lovell*

This edition of The Bridge concentrates on neurodevelopmental disorders. Research, particularly on treatments in children within the neurodevelopmental arenas is limited and in many ways behind general mental health research for children or adults. In this bridge, there are summarised versions of JCPP (ACAMH's world leading multidisciplinary child and adolescent mental health journal) papers on the topics of speech, language and communication, ADHD and ASD, highlighting the advancement of research in these areas. It is acknowledged that more research is required to produce evidence based treatments, and even more work is required to get them from scientific papers into clinical practice, but also that this is a step wise process with understanding the conditions from a scientific perspective being part of it.

Mary Busk and Sue North from NHS England have also contributed updates and their views on the importance of identifying an Intellectual Disability for parents, carers, services and where national policy has a part to play. Mary has also contributed a separate piece on the importance of research for children with neurodevelopmental conditions.

Neurodevelopmental disorders are getting increased national attention, particularly in England, with the next 10 year NHS plan including Learning Disabilities, Autism and Mental Health as priorities and next steps for the transforming care agenda (home not hospital, for people with Autism and or Intellectual Disabilities) being considered. Prescribing practices in people with Intellectual Disabilities by GPs are being reviewed by Public Health England as part of the STOMP-LD agenda and Health Education England have recently concluded a project on workforce and are now progressing with considering other aspects of Intellectual Disability services eg leadership. The Royal Colleges of Psychiatry, Paediatrics and Child Health and General Practitioners are all working towards a joint response to the Lenehan report 'These are our children' which highlighted the issues faced by a select complex group of children with Intellectual Disabilities and/or Autism concentrating on their care, support and treatment. The government's green paper on education and mental health highlights vulnerable groups which include children with neurodevelopmental disorders. There have also been updates recently to NICE guidance on ADHD, ASD and a new guidance on services for people with behaviour that challenges, to supplement the guidance on assessment and treatment for this group.

This edition of the bridge is timely, with the publication of the Intellectual Disability Topic guide on the ACAMH website including an extended version of the IDIDA2H© framework.

I hope that you enjoy reading this version of the bridge

**Mark Lovell**

ACAMH Lead for CPD and Training



Research highlights in this edition are prepared by Dr Jessica K Edwards. Jessica is a freelance editor and science writer, and started writing for 'The Bridge' in December 2017.

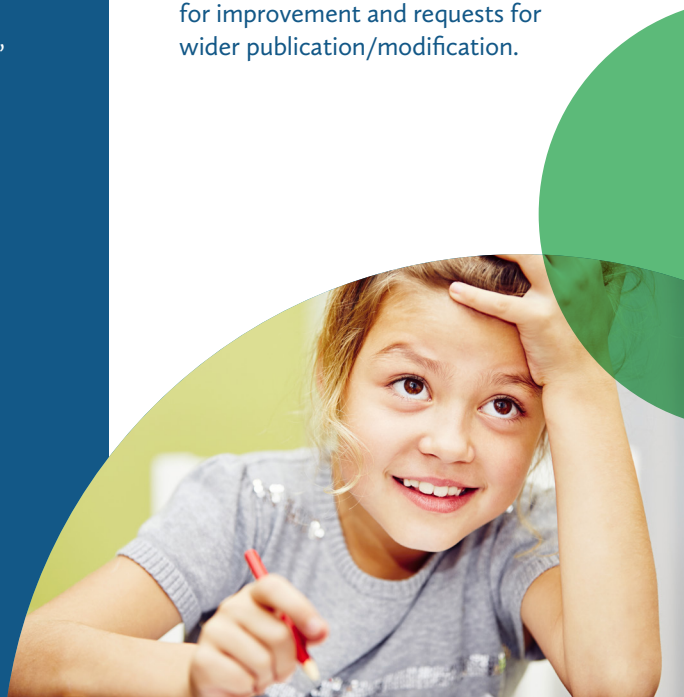
## ID topic guide

ACAMH Intellectual Disability topic guide is now online... with downloadable resources

The identification of an Intellectual Disability can be simple at times with clear evidence of an IQ below 70 and significant difficulties in adaptive behaviours. On other occasions the identification can be complex with lack of credible evidence, conflicting views or a range of reasons for impaired adaptive behaviours or significantly low IQ scores upon testing.

ACAMH's Intellectual Disability Topic Guide is now available on the website **[www.acamh.org/learning](http://www.acamh.org/learning)**. It encompasses a framework (IDIDA2H©) to assist professionals in the identification of an Intellectual Disability.

It follows an earlier publication by ACAMH which described the IDIDA2H© in a short version **[www.acamh.org/blog/what-is-an-intellectual-disability/](http://www.acamh.org/blog/what-is-an-intellectual-disability/)**. This is a longer more detailed version with additional resources including a parent/carers leaflet about the information required, a professional's information collection tool and a powerpoint presentation for use by professionals. The IDIDA2H© resources are free to use and can be reproduced. Feedback on the tool is welcomed by the author, please email **[mark.lovell@nhs.net](mailto:mark.lovell@nhs.net)** with comments, suggestions for improvement and requests for wider publication/modification.





