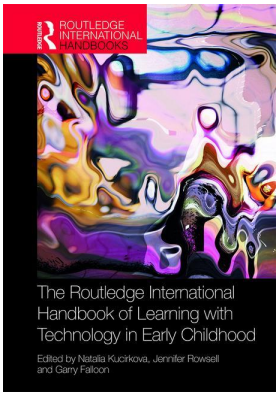

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RESEARCH WITH CHILDREN WITH SPECIAL EDUCATIONAL NEEDS

A focus on Autism Spectrum Disorder

Melissa L. Allen and Shu Yau

Defining special educational needs

The term 'special educational needs' (SEN), originally coined by the Warnock report (Great Britain & Warnock 1978), is purposefully broad, as it captures a wide range of learning disabilities that can affect an individual's ability to learn. Areas which can be affected in children include behaviour, literacy, comprehension, concentration levels or physical ability, and typically supports are put in place in mainstream or special schools to facilitate development across areas of need. According to the Children and Families Act 2014, a child or young person has SEN 'if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her'. School age children are considered to have a learning difficulty or disability if they have a significantly greater difficulty in learning than same aged peers or have a disability which prevents or hinders them from using existing facilities found in mainstream settings. Care is taken to specify that differences in a language spoken at home do not equate to disability.

Norwich (2013) outlines the controversy in classifying children by such categories, which can conflate causation, severity and setting or use of norms. Further to this, Beveridge (1999) points out that the concept of special need is a social construction, shaped by economic concerns, which morphs over time in line with current political climate. The stability of the label, how children are characterised by it and indeed which children are themselves characterised are thus fluid processes.

Although some argue that the use of a SEN label reduces empowerment amongst individuals described by the term (Keil et al., 2006), and causes discrimination (Warnock & Norwich, 2010; Terzi, 2005), it is generally acknowledged that the label is used to provide remediation and access to services that would otherwise not be available (Norwich, 2013). There does exist tension between a social model of disability, which highlights the interaction between a child and his or her environment, and a medical model, which attempts to provide descriptors based upon within-child factors. Warnock (2005) argues that the current educational framework is marked by the apparent contradiction between the intention to treat all learners the same while acknowledging and responding to the needs that stem from their individual differences. This 'dilemma of difference' parallels a debate seen in the field of Autism Spectrum Disorder (ASD),

where incredible heterogeneity of the condition makes educational, clinical and research-based generalisation across the spectrum fraught with difficulty.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by impairment in two broad domains: social communication, and restricted and repetitive behaviours (American Psychiatric Association, 2013). Evidence from family and twin studies, and research in genetics, neuropathology and neuroimaging converge to inform our understanding that ASD is genetically and biologically based (Damiano et al., 2014, Folstein and Piven, 1991; Ronald and Hoekstra, 2011). It is unclear, however, how genetic risk factors interact with environmental influences to result in individual symptoms.

In clinical practice, ASD is often diagnosed around ages 3–4 (Christensen, 2016). In England, the National Institute for Health and Care (NICE) guidelines recommend that children who show regression in social skills, language or motor abilities be referred for an ASD diagnosis (National Institute for Health and Clinical Excellence, 2011). In research, behavioural studies suggest identifiable symptoms of ASD emerge at around 1 (Ozonoff et al., 2010) (Ozonoff et al., 2010) and neuroimaging studies have shown that infants at risk show atypicalities as young as 6 months of age (Elsabbagh et al., 2012; Wolff et al., 2012).

ASD is considered a lifelong condition where the diagnosis is relatively stable over time. This means that a child diagnosed with autism at 2 years old will continue to meet criteria for diagnosis at 9 years old (Lord et al., 2006) and across the lifespan (Seltzer et al., 2004). Despite a retained diagnosis, studies have revealed that some parent-reported adaptive behaviours and social involvement improve in adolescence (McGovern & Sigman, 2005). A positive developmental trajectory has been linked to an individual's communication skills and person related cognition (Darrou et al., 2010), early IQ scores (Howlin et al., 2000) and implementation of intervention programmes (Klintwall et al., 2015). Thus, an early diagnosis is preferable in order to provide appropriate supports and tailor intervention strategies.

