Lay abstracts

Title: Estimation of the prevalence of autism spectrum disorder in South Korea, revisited
Authors: Pantelis and Kennedy
DOI: 10.1177/1362361315592378

Lay abstract: When embarking on the difficult task of estimating the proportion of the population with autism spectrum disorder (ASD), it is not typically possible to assess every individual in the target population with costly “gold standard” diagnostic procedures. Some studies first screen the total population using an inexpensive assessment tool (e.g. with a questionnaire), and then concentrate full diagnostic evaluations on individuals who have been identified as being more likely to have ASD during the preliminary screening. Statistical procedures are used to generalize back to the entire population. Although this “two-phase” design can potentially allow for a more efficient deployment of resources, this approach can also introduce methodological complications, leading to estimates that may be inaccurate or imprecise. We examined these potential pitfalls in the context of a recent high-profile finding by Kim et al. (2011, Prevalence of autism spectrum disorders in a total population sample: American Journal of Psychiatry 168: 904–912), who estimated that ASD affects 2.64% of children in a South Korean community. We reconstructed the study’s methodology and used computer simulations to reassess whether their point estimate (2.64%) and reported precision (a plausible range of 1.91%–3.37%) were reasonable, given what was known about their screening instrument and their participants. We found the original estimate to be highly dependent upon certain initial assumptions (for example, assumptions about whether families who chose to participate in the study differed meaningfully from those who chose not to). Further, although the authors reported a plausible range of 1.91%–3.37%, we suggest that this range should probably be twice as wide. Future studies should give serious consideration to the additional sources of uncertainty introduced by two-phase designs, which may easily outstrip any expected gains in efficiency.

Title: Factor structure and psychometric properties of the revised Home Situations Questionnaire for autism spectrum disorder: The Home Situations Questionnaire-Autism Spectrum Disorder
Authors: Chowdhury, Aman, Lecavalier, Smith, Johnson, Swiezy, McCracken, King, McDougle, Bearss, Deng and Scahill
DOI: 10.1177/1362361315593941

Lay abstract: Most children display some degree of non-compliance (or rule breaking), and children with autism spectrum disorder (ASD) are no exception. In this study, we set out to improve the Home Situations Questionnaire for pervasive developmental disorders (HSQ-PDD), a measure of noncompliance, for children with ASD. The HSQ-PDD had two parts, one called Socially Inflexible (comprising 14 questions) and the other called Demand Specific (6 questions). We added seven potential questions that we thought would contribute to the Demand Specific score and thus make it more comprehensive and more reliable. Parents rated a total of 242 children on this expanded version of the HSQ-PDD. We found 180 had ASD and symptoms of irritability; 62 had ASD and attention deficit hyperactivity disorder. We used a statistical procedure called factor analysis, which takes responses to individual questions and looks at how they cluster together. We found that 12 questions clustered with the Socially Inflexible part of the scale and that another 12 questions clustered with the Demand Specific part. This meant that the questions within each part correlated well with one another. We named the newer scale the “HSQ-ASD.” Parents rated and re-rated 29 children over a time period averaging slightly more than 2 weeks, and ratings were moderately consistent over time. We also found that, as anticipated, ratings on the HSQ-ASD were moderately correlated with parent ratings of irritability and hyperactivity/noncompliance on other rating scales but not with a measure of adaptive behavior (i.e. practical behaviors essential for daily living). Overall, the findings suggest that the HSQ-ASD holds promise for assessing noncompliance in children with ASD.
**Title: Joint attention revisited: Finding strengths among children with autism**

**Authors:** Hurwitz and Watson

**DOI:** 10.1177/1362361315593536

**Lay abstract:** Children with autism spectrum disorders (ASD) often have difficulty engaging in joint attention (the act of two people attending to the same thing at the same time). This study examined a subset of children with ASD to see how their joint attention abilities compared to children with developmental disabilities other than ASD. It turned out that children with ASD entered into joint attention less often than other children but unexpectedly, once they were sharing attention, they did many of the same things (e.g., pointed out objects, showed a toy, had a positive look on their face, etc.). This implies that some children with ASD can engage in joint attention in similar ways to other children with disabilities but that they need more support to get the engagement going. Adults may need to be more persistent and provide additional opportunities for children with ASD to engage in joint attention so that they can benefit from the language and social skills interactions that occur when sharing attention with others.