# Children with a language disorder are vulnerable to sexual abuse

By Dr Jessica K Edwards

Preliminary data suggest that children with language disorder may be at an increased risk of child sexual abuse (CSA)<sup>1,2</sup> but few have studied the CSA experiences, disclosure patterns or reactions to disclosure in these children. Brownlie and colleagues have now addressed this question in a prospective longitudinal study of a nonclinical community sample of 5-year-old children with a language and/or speech disorder. The children were followed to adulthood and at age 31 years were asked to complete questionnaires regarding their experiences of CSA, their disclosure of CSA (including context, timing and outcome) and the subsequent social reactions. Women with Language Disorder who reported CSA by age 18 experienced a higher level of sexual invasiveness and severity compared to women without Language Disorder who had experienced CSA. Those with Language Disorder were also

more likely to report CSA than those without Language Disorder (43 vs. 16%, respectively). Interestingly, 63% of affected women with Language Disorder felt that their situation improved following disclosure or discovery of the event, compared to only 16% of women with no Language Disorder. Despite this difference, the likelihood of disclosing the event, latency of disclosure and social reactions to disclosure was the same between the two groups. The researchers propose that communication difficulties in girls may be a risk factor for CSA, and recommend that further studies now be conducted to understand how Language Disorder mediates this risk.

Referring to:

Brownlie, E.B., Graham, E., Bao, L., Koyama, E. & Beitchman, J.H. (2017), Language disorder and retrospectively reported sexual abuse of girls: severity and disclosure. *J Child Psychol Psychiatr.* 58: 1114-1121. doi:10.1111/jcpp.12723

Further reading:

<sup>1</sup>Brownlie, E.B. et al. (2007), Language impairment and sexual assault of girls and women: Findings from a community sample. *J Abnorm Child Psychol* 35:618-626. doi: 10.1007/s10802-007-9117-4

<sup>2</sup>Sullivan, P.M. et al. (2000), Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse Negl*, 24: 1257-1273

## Glossary:

**Language disorder:** Persistent difficulties in the acquisition and use of language across modalities due to deficits in comprehension or production. According to the DSM-5, these deficits can include reduced vocabulary, limited sentence structure and impairments in discourse. Such language difficulties result in functional impairment in school performance, in communicating with peers and caregivers and in participating in social settings broadly. Language difficulties are not attributable to other medical or neurological reasons and are not better explained by intellectual disability or global developmental delay. Symptom onset occurs during childhood development.

# Early speech sound disorder alone confers a low risk on reading difficulties

By Dr Jessica K Edwards

Early speech sound disorder (SSD) combined with other risk factors, such as language impairment (LI) and dyslexia, can have negative consequences on literacy development, according to new research from Marianna Hayiou-Thomas and colleagues. The researchers screened a cohort of 245 children for SSD at age 3.5 years using the Diagnostic Evaluation of Articulation and Phonology. A total of 68 children with SSD were identified, of which >50% still exhibited SSD at age 5.5 years. The children completed assessments for literacy skills based on measures of phoneme (language sounds) awareness, word-level reading, spelling and reading comprehension at age 5.5 and 8 years. Those with SSD showed weak emergent literacy skills compared to typically developing controls in terms of phonemic skills at age 5.5 years and word reading at age 8 years. When subdividing those with SSD according to co-occurring conditions, children with isolated SSD showed problems in literacy only at age 3.5 years thus suggesting that poor literacy due to SSD alone is short-lived and has only a modest effect on literacy development. Those with SSD and LI, however, showed worse literacy skills than those with SSD alone at ages 5.5 and 8 years, and this effect was even more pronounced in those also at familial risk of dyslexia. The researchers advise that clinicians should monitor children through the early stages of literacy development if they have SSD and a family risk of dyslexia or a co-occurring LI.

Referring to:

Hayiou-Thomas, M.E., Carroll, J.M., Leavett, R., Hulme, C. & Snowling, M.J. (2017), When does speech sound disorder matter for literacy? The role of disordered speech errors, co-occurring language impairment and family risk of dyslexia. *J Child Psychol Psychiatr.* 58: 197-205. doi:10.1111/jcpp.12648

**Glossary:**

**Speech sound disorder (SSD):** A persistent difficulty with speech sound production that interferes with speech intelligibility or prevents verbal communication. Symptoms first emerge in early childhood and are not attributable to congenital or acquired conditions. Affected children make systematic omissions, substitutions or distortions of phonemes within words, despite being able to repeat these phonemes in isolation.







# Machine learning improves ADI-R efficiency

By Dr Jessica K Edwards

Early interventions in autism spectrum disorder (ASD) are essential to improve communication and behavioural skills in affected children. Now, researchers have used machine learning to derive new instrument algorithms that may help practitioners screen for autism more efficiently and effectively. The study, published in the *Journal of Child Psychology and Psychiatry* in 2016 used scores from two well-established caregiver-report tests — the Autism Diagnostic Interview-Revised (ADI-R) and the Social Responsiveness Scale (SRS) — from 1,264 individuals with ASD and 462 with non-ASD developmental or psychiatric disorders. The researchers used their machine learning technique to correlate the caregiver responses to individual questions with the child's clinical

diagnosis. In this way, the researchers identified redundant questions in the two tests, and specifically reduced the ADI-R to only five questions that they say could maintain instrument performance at 95%. These questions included ADI-33, 34, 35, 50 and 73, which assess stereotyped language, social verbalization / chat, reciprocal conversation, gaze and abnormal responses to sensory stimuli, respectively. The researchers thus consider that certain diagnostic constructs may be more important than others in predicting a clinical diagnosis. Furthermore, they propose that with further clinical testing, machine learning may help make the diagnosis of ASD more effective and systematic, reducing the frequency of misdiagnosis.