Recent changes in the Diagnostic and Statistical Manual (DSM-V) (American Psychiatric Association, 2013), have changed the way an ASD diagnosis is formulated. The main distinction was a shift from the classic 'Triad of Impairments' – impaired social interaction, impaired social communication and restricted behaviours – to two broader categories in DSM-V (impaired social interaction and communication, and restricted behaviours). This is supported by empirical evidence showing that the triad is 'fractionable', with different genes accounting for different elements, suggesting that no single unitary cognitive account can explain autism (Happe & Ronald, 2008).

As autism is inherently a spectrum disorder, individuals present with a considerable variation in skills and behaviour, governed by the complex interaction between such behaviour with genes and the brain over development (Pelphrey et al., 2011). For example, some children may show no interest in interacting with others, while others may have an interest but be unable to decipher the more subtle social cues that govern effective communicative exchanges. Six developmental pathways have been identified (Fountain et al., 2012), making the ability to predict educational attainment and independence a challenge. On a genetic level, it is speculated that the aetiology of ASD encompasses perhaps hundreds of genetic and genomic disorders, some of which are also causally implicated in intellectual disability (Betancur, 2011).

Indeed, understanding of ASD can be compounded by issues of comorbidity. Comorbid conditions are exceedingly common ASD, with 46% individuals with ASD having at least one

comorbid disorder such as attention deficit/hyperactivity disorder, epilepsy or gastrointestinal or sleep conditions; if intellectual disability is included the prevalence rate rises to 79% (Mannion & Leader, 2013). Other genetic disorders, such as Fragile X syndrome and tuberous sclerosis (Geschwind, 2011) have also been associated with ASD. Overall, this heterogeneous condition may be best characterised as 'the autisms' (Coleman & Gillberg, 2012), a multi-faceted collection of genetic disorders that need to be considered on an individual basis.

Cognitive and language profile: heterogeneity

Although language difficulty is a core diagnostic feature of ASD, how it manifests across different individuals can vary dramatically, in line with the overall heterogeneity of the condition. Some individuals (around 30%) are considered minimally verbal, characterised by the use of less than 20–30 words or phrases in limited contexts (Tager-Flusberg & Kasari, 2013). Many of these individuals rely upon alternative modes of communication such as the Picture Exchange Communication System (PECS) or alternative/augmentative communication (AAC) systems (Kasari et al., 2013). These individuals tend to learn word-referent and picture-referent relations associatively (Preissler, 2008; Hartley & Allen, 2015), rather than symbolically, showing a fundamental difference and delay in processes of language acquisition and symbolic understanding (Hartley & Allen, 2014a; Hartley & Allen, 2014b; Field et al., 2016).

Other individuals may have stronger expressive and receptive skills, but struggle with pragmatic abilities (Tager-Flusberg & Caronna, 2007), including turn-taking and sustaining fluid, dyadic conversations (Rapin & Dunn, 2003). Prosodic differences are also common (Rapin & Dunn, 2003), as well as difficulty with the understanding and use of nonliteral language (e.g. irony, sarcasm, humour) (Kasari & Rotheram-Fuller, 2005). A significant delay in the onset of verbal language is seen across the spectrum, with words first produced at approximately 38 months of age, compared to 8–14 months in children without ASD (Howlin, 2003). Language difficulties are compounded by impairment in socio-pragmatic skills, meaning that children with ASD have fewer opportunities to engage in interactions and fail to make meaning of social cues that naturally enforce word-referent mappings.

Children with ASD also present with an uneven cognitive profile characterised by discrepancies between core verbal and non-verbal skills (Happe, 1999). Unlike in typical development, a relative strength has been repeatedly documented in the non-verbal domain (Mayes & Calhoun, 2003; Joseph et al., 2002; but see Siegel et al., 1996). Interestingly, Joseph et al. (2002) documented this pattern in 5-year-old children with high-functioning ASD but found that discrepancies between domains occurred equally in favour of verbal and non-verbal abilities in 8-year-old children, implicating a qualitative developmental shift.