**Title: A description of medical conditions in adults with autism spectrum disorder: A follow-up of the 1980s Utah/UCLA Autism Epidemiologic Study**

**Authors:** Jones, Cottle, Bakian, Farley, Bilder, Coon and McMahon

**DOI:** 10.1177/1362361315594798

**Lay abstract:** This is a study that looked to discover common medical problems that occurred in adults who have autism. A group of adults with autism were originally part of a study in Utah in the 1980s. A total of 92 people of the original 305 studied were found in a follow up study and participated in a medical history survey. Eleven of the 92 had died, and the survey was filled out by a caregiver. The ages of the adults ranged from 23 to 50, and 62% had intellectual disabilities (formerly called mental retardation). The most common medical problems were seizures, obesity, sleep problems, and constipation. The average person in this study had 11 long-term health problems and used over 4 different medications a day. Females were more likely to have more medical problems, but those individuals who had intellectual disabilities were not more likely to have more medical problems. Those who had been in the hospital for a life-threatening problem, and those who had a major surgery, were not more likely to have a high number of medical problems. This study shows that adults who have autism have a lot of health problems that require close medical attention to keep them healthy.

**Title: Bullying-related behaviour in a mainstream high school versus a high school for autism: Self-report and peer-report**

**Authors:** Begeer, Fink, van der Meijden, Goossens and Olthof

**DOI:** 10.1177/1362361315597525

**Lay abstract:** The majority of children with autism spectrum disorders (ASD) experience bullying, in particular in school settings. Various types of bully-related behaviour can be distinguished, including bullying (repeated aggressive actions aimed at causing harm to someone who has relatively less power), victimization (being the victim of bullying), but also defending behaviour (standing up for the victims and intervening to defend and help them). Studying these behaviours is usually done by asking children (self-report), or peers (peer-report) about the occurrence of bullying in the classroom. However, we know very little about the correspondence between self- and peer-report (i.e. how well these views ‘match up’) in children with ASD. The current study showed that self- and peer-reported bully and victimization rates did not differ between boys with ASD, who were all in a special needs school, compared to typically developing boys, who were enrolled in a mainstream school. Self-reported defending behaviour was less likely to be reported by boys in the ASD school, compared to the typically developing boys; however, there was no such difference for peer-reported defending behaviour. This finding may indicate that typically developing children overestimate the rates of self-reported defending behaviour. Importantly, children with ASD do show defending behaviours (supporting their peers against bullies) and can competently report on this behaviour. This makes children with ASD particularly receptive to school-wide bullying interventions specifically targeting defending to combat bullying.

**Title: Sensory symptoms in children with autism spectrum disorder, other developmental disorders and typical development: A longitudinal study**

**Authors:** McCormick, Hepburn, Young and Rogers

**DOI:** 10.1177/1362361315599755

**Lay abstract:** Sensory symptoms are very common in autism spectrum disorder (ASD) but little is known about...
how these symptoms develop in childhood. Sensory symptoms include a broad range of behaviors like extreme sensitivity to sensory experience (e.g. avoiding certain food textures), diminished sensitivity to sensory experiences (e.g. not responding to loud sounds), and sensory seeking behaviors (e.g. repeatedly sniffing objects). This study examined the development of sensory symptoms and the relationship between sensory symptoms and adaptive behavior (life skills) during early childhood. Parents of children with ASD, children with developmental delays, and typically developing children filled out questionnaires about sensory symptoms and adaptive behavior at three times between the ages of two and eight. Across early childhood, the amount of sensory symptoms reported by parents decreased in typically developing children. However, children with ASD and children with developmental delays had more reported symptoms that did not decrease (they remained stable). Although sensory symptoms were related to adaptive behavior, adaptive behavior was most strongly predicted by verbal ability. The results suggest that sensory symptoms are present early in ASD and other developmental disorders, and remain stable over time.