Referring to:

Bone, D., Bishop, S.L., Black, M.P., Goodwin, M.S., Lord, C. & Narayana, S.S. (2016), Use of machine learning to improve autism screening and diagnostic instruments: effectiveness, efficiency, and multi-instrument fusion. *J Child Psychol Psychiatr.* 57: 927-937. doi:10.1111/jcpp.12559

## Glossary:

**Machine learning:** A computer-based method in which statistical techniques permit computers to progressively improve performance (learn) on a given task without being explicitly programmed.



# Children with ASD show intact statistical word learning

By Dr Jessica K Edwards

Children with autism spectrum disorder (ASD) and specific language impairment (SLI) exhibit word-learning difficulties early in childhood development. Although the mechanisms underlying these deficits are largely unknown, the Procedural Deficit Hypothesis (PDH) puts forward that abnormalities to the brain structures that constitute the procedural memory system lead to impaired linguistic and non-linguistic function.<sup>1</sup> Researchers at the University of Wisconsin have now examined two word-learning mechanisms in school-aged children with SLI (n=23) and ASD (n=25): statistical learning and fast mapping. Statistical learning is a procedural learning process through which regularities and patterns in word sequences are extracted. Under the PDH, statistical learning is crucial for learning rule-based features of language such as grammar and phonology (sounds). Conversely, fast mapping is a declarative learning process through which rapid word acquisition occurs after only a brief exposure to new information. Here, children with SLI exhibited poorer statistical learning compared to typically developing (TD) controls, which is in line with the PDH. However, they also exhibited poorer fast mapping compared to typically developing (TD) controls. Conversely, children with ASD with normal language abilities showed intact statistical learning and fast mapping. Furthermore, those with ASD co-existing with language impairment showed only subtle weaknesses in fast mapping. Despite exhibiting deficits in statistical learning and fast mapping individually, children with SLI showed equivalent word acquisition to children with ASD and TD controls in a combination task, in which they were first exposed to an artificial language to reinforce phonemes before fast-mapping. The researchers propose that here, the additional phonological exposure boosted word-learning performance in children with SLI. These findings counter those that imply that language impairments in ASD stem from deficits in procedural learning,<sup>1,2</sup> and also suggest that children with SLI may benefit from additional phonetic input.



## Referring to:

Haebig, E., Saffran, J.R. & Weismer, S.E. (2017), Statistical word learning in children with autism spectrum disorder and specific language impairment. *J Child Psychol Psychiatr*. 58: 1251-1263. doi:10.1111/jcpp.12734

## Further reading:

<sup>1</sup>Ullman, M.T. et al. (2005), Specific language impairment is not specific to language: The procedural deficit hypothesis. *Cortex*. 41: 399-433. doi: 10.1016/S0010-9452(08)70276-4

<sup>2</sup>Walenski, M. et al. (2006), Language in autism. In so.o. Moldin & J.L.R. Rubenstein (Eds.), *Unverstanding autism: From basic neuroscience to treatment* (pp.175-203). London, UK: CRC/Taylor & Frances Books.

## Glossary:

**Procedural Deficit Hypothesis (PDH):** abnormalities of the brain structures that constitute the procedural memory system in the frontal/ basal ganglia, lead to impairments of the linguistic and non-linguistic functions that depend on it and thus specific language impairment.

**Procedural learning:** the acquisition of a skill (i.e. how to do something) through repeated performance and practice.

**Declarative learning:** the acquisition of a declarative piece of information (i.e. knowing that something is the case).

**Phoneme:** the smallest unit of sound in speech. Phonemes are not the letter itself, but the sound that is made, and thus can consist of more than one letter.





# Parent-delivered teaching supports children's early language development

By Dr Kelly Burgoyne, University of Manchester

*This article is a summary of the paper 'An evaluation of a parent-delivered early language enrichment programme: evidence from a randomised controlled trial' by Burgoyne et al. (2018), published in the Journal of Child Psychology and Psychiatry.*

In the UK, children start school at the beginning of the school year in which they turn 5 years of age. By this time, children are expected to have well-developed language skills: we expect them to be able to listen to other people and understand what they are saying, to follow instructions, and to use language to express their own ideas, thoughts, wishes, and needs clearly. Children who start school without these language skills may not be able to meet the academic and social demands of the classroom and, consequently, may be at risk of poorer academic progress and difficulties with behaviour. Supporting early language development in the pre-school years therefore has the potential to make a considerable difference to later outcomes.

Parents are their child's first teachers and they are well-placed to support early language development. Providing parents with the tools to promote their child's language development has long been regarded as a potentially effective strategy for boosting early language skills in the pre-school years, but there has been little robust evidence to support this idea. To explore this further, we received funding from the Nuffield Foundation to develop and evaluate a language teaching programme designed for

parents to use with their pre-school child at home. We called this programme Parents and Children Together (PACT).