It is possible that the discrepancy in cognitive skills and heterogeneity manifests from the subtests used to measure ability, rather than reflecting true cognitive constructs. For instance, Charman et al. (2011a) studied 156 children with ASD aged 10–14 years and found mixed evidence of a characteristic subtest profile. Whereas some individuals showed a higher performance relative to verbal IQ, others did not show a characteristic peak on block design or object assembly or a clear verbal/non-verbal distinction. The authors also reported that individuals with a non-verbal advantage did not have putatively higher levels of social impairment, refuting the idea of a consistent subtype. Charman et al. (2011b) stress the difficulty identifying a cognitive phenotype, but acknowledge it could enrich remediation programmes, understanding of the relation between brain and behaviour, and the 'autistic experience'.

Challenges of testing ASD and how to design effective studies given challenges

Despite the heterogeneity mentioned in the previous sections, most research in autism samples from high-functioning individuals or those with an Asperger's Syndrome diagnosis. As a result, the heterogeneity is not entirely captured, with the minimally verbal and/or low-functioning subgroup neglected in studies and their practical implications (Tager-Flusberg & Kasari, 2013).

While the natural default of experimental psychologists and scientists is to standardise testing measures for scientific rigour, working with this population may often call for individualised or modified testing approaches. This is a necessary step to be inclusive and to address the specific (and often complex) needs of individual children. Choice of standardised tests need to be carefully considered for practicality in terms of total test-time, language and attentional requirements, validity and age-appropriateness. An individualised approach may also mean considering raw scores over time in single participants, and working on untimed tests. These modifications are important as standardised tests often require responses (reliable gesturing, pointing, attention, language) that are outside of the abilities of those who are nonverbal or very low functioning. Courchesne et al. (2015) found that children with non-verbal autism were unable to complete standardised tests typically used by school psychologists or clinicians to evaluate cognitive ability, such as the Wechsler Intelligence Scale for Children (WISC-IV) and Leiter-R. To avoid underestimating the cognitive abilities in this group, the authors recommend using strength-based assessments such as visual search tasks and the Raven's Coloured Progressive Matrices instead, with suggestions around using touch technology to maintain interest throughout testing.

Another option to reduce the risk of underestimating the cognitive and perceptual abilities in this group is to move away from traditional methods of testing – that typically involves active responses, higher order language use and focused attention – towards passive testing using neurotechnologies. This is done using a creative mix of neuroimaging techniques such as modified functional magnetic resonance imaging (fMRI) protocols, the use of magnetoencephalography (MEG), event-related potentials (ERPs), eye-tracking and the use of virtual reality.

MEG is a brain imaging tool that measures the electromagnetic fields emitted from the cortex in millisecond precision (Hari & Salmelin, 2012). Key advantages of using MEG are that, compared to many other brain imaging tools (e.g. MRI), it is silent and participants are not confined within a tube, which naturally improves comfort levels and compliance. Depending on the MEG system available, participants can opt to lie down or sit up with only their heads inside a helmet. MEG is also useful for research questions on lateralisation of brain function. Magnetic fields do not get distorted by the scalp and skull like in other methods (e.g. ERPs), resulting in clear signals recorded from both hemispheres. However, this method requires participants to keep their heads still during testing, which may be difficult for individuals with more complex needs. It is also not portable, which excludes participants who are not able to travel to the few sites that house these systems. The MEG and its magnetically shielded room is also very expensive to build and maintain.

MEG studies have been successful in investigating auditory or visual processing in the brains of those with high-functioning ASD (Bailey et al., 2005, Gage et al., 2003; Roberts et al., 2010). Our experiences using MEG and ERPs in children with ASD, including those who are low functioning and nonverbal, have been positive. In Yau et al. (2015) and Yau et al. (2016), we used modified MEG protocols and portable EEG (see Figure 19.1) to test auditory processing of social and non-social sounds in a sample of children with ASD aged 6 to 14. We used a passive listening paradigm, and tested children with varying degrees of autism, from minimally verbal/low functioning to high functioning. We observed that modifying test protocols to fit more complex