Title: Easing the transition to secondary education for children with autism spectrum disorder: An evaluation of the Systemic Transition in Education Programme for Autism Spectrum Disorder (STEP-ASD)

Authors: Mandy, Murin, Baykaner, Staunton, Cobb, Hellriegel, Anderson and Skuse

DOI: 10.1177/1362361315598892

Lay abstract: In mainstream education, the transition from primary to secondary school (‘school transition’) is difficult for children with autism spectrum disorder (ASD), being marked by high levels of emotional and behavioural difficulties. The Systemic Transition in Education Programme for ASD (STEP-ASD) is a new intervention for helping children with ASD make the school transition. We investigated whether it is practical to implement STEP-ASD, and whether it is helpful for children diagnosed with ASD. We did this by comparing emotional and behavioural difficulties during the school transition between children with ASD who had STEP-ASD with those who received no extra support. Teachers found the intervention acceptable and mostly reported that they were able to implement it fully. The 17 children receiving STEP-ASD showed a large reduction in school-reported emotional and behavioural difficulties, whereas the 20 children without extra help showed a slight increase. These encouraging findings suggest the value of STEP-ASD as a low-intensity intervention for reducing problem behaviours and distress in children with ASD as they transition to mainstream secondary school.

Title: Comparing methods for assessing receptive language skills in minimally verbal children and adolescents with autism spectrum disorders

Authors: Plesa Skwerer, Jordan, Brukilacchio and Tager-Flusberg

DOI: 10.1177/1362361315600146

Lay abstract: Children and adults with autism spectrum disorder (ASD) who have little or no spoken language (i.e. minimally verbal/MV) comprise about 30% of the ASD population. Because of difficulties in testing MV individuals they usually have not been included in research studies so little is known about them. In our study we addressed the challenges of measuring how much language MV children and adolescents with ASD understand (their ‘receptive language’). We compared several adapted measures for assessing which words were understood by the MV children and adolescents who participated in this project, including a standardized assessment of words understood (i.e. Peabody Picture Vocabulary Test); measures completed by caregivers indicating their child’s receptive language; a task in which we showed two images on a computer screen and tracked where participants looked when an audio word matching one of the images was played (assuming that they would look longer at the matching image if they understood the word played); and a similar task in which the participant touched the matching image on a computer screen. Results of this ‘multiple methods’ approach showed a wide diversity of receptive language abilities across participants and across assessment methods. Our findings underscore the need to develop individualized approaches to measure the potential for language comprehension of MV children with ASD who remain otherwise untestable, using several types of assessment that could include experimental methods based on eye-tracking or touch screen responding.

Title: Family planning and family vision in mothers after diagnosis of a child with autism spectrum disorder

Authors: Navot, Jorgenson, Vander Stoep, Toth and Webb

DOI: 10.1177/1362361315602134

Lay abstract: The diagnosis of a child with autism has short and long term impacts on families. If a diagnosis
occurs when the child is relatively young, the diagnostic process is likely to co-occur with decisions related to family planning (i.e. whether or not to have another child). However, little is known about how parents navigate this process. We interviewed 22 mothers of first born, young children with ASD (diagnosed between 2 and 4 years of age) about their family vision prior to and after the process of their child’s diagnosis. We analysed these interviews and identified several themes that were highly influential in future family planning decisions. These included: the coherence of the mother’s vision about her future family, her ability to respond flexibly to the changes in family life, and the way she responded to her child’s diagnosis. Specifically, the decision to have additional children reflected a high level of ability in adapting to having a child with ASD, which was built upon a solid, well-defined family model and a flexible approach to life. The decision to stop childrearing reflected a relatively less coherent family model and more rigid cognitive style followed by ongoing hardship managing life after the diagnosis. These findings may be useful in helping parents after the diagnosis of a young child with ASD.