The PACT programme aims to support children's early language skills using three key strategies: interactive reading, vocabulary teaching, and narrative (storytelling) activities. During interactive reading, parents and children read a storybook together and talk to each other about the story. Parents encourage and support their child to play an active role during shared reading by, for example, commenting on the pictures, asking questions, and pointing out ways that the story relates to the child's life. Vocabulary teaching focuses on learning a set of words that are related to the story. Teaching activities and visual resources are provided to support learning the meaning of the words in different contexts. Narrative and extended language skills are developed through sequencing activities, summarising pictures from the story, and telling and retelling stories.

Parents and children use the PACT programme every day (5 days a week) for about 20-minutes. The daily teaching activities follow a consistent structure and routine (see Box 1). Families are provided with everything they need to deliver the programme over 30-weeks of teaching (i.e. 150 teaching sessions in total), including storybooks, scripted teaching sessions, and visual materials to support the teaching activities.



We conducted a Randomised Controlled Trial (RCT) to evaluate the effect of the PACT programme on children's early language skills. To do this, we worked with 22 Children's Centres in 3 Local Authorities in the North-West (Blackpool) and Greater London (Bexley and Lambeth). Children's Centre staff helped us to recruit 208 pre-school children (aged between 2 years, 7 months and 3 years, 6 months at the start of the study) and their families to take part in the project. Families were randomly assigned to one of two groups: one group received the language programme, and the other group received an active treatment control programme (developed by the research team for the project) which targeted early movement and self-care skills. This programme was delivered in the same way as the language programme which meant that we could be confident that any effect of the language programme was due to the nature of the teaching involved rather than the extra attention parents were giving to their child.

We measured children's language and narrative skills three times over the course of the project: at the beginning, after 30-weeks of working on the PACT programme, and 6-months after teaching at which time children were in the first few months of school. There were no differences between the two groups of children at the start of the project. Immediately after teaching, children who had received the language programme had made more progress in their language and narrative skills than children who had received the motor skills programme. Importantly, these children still showed stronger language skills when we assessed them again 6-months later. We also assessed their emerging literacy skills at this time and found that children who had received the language programme could read more (regular) words and knew more letter sounds than children in the motor skills group.

This study showed that the PACT language teaching programme can help parents to effectively support their child's language skills in the year before they start school. The results also suggest that this might help to support children in the early stages of learning to read. Parents were generally very positive about the programme, reporting that they and their child enjoyed it and they believed it made a difference to their child's development. There are some limitations to our study which are worth bearing in mind when considering these findings. For example, parents need to have a basic level of literacy to be able to deliver the programme which means it may not be suitable for those with severe reading difficulties. The programme is also relatively intensive and some families may find it difficult to deliver the programme consistently.

Notwithstanding these limitations, the findings from this study are encouraging and suggest that parent-delivered teaching can make a significant difference to children's learning and development. It is worth noting that the form of that teaching appears to be critical: we found no effect of the motor skills programme on children's motor skills. Further work is needed to evaluate parent-delivered teaching programmes and identify those that are most effective.

We are continuing to develop the PACT language programme. We are working with Book Trust, the UK's largest children's reading charity, to revise the programme materials and produce them to a professional standard. We are also working with The Education Endowment Foundation (EEF) who are funding a new RCT to evaluate the revised programme with a large number of children and their parents in the UK. The project will start in September 2018.

*For more information about the PACT language teaching programme or the EEF-funded trial, please contact Dr Kelly Burgoyne, email: [Kelly.Burgoyne@manchester.ac.uk](mailto:Kelly.Burgoyne@manchester.ac.uk)*

### Box 1: Overview of language teaching programme


PACT Language Teaching Session (20 minutes)		
Introduction	Settling the child into the session	2 minutes
Interactive reading	Sharing books together - exploring, talking and having conversations linked to books and stories	5 minutes
Vocabulary	Exploring new words and talking about what they mean	5 minutes
Narrative	Activities designed to support narrative and extended language skills including sequencing, summarising, and retelling stories	5 minutes
Plenary	Review of session and sticker reward	3 minutes



#### Author Bio:

Dr Kelly Burgoyne: Kelly is a lecturer in language disorders in the Division of Human Communication, Development and Hearing at the University of Manchester. Kelly's research focuses on understanding children's cognitive development and the nature and causes of children's learning difficulties. She is particularly passionate about the development and evaluation of resources to support parents, schools and professionals to support children's development effectively.





# Routine screening is needed to identify language problems in children with ADHD

*By Dr Jessica K Edwards*

In 2017, Emma Sciberras and colleagues conducted a Research Review for the Journal of Child Psychology and Psychiatry to rigorously analyse how common are language problems in children with Attention-Deficit Hyperactivity Disorder. Here, the researchers discuss their main findings and explain why they consider that a screen for language function would be a valuable addition to current ADHD assessments.

In 1986, Beitchman and colleagues performed the first population-based study of co-morbid language problems and Attention-Deficit Hyperactivity Disorder (ADHD)<sup>1</sup>. They found that 5-year olds with language impairments had >6-fold increased risk of also having ADHD. Subsequent studies have confirmed these original findings and the reciprocal association between ADHD and a higher risk of language problems. However, many of the studies conducted to date have been limited by inconsistent or inadequate methods for diagnosing ADHD or assessing language, or have focused on clinical samples where children with severe ADHD and greater co-morbid conditions may be over-represented.