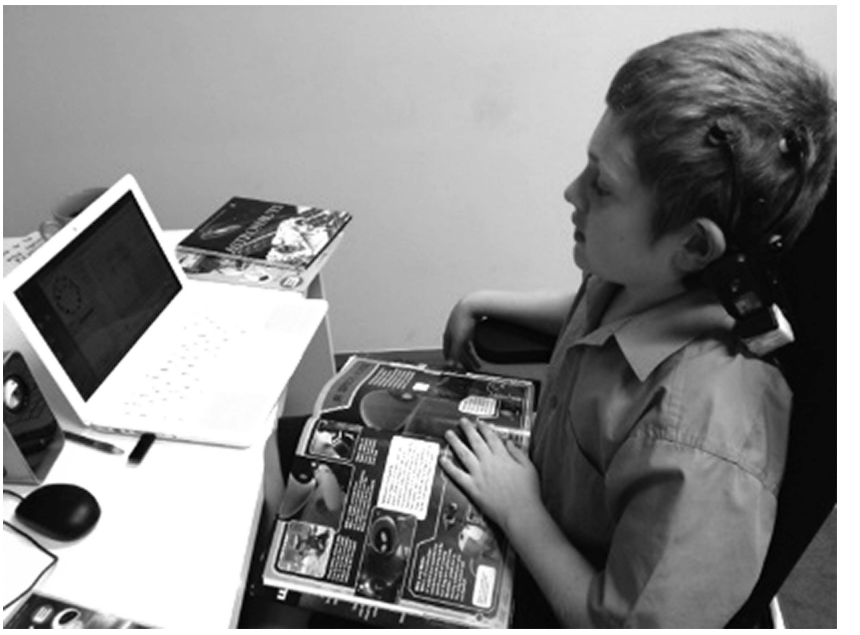

Figure 19.1 Portable electroencephalography (EEG) set up on a child, from Yau et al. (2015)

needs, such as multiple de-sensitising visits, and the use of weighted blankets and engaging videos, improved compliance and reduced head movements. Our findings suggest that auditory processing was generally impaired, showing signs of a maturational delay in the auditory cortex. This perceptual impairment was correlated to degree of language impairment in children with ASD. Additionally, a minimally verbal child with profound autism who became our case study showed a unique pattern of dissociation between social and non-social sounds. Specifically, non-social sounds elicited strong and early brain responses, while brain responses to social sounds were almost absent. We are now extending on this work using modified functional magnetic resonance imaging (fMRI) protocols and scan sequences to make testing sessions more comfortable.

Eye-tracking technology is another promising avenue useful in the study of visual preferences and looking behaviours in autism (Chawarska et al., 2012; Pelphrey et al., 2002). An experiment by Skwerer et al. (2016) used eye-tracking to test word comprehension as part of their multi-method study in minimally verbal children with ASD. Using a range of tests including standardised language tests, caregiver reports, a word-image pair paradigm and a word comprehension test on touch-screen, they found vast heterogeneity in receptive language abilities within this group of participants and across the tests. Similarly, Edelson et al. (2008) used eye-tracking to test for receptive language in 2- to 6-year-old children with ASD and found that looking times are longer in minimally verbal children for pictures for words they know but not for words they did not understand.

A more recent development is the use of eye-tracking within a virtual reality set-up (see Figure 19.2). In Caruana et al. (2017), adults with ASD were tested in an interactive game with a pre-programmed avatar who initiates or responds to joint attention bids. Joint attention is important in language and social skills development, with impairments or delays often being an early diagnostic indicator (Charman, 2003; Mundy et al., 1990). They found that their

Figure 19.2 Virtual reality research using eye-tracking and an interactive paradigm at Macquarie University
Source: Picture courtesy of Nathan Caruana

participants with ASD were slower to respond to the avatar's cues, and had difficulty using eye-gaze information. This is corroborated by subjective reports given by participants who found it difficult to communicate using eye gaze in social situations.