Title: Impact of employee benefits on families with children with autism spectrum disorders
Authors: Gnanasekaran, Choueiri, Neumeyer, Ajar, Shui and Kuhlthau
DOI: 10.1177/1362361315598891

Lay abstract: Parents face challenges caring for their child and participating in the work environment. Employee benefits such as family leave and flexible work arrangements can help parents of children with autism-spectrum disorders with high caregiving demands; providing the flexibility to address their child’s needs and maintain employment. This study evaluates employee benefits that 161 parents in the United States have and use, as well as their experience with employment and job satisfaction. Results demonstrated that employee benefits included non-insurance benefits such as paid and unpaid leave and flexible work arrangements. Approximately half of respondents who were offered family leave used it and 91% of those offered flexible work arrangements used it. Approximately 43% of respondents reported stopping work, cutting down on hours worked, or changing jobs due to their child's autism spectrum disorder. Parents reported that these changes were due to a lack of employee benefits, mainly paid leave and flexible work arrangements. Job satisfaction was related to paid family leave and flexible work arrangements. Overall, employee benefits are important to help parents remain in the workplace and feel satisfied with their jobs. Leave policies and flexible work arrangements may help parents provide their children with the care they need. Employers may want to provide education to employees about employment benefits that can aid families to provide care to their children with autism-spectrum disorders and help families navigate their use.

Title: The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: A clinic report
Authors: Russell, Murphy, Wilson, Gillan, Brown, Robertson, Craig, Deeley, Zinkstok, Johnston, McAlonan, Spain and Murphy
DOI: 10.1177/1362361315604271

Lay abstract: People with autism are reported to experience mental health problems more frequently than people without autism. Previous studies have looked at both children and adults, have had relatively small numbers and have included people who were already referred for help with problems. This study tried to overcome some of these problems by investigating a large number of adults (total=859) referred for assessment for possible autism. Mental health problems were assessed by a psychiatrist and autism diagnosis was considered using standardised tools (i.e. those administered and scored in a consistent manner). Just over half of the adults received a diagnosis of autism, and high rates of mental health problems were recorded in over 50% of adults with and without autism. Anxiety disorders were very common in adults with autism. Obsessive compulsive disorder (OCD) was the single mental health problem that was more common in the people with autism than those without autism. Rates of mental health problems in both groups were higher than general population rates for a number of conditions. There were some problems with the study, for example standardised instruments were not used to make the mental health diagnosis. Nonetheless, these clinic data suggest that adults referred to autism assessment clinics have high rates of co-occurring mental health problems. This means that autism assessment clinics should routinely assess for co-occurring mental health difficulties in order to identify treatment needs in adults referred to the clinics who may or may not have autism.
Title: Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder

Authors: Rutherford, McKenzie, Johnson, Catchpole, O’Hare, McClure, Forsyth, McCartney and Murray

DOI: 10.1177/1362361315617879

Lay abstract: This paper presents findings from a national study of 150 children and adults recently diagnosed with an Autism Spectrum Disorder (ASD) in Scotland. Case notes (made by clinicians during the process of diagnosis) were subsequently analysed to report on the gender ratio (the proportion of males to females), age of the individual at diagnosis, and the duration of assessment (from the point at which a referral for an ASD assessment was made until the diagnosis was confirmed). The study found that the gender ratio was lower than anticipated in some age groups and that this reduced with increasing age, so that there was greater proportion of females newly diagnosed in the older groups than in younger groups. There was a difference in the average age of referral and diagnosis for girls compared to boys: girls were being diagnosed later, which suggests that there is delayed recognition of ASD in girls. In adults, gender did not significantly affect the average age of diagnosis, which was between 30 and 32 years of age. There was no significant difference in duration of the assessment process for males and females suggesting that delays in the diagnosis of females occur prior to them being referred for assessment. Implications of these findings for practice and research are discussed.