“We were aware of some small studies that have pointed to children with ADHD having an increased risk of language problems, such as difficulties in expressing themselves with language and difficulties in understanding language”, explains Sciberras. “Our review, therefore, aimed to provide clarity on whether children with ADHD are at a higher risk for language problems compared to children without ADHD, and the types of language problem that may be experienced”.

The researchers first explain that there is no real consensus for defining language and its associated disorders, and even the Diagnostic and Statistical Manual (DSM) of Mental Disorders has altered its definition of communicative disorders in its various editions. The most commonly used system for defining language is based on language modalities, being (i) expressive (i.e. vocalising and expressing thoughts) and (ii) receptive (i.e. listening and understanding), and the domains of language structure, being vocabulary, grammar and discourse. In addition, there is an element

of pragmatic language to consider, which describes the appropriate use of language depending on the social context. In their review, Sciberras uses “language problems” to describe the broad range of language difficulties.

Sciberras et al. identified 21 studies that met the following inclusion criteria: (a) confirmed ADHD at the time of the study, (b) inclusion of a non-ADHD control group, (c) use of a validated language measure, and (d) age ≤18 years. These studies captured >1,000 children with ADHD and healthy controls, and of the 68 separate analyses conducted across these studies, 60 showed a significant difference between the ADHD and control group in terms of language measures. Overall, they found meta-analytic evidence supporting that children with ADHD experience substantially poorer language functioning across multiple domains compared to children without ADHD.

The domains affected included overall language, and receptive, expressive and pragmatic language functioning. Expressive language produced the largest weighted mean effect size (ES=1.23), followed by overall language (ES=1.04), pragmatic language (ES=0.98) and receptive language (ES=0.97), which all remained robust after adjusting for possible publication bias. Thus, these data confirm that ADHD is strongly associated with weaknesses across several language modalities. “We did expect children with ADHD to have difficulties with language, but we didn’t expect that the effect sizes would be so large”, notes Sciberras. “Difficulties with expressive, receptive and pragmatic language should, therefore, be considered a core component of the profile of ADHD deficits”.



The researchers highlight in their review that the cause of language problems in children with ADHD is still unclear and hotly debated. They explain that gaining clarity on the root cause of language deficits in affected children with ADHD will open up opportunities to develop cost-effective, tailored interventions. “Some research from our group has shown that language problems in children with ADHD contribute to substantially poorer academic functioning”, says Sciberras. “However, it unclear whether it is possible to intervene to improve the language problems in children with ADHD and whether such interventions would lead to flow-on benefits to academic functioning”.

Theoretical models have postulated that language deficits in ADHD may be an expression of the ADHD symptoms that have a secondary, indirect effect on language performance, such as deficits in learning and concentration<sup>2</sup>. Alternatively, language deficits in ADHD may occur irrespective of secondary influences. In support of the latter, another study conducted by Sciberras found that within a diagnostically confirmed ADHD cohort, ADHD status was the only unique predictor of co-morbid language problems. Other co-morbidities (such as internalizing disorder, externalizing disorder or autism spectrum disorder) and socio-demographic factors did not independently contribute to language deficits in ADHD<sup>2</sup>.

Some preliminary research suggests that there may be a neurodevelopmental explanation underlying the association between ADHD and language problems. For example, two studies from Kibby et al. found that children with ADHD have smaller bilateral cerebral volume and an atypical pars triangularis compared to healthy controls, which are associated with receptive and expressive language function, respectively<sup>3,4</sup>. Another study documented atypical morphology of the right hemisphere in patients with ADHD, which is associated with poor social comprehension<sup>5</sup>.

Unfortunately, only a few have used such neuroimaging approaches to identify aberrations in the language networks in children with ADHD. Such studies, however, have the potential to provide support for interventions that develop speech-language skills or compensatory language strategies. Consequently, this is an area of research that Sciberras and her research team are actively addressing. “We are currently completing a longitudinal neuroimaging study involving 180 children with and without ADHD”, describes Sciberras. “The children have been assessed at age 10, 11.5 and 13 years using multi-modal imaging and language assessments, and the data are anticipated to help us examine the neurobiological underpinnings of language problems in children with ADHD”.

Going forward, the researchers hope that a thorough evaluation of language function in children presenting with ADHD can be clinically implemented. In 2000, the DSM-IV-TR differentiated between expressive and mixed receptive-expressive disorders but this was removed from the DSM-5 published in 2013. The DSM-5 did, however, include a new diagnostic category of social (pragmatic) communication disorder (SCD) for persistent difficulties in the social use of verbal and nonverbal communication. According to the DSM-5, SCD can co-occur with other communication disorders but cannot be diagnosed in the presence of another mental disorder.

“We hope that over the next 10 years, it is recognised that difficulties with expressive, receptive and pragmatic aspects of language in children with ADHD are common and that these domains are more systematically assessed and considered as part of the child’s ADHD management plan”, says Sciberras. “We also hope that more is understood about the origins of language problems in children with ADHD. For example, we need to determine whether attention deficits or global developmental problems experienced by children with ADHD drive increased rates of language problems.”