Issues in matching

In order to elicit useful comparisons in special needs and ASD research, typically a target group is compared to a separate population matched on one or more crucial variables. Whether to match and precisely how groups should be matched is an issue of some debate (Burack et al., 2002; Jarrold & Brock, 2004; Mottron, 2004; Mervis & Klein-Tasman, 2004). Researchers have highlighted numerous methodological challenges (Charman, 2004; Tager-Flusberg, 2004) and conceptual issues (Burack et al., 2002) that arise during this process, and in conducting research in ASD in general.

Tager-Flusberg (2004) notes four methodological concerns when conducting research on language in ASD, including concomitant intellectual disability, heterogeneity, developmental change with age and limited sample sizes. Many children with ASD also have intellectual disability, estimated to be up to 70% of the spectrum (Fombonne, 2003), and it can be difficult to ascertain any differences which are specific to the autism, rather than autism with intellectual disability. Heterogeneity, as noted, poses challenges of generalisation and standardisation of testing materials. The developmental component of ASD should also not be overlooked; development changes as a result of the interaction between genetic predisposition and environmental actions (Karmiloff-Smith, 1998). This means that an individual's specific level of input in early

years will affect their developing abilities and level of impairment in a future end state, in a positive or negative direction. Tager-Flusberg (2004) emphasises that researchers often include wide age ranges of participants and implicitly (and falsely) assume that performance on a language task is not influenced by developmental change. The final methodological concern she highlights plagues research of any syndrome or clinical population: limited sample sizes. Although no longer seen as a rare disorder (Baird et al., 2006; Hill et al., 2015), most studies of individuals with ASD report relatively few participants which also contributes to issues of generalisation and interacts with the heterogeneous nature of the condition.

Other issues that have been identified include the use of a control or comparison group. The strengths and weaknesses in ASD, also termed peaks and valleys of social and cognitive ability, are core to the diagnostic formulation of ASD and thus specific to the condition and not found in other populations (Burack et al., 2004). This makes comparison to others already uneven. Studies of broader autism phenotype, traits of the condition found in relatives that do not reach diagnostic threshold, are also problematic in the sense that sensitivity and specificity of measures may vary between comparison groups (Szatmari et al., 2004). Comparison groups are only helpful when considering the context of the particular research questions that are asked, including a consideration of a focus on either investigating normality or uniqueness (Burack et al., 2004). When comparison groups are implemented, how they are matched needs to be carefully considered.

Charman (2004) advocates the use of language as a matching variable in preschool children with ASD, given the central role of language and communication impairment across individuals across the spectrum. In very young children with significant language impairment, though, some tests may not be appropriate with children failing to establish basal levels. One common test of receptive language abilities, used as it requires children to point to pictures thus removing verbal language demands, is the British Picture Vocabulary Scale (BPVS-3) (Dunn et al. 2009). It contains norms for children aged 3–16, thus standardised scores would be unavailable for some children who present with significant language impairment; it also has been suggested to overestimate performance in ASD (Mottron, 2004). Charman (2004) advises that parent measures may provide an alternative but are met with their own challenges including over-estimation of ability, and low rate of agreement between parental report and structured language assessments for language comprehension (Charman et al., 2003). Using multiple assessments can provide a composite of ability and may better characterise a target population and individual differences.

Some researchers use multiple scales to provide different areas for matching. For instance, Gillespie-Smith et al. (2014) compare performance of children with ASD to three comparison groups, one matching on chronological age, a second on receptive language and a third on non-verbal ability. This method of matching provides one systematic way to tease apart effects of background cognitive abilities on performance. On a practical level, though, incorporating multiple measures may be difficult to achieve with limited testing time and attention levels that vary and can be challenging to sustain in target populations. Other criticisms of this approach have also been identified, including the difficulty using an average measure like verbal or non-verbal age, which masks the fact that IQ profiles are not flat in ASD and, as mentioned in the prior section, that non-verbal scores tend to be higher than verbal abilities in many individuals (Jarrold & Brock, 2004). To eliminate these confounds, Jarrold and Brock (2004) suggest that recruiting a large sample of typical participants can allow researchers to determine a normative relation between task performance and background cognitive measures. Performance against age or ability can then be regressed in this population and differences amongst individual members of the clinical group of interest can be determined by evaluating the discrepancy between observed and expected performance for their specific age and ability level. The researchers also suggest that using a task that is designed to match a multitude of non-central features of the

main experimental measure, yet is also sensitive to variation in ability, is perhaps the best way to maintain control when matching groups (Jarrold & Brock, 2004).