In summary, Sciberras et al., found large deficits in language functioning in children with ADHD across all language modalities. They explain that despite the increasing acknowledgement that language problems often accompany ADHD, there has been little translational change, such as the development of appropriate language interventions for children with ADHD or the implementation of screens for language problems. “A previous study from our group<sup>2</sup> found that less than half of children with ADHD and language problems have ever accessed speech pathology services”, says Sciberras. “A brief screen for language problems in clinical practice could, therefore, assist in identifying this co-morbidity”.

Referring to:

Korrel, H., Mueller, K.L., Silk, T., Anderson, V. & Sciberras, E. (2017), Research Review: Language problems in children with Attention-Deficit Hyperactivity Disorder – a systematic meta-analytic review? *J Child Psychol Psychiatr.* 58: 640-654. doi:10.1111/jcpp.12688

Further reading:

<sup>1</sup>Beitchman, J.H., et al. (1986). Prevalence of psychiatric disorders in children with speech and language disorders. *J Am Acad Child Psychiatry.* 25: 528-535. doi: 10.1016/S0002-7138(10)60013-1

<sup>2</sup>Sciberras, E. et al. (2014). Language problems in children with ADHD: A community-based study. *Pediatrics.* 133: 793-800. doi:10.1542/peds.2013-3355

<sup>3</sup>Kibby, M.Y. et al. (2009). The pars triangularis in dyslexia and ADHD: A comprehensive approach. *Brain Lang.* 111: 46-54. doi: 10.1016/j.bandl.2009.03.001.

<sup>4</sup>Kibby, M.Y. et al. (2009). The relationship between cerebral hemisphere volume and receptive language functioning in dyslexia and attention-deficit hyperactivity disorder (ADHD). *J Child Neurol.* 24: 438-448. doi: 10.1177/0883073808324772

<sup>5</sup>Miller, S.R. (2006) Right hemisphere brain morphology, attention-deficit hyperactivity disorder (ADHD) subtype, and social comprehension. *J Child Neurol.* 21: 139-144. doi: 10.1177/08830738060210021901

#### Learning Outcomes:

1. Children with ADHD experience large deficits in their language functioning across expressive, receptive, and pragmatic language modalities.
2. This review supports the need for thorough evaluation of language function in children presenting with ADHD.

#### Policy Impact:

Although there is increasing acknowledgement of the language problems that often accompany ADHD, this does not appear to have translated to the implementation of consistent language screens or language interventions for children with ADHD. A brief screen for language problems in clinical practice could assist in better identification of such co-morbid problems.



# The importance of identifying an Intellectual Disability/Learning Disability for the individual, parents/carers and from a service/policy perspective

*By Mary Busk, Family Carer Adviser, NHS England & Sue North, National Children and Young People's Lead*

Mary is a Family Carer Adviser in the Improving Health and Quality Team, part of the Learning Disability Programme for NHS England. Mary is also involved with the CYP part of the Transforming Care programme. Mary previously co-founded the National Network of Parent Carer Forums and was the Steering Group member for London.

Sue North is the National Children and Young People's lead in the Transforming Care Programme, part of the Learning Disability Directorate at NHS England and has 24 years of experience working with disabled children, young people and their families in a range of social care, education and health settings.

It is a good time to reflect on the importance of identifying an Intellectual Disability or a Learning Disability given Dr Mark Lovell's IDIDA2H new framework. Although it is sometimes suggested that services and support should be available without a diagnosis, it remains the case that understanding needs fully is important to meeting them and planning for the future for the child, young person and family. This enables good commissioning as well as giving legal protections under the Equality Act.

## The importance of early identification and early intervention

The principles underpinning Transforming Care for children and young people reflects this early identification and early intervention approach. For example the Developing and Support and Services National Guidance[1] states:

"2.1 Children with a learning disability, autism or both should be identified at the first opportunity. Local authorities are required by law to identify children and young people who have or may have special educational needs and who have a disability, and when a clinical commissioning group, NHS trust or NHS foundation suspect that a pre-school child has (or probably has) special educational needs or a disability, they have a responsibility to discuss this with the parents and in turn inform the appropriate local authority. Staff working across health, education and social care (but particularly Health Visitors and School Nurses) should have the skills and knowledge to identify the signs and symptoms of learning disability and autism. Transforming Care Partnerships (TCPs) should ensure that the Healthy Child Pathway plays a key role in early identification of children with a learning disability, autism or both.

2.2 When a learning disability or autism is first suspected children, young people and their families should have access to timely assessment and/or diagnosis. There should be clear local assessment pathways; timescales for autism assessment should be in line with NICE guidance and formal assessments for learning disability should follow a similar process. Practical support should not be dependent on diagnosis and should be offered alongside assessment processes."

This National Guidance also makes clear that the workforce should have the necessary skills to identify needs and local areas should have in place the necessary assessment pathways and processes, informed by national best practice to support this. The Children and Families Act 2014 reflects these same ambitions and seeks to ensure that children, young people and their families are at the heart of decisions about their journey and "being provided with the information and support necessary to enable participation in those decisions...in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes"[2].

## Addressing health inequalities

It will be really important that local areas understand the changes to the diagnostic process for Intellectual Disability/Learning Disability and have the right workforce with the right skills to ensure that the new requirements can be met and needs are identified early. It is vital that health inequalities, identified through the Learning Disabilities Mortality Review (LeDeR)[3] and in other research are addressed. NHS England leads a large programme of work to seek to help tackle these health inequalities[4]. This will include local areas knowing and making the right reasonable adjustments as required by the Equality Act 2010, Accessible Information Standards and other laws and policies, including relating to complaints. Recent work led by NHS England called Ask Listen Do has found that people with a learning disability and their families do not always feel listened to and can be afraid to raise concerns[5].

## The family journey

Practically, children may not realise they are being taken by their parent/carers for assessments for potential "diagnoses" to Child Development Centres or other locations when they are young. That journey rests with the parent/carer in the expectation that by identifying needs, there will be more understanding and support and services to meet needs, including from Allied Health Professionals. Many (although





not all) parent/carers know instinctively that early intervention is essential to develop and maintain skills especially in the area of Learning Disability/Intellectual Disability. Families should not have to fight for services for their children and young people with an Intellectual Disability/Learning Disability. Ensuring there is appropriate support post-diagnosis is also essential to help parent carers navigate through the emotional and practical challenges they may face.

Parent carers are also very conscious, as the Children and Families Act requires, of the need to be aspirational for their children and young people with disabilities. That includes being able to do the same things as other children and young people, having friends, being visible in their communities and getting a job. There can be a worry that labels such as 'severe Intellectual Disability/Learning Disability' might imply the child or young person does not have much potential or might not merit interventions. That is not the case as all young people can make a valid contribution and have positive and successful lives as part of their communities. It is essential that all in the workforce know and understand this vision and are very aspirational from the earliest stages to ensure and enable this for individual children and young people.

Children and young people with an Intellectual Disability/Learning Disability may have additional co-morbid disabilities such as autism and other needs. In order to inform needs based commissioning, NHS Digital has mandated data collection for children and young people including diagnoses and long term conditions.[6] Work is continuing to support implementation of this dataset through the SEND Complex Needs Board chaired by NHS England[7].

Transition can be a particularly challenging time for young people and for families. Before the Children and Families Act and Care Act 2014, IQ could be used as a measure of accessing adult social care. If diagnoses were not complete, families and young people could struggle to get the right support. The Children and Families Act now covers the ages 0-25 which focuses on aspirational outcomes for adulthood and remove this cliff edge in services. That includes a renewed focus on employment for all. NHS England employs people with a learning disability and autism, like Carl Shaw, who lead on national programmes of work[8].

### **Understanding the use of language across health, education and social care**

Work in the Transforming Care Steering Group for children and young people[9] led by Jane Ramsey, an independent Chair, identified a practical barrier to understanding needs across education, health and social care through a different use of language in education, health and social care. While health uses the term Intellectual Disability/Learning



Disability, education uses the term Learning Difficulty and social care may refer to 'children in need' or disabilities.

A lot of work has been done within the Group and across Government Departments to understand this use of language better and to use that to inform the needs of different groups of children and young people including those with very complex needs. This work has led to the production of the diagram link [bit.ly/zz2XodY](https://bit.ly/zz2XodY) that shows the language and population information. It is really important that this is understood by commissioners and by practitioners in local areas.

### **The use of language**

While we recognise that the two major international classification systems have chosen to use the term Intellectual Disability, families or people do not necessarily see this as a positive step. That is why they prefer the term Learning Disability. People and their families do not want to feel that they cannot be fully members of society and to have the same life chances and life expectancy as everyone else. It would be a positive step if, in future, these international bodies took account of the wishes and feelings of people and their families before making decisions on such important issues in the spirit of co-production.

Referring to:

- [1] <https://www.england.nhs.uk/publication/developing-support-and-services-for-children-and-young-people-with-a-learning-disability-autism-or-both/>
- [2] Section 19 Children and Families Act 2014
- [3] <https://www.england.nhs.uk/wp-content/uploads/2017/04/LeDeR-program-secondary-briefing.pdf>
- [4] <https://www.england.nhs.uk/learning-disabilities/improving-health/>
- [5] <https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/>
- [6] <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/children-and-young-people-s-health-services-data-set>
- [7] <https://www.england.nhs.uk/learning-disabilities/care/children-young-people/send/>
- [8] <https://www.england.nhs.uk/author/carl-shaw/>
- [9] <https://www.england.nhs.uk/learning-disabilities/care/children-young-people/>

# Research issues for children, young people and adults with learning disability and/or autism and their families

## – some personal reflections

By Mary Busk

One of the most positive experiences I have ever had was being part of the Childhood Disability Research Priority Setting Partnership through the British Academy of Childhood Disability, the James Lind Alliance and others. You can read more about it at this link [bit.ly/2OO2cMz](https://bit.ly/2OO2cMz)

Another was being part of the team of people who developed the national data set for children and young people with disabilities, including learning disability and autism, as part of the Community Services Data Set. Without data and knowing what needs there are, it is not possible to commission well for this group. More can be read about it at this link [bit.ly/2QBjgT7](https://bit.ly/2QBjgT7)

Recent publications about research have caused me to reflect on why research matters to children and young people and adults with learning disabilities, autism or both and their families. These have included:

NHS England's consultation to simplify research in the NHS link at [bit.ly/2CysrAG](https://bit.ly/2CysrAG)

Department of Health's framework for mental health research link at [bit.ly/2BcoMrA](https://bit.ly/2BcoMrA)

### According to NHS England:

"Research is vital in providing the evidence we need to transform services and improve outcomes e.g. in developing new care models, redesigning urgent and emergency care, strengthening primary care and transforming mental health and cancer services.