How atypical research can inform typical development

Research into ASD is essential to provide data-grounded rationale for appropriate educational and behavioural interventions, to directly benefit children and adults with the condition (Schopler et al., 2001). One of the arguably most popular interventions, applied behaviour analysis (ABA), was investigated in a ground-breaking two-year study by Lovaas (1987) and remains heavily researched and influential. Other inventions follow from careful work on joint attention (Kasari et al., 2006; Jones & Carr, 2004), the potential for digital technology (Allen et al., 2016) and the extensive literature base on social skills in ASD (Gates et al., 2017). It is clear that research in ASD in the last several decades has advanced knowledge of the cognitive and neuropsychological differences and unique patterns of behaviour seen in those across the spectrum.

Research into atypical developmental trajectories and populations can inform not just specific disorders, but also typical development (Leslie & Thaiss, 1992). Pennington (2009) emphasises that 'we cannot understand clinical phenomena without a theory of normal function, but clinical phenomena sometimes force revisions in our theories of normal function' (p. 72), suggesting the need for parallel study and an interdisciplinary approach. Karmiloff-Smith (1992) was a key proponent of the importance of studying different trajectories alongside one another, using a framework of progressive modularisation of cognitive modules that applied both to neurodevelopmental disorders and typical development (D'Souza & Filippi, 2017). She argued that cross-syndrome dissociations are key and studying a disorder in isolation fails to capture important information about subtle developmental differences and interactions. One paradigmatic literature base in the typical domain that has been greatly enriched by the study of ASD in particular is theory of mind.

The ability to infer mental states such as desire, belief and want, and use such inferences to predict behaviour is a crucial foundation for effective human communication. In Premack and Woodruff's (1978) seminal paper, the authors first questioned whether chimpanzees have a 'theory of mind', thus giving rise to a burgeoning area of research across comparative, typical and atypical development. Early studies with preschoolers looked at when this ability develops and concentrated on points of failure. The classic 'false belief' test initiated by Wimmer and Perner (1983) demonstrated that children below the age of 5 provided realist errors when asked where a doll (Maxi) would look for his hidden chocolate, after it was moved by another doll (his mother). Subsequent adaptions of the task explicitly pointed out that the protagonist was absent when the object of interest changed location, and consistently identified a transition between age 3 and 4 from failure to success on the task (Wellman, 2017). False belief research dominated the theory of mind realm for years (Wellman et al., 2001), but it was not until theory of mind was considered as a core deficit in ASD that researchers began to consider the breadth of precursor theory of mind skills (e.g. joint attention, preference for human biological motion) and how this might be represented in the brain.

Leslie (1994) and Baron-Cohen (1997) endorsed a modular approach postulating that theory of mind was encapsulated, and this module was uniquely impaired in individuals with ASD (see also Baron-Cohen et al., 1985). Research that followed over the next decades documented the extent of theory of mind difficulties in individuals across the spectrum (Baron-Cohen, 2000), changing how the disorder was characterised. The impact of this proliferation of theory of mind research stretched to typical development, with new investigations into neural substrates (Saxe &

Kanwisher, 2003; Schurz et al., 2014), theory of mind processing in typically developing adults (Schneider et al., 2017) and differences between explicit and implicit processing (Kulke et al., 2017). The modular approach advocated by Baron-Cohen (1997) and Leslie (1994) also shed light on the developmental origins of social cognition and brain plasticity (Mundy & Neal, 2000; Scholl & Leslie, 1999).

Conclusion

Studying any population with special needs can be challenging, and ASD is no exception. Researchers need to consider the enormous heterogeneity of the condition in terms of cognitive and linguistic profiles, and develop appropriate testing methods for individual populations. Passive neuropsychological and neuroscientific methods are one promising means of testing individuals who are minimally verbal. Despite the challenges, research in ASD is important for informing atypical and typical development, as well as providing a data-driven evidence base to evaluate intervention outcomes.

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