By fully integrating research into our organisation we can outperform organisations that do not, leading to better quality care and improved use of resources.

Pursuing the use of evidence and evaluation will improve how we measure the impact of our work, meaning we can learn from what works well, and what doesn't. We wish to foster a culture in the NHS that seeks out research evidence and applies this evidence in decision-making. All of this will be underpinned by a strong infrastructure that is supportive of research and evaluation." More at this link [bit.ly/2PnLMrb](https://bit.ly/2PnLMrb)

This matters because national and local decisions about service commissioning, development and investment can be influenced positively by research evidence (and negatively by lack of it), especially when funding is tight.

Families and decision makers can also have different perspectives of evidence: families see what works practically (experiential) while decision makers/gate keepers can insist on "empirical evidence".

I have seen first hand how this leads to lack of understanding of children and young people like my son (who eventually got a diagnosis of autism and severe learning disability) and impacts on the availability of services that are needed to support them from the earliest years. Although my son was born with these needs, he did not benefit from early identification or early interventions. No one told me he would not sleep and I did not know to seek help until some was offered through a sleep trial many years later. A private speech and language with autism expertise told me when my son was about 3-4 years old that he had receptive and expressive language disorders and virtually no means of communication. I struggled to support him through Special Educational Needs Tribunals to get basic things like speech and language therapy. I had to buy his PECS materials and pay for a Makaton course for myself. I also had to beg for help with his eating issues and was fortunate to get support from a specialist service over a number of years recognising that these issues are complex and not easy to fix.





A limited understanding of and interest in sensory processing issues, which were apparent from a very young age, left me struggling when my son became very agitated and at times violent, forcing me to find the answers myself and then fight for that to be recognised and help provided, including having to go to the (then) Local Government Ombudsman. This lack of understanding of these sensory issues and his problems with transitioning (which were not recognised by anyone but me) led to the collapse of his secondary school placement in a special school and he was unwell at home for months, refusing to leave the house, leading to the need for him to go to a residential special school. There is virtually no understanding of why transitioning is such a problem and anxiety becomes so great for our young people.

I need to advocate for everyone to be aspirational for what my son can achieve with his life, and at the same time help ensure that all his needs are recognised and understood so that he is not put in situations where he would become very unhappy.

Despite what law and policy says about working in coproduction with people and families there is not a lot of understanding of how to do this well, both at an individual and strategic level. There is also a broad lack of understanding about autism and learning disability with other comorbid conditions in society and among many practitioners in education, health and social care. At one stage I was told he had emotional lability but I did not understand how that related to his other needs. Many people do not fully understand the presentation. When sensory interventions support my son to be in a calm and alert state, I have been asked if he is medicated, as when he is not in a calm alert state he is very different. There are also other things that make him unique like being sensitive to small spaces, not liking loud voices or knowing when people do not like or are scared of him. Those are really important to him but they are hidden except from those who know him very, very well. That's why I was delighted we could make a start to answering some of these questions through the Childhood Disability Research Priority Setting Partnership, but there remains so much more to be done.

#### **Against this background, I have a series of questions**

To what extent are families, children and adults with learning disability or autism or both influencing national and other research agendas?

Why are ID-CAHMHS and child intellectual disability psychiatry relying on extrapolating evidence about treatments from adult studies, or from neurotypical research?

What are the arrangements for dialogue with the research community, families, children young people and adults themselves?

Are knowledge gaps systematically identified and shared with the research community in all areas?

Is there scope for research prioritisation exercises for any other groups of children and young people (e.g. where questions are not covered by those identified through the prioritisation exercises for neurodisability and autism)?

What research gaps might exist within Public Health (national and locally) that could impact on gaps in local decision making, and thereby impact negatively on experiences and services for people and families?

What is the scope of NIHR funding, and are there other research bodies that will be interested in other aspects of research of interest to and importance to families and people themselves (e.g. education and social care, joint commissioning, whole life issues)? Are research questions being missed because this is unclear?

NHS England's Children and Young People's Transforming Care Team, led by Sue North, working with national partners, the Council for Disabled Children and Challenging Behaviour Foundation, leading researchers in these fields and practitioners, including Mark Lovell, are seeking to address these issues for children and young people with a learning disability, autism or both. A recent research and evidence day recommended inter alia the need for an NIHR commissioned call on learning disability and autism, as there has been for dementia; a framework to help identify interventions and disseminate evidence to inform strategy and policy development nationally, regionally and locally; and thinking about links to NICE and CPD for practitioners across education, health and social care. As part of taking this work forward NHS England held a learning and evidence day with Transforming Care Partnership leads for Children and Young People in September 2018 to share best practice and some of what the evidence tells us. More events are planned.

In conclusion, we need to do more to create sustainable means for a dialogue about research priorities and questions for this group of people and their families. We need that research to be funded. We also need to know more about existing research and working out how best to share that nationally, regionally and locally to make a difference for families and people themselves in their daily lives. I am looking forward to being part of making this happen, working with colleagues in NHS England and with other partners.

