Lay abstracts

Title: Daily living skills in individuals with autism spectrum disorder from 2 to 21 years of age

Authors: Bal, Kim, Cheong and Lord
DOI: 10.1177/1362361315575840

Lay abstract: Daily living skills (DLS), such as personal hygiene, meal preparation and money management, are important to independent living. Research suggests that many individuals with autism spectrum disorder (ASD) have more difficulty completing DLS tasks independently than would be expected for someone of their intellectual ability. This study examined the development of DLS in a group of individuals referred for possible ASD at approximately 2 years of age and followed until they were 21 years old. Consistent with previous studies, participants made gains in DLS throughout childhood and adolescence. Based on their development of DLS, individuals with ASD fell in two groups: over the 19-year study period, the first group made average gains of only 3–4 years, whereas the second group made gains of approximately 12 years. Despite these gains, however, DLS levels for both groups of young adults with ASD remained considerably below what would be expected for a person of their age. Several factors influencing DLS group membership were evident from early childhood. These included nonverbal problem solving skills, understanding of language, level of social-communication impairment, and enrollment in early intensive parent-implemented intervention. Results suggest that DLS should be a focus of treatment plans for individuals with ASD, particularly adolescents transitioning to young adulthood.

Title: Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ

Authors: Taylor, Henninger and Mailick
DOI: 10.1177/1362361315583818

Lay abstract: Although getting a job or vocational placement is difficult for adults with an autism spectrum disorder (ASD), maintaining these activities over time may pose an even greater challenge. The present study investigated this issue, by examining patterns of postsecondary education (PSE) and employment over 12 years for 73 adults with ASD. All of the adults in this study had IQ scores in the average-range. We also looked at which characteristics of the adults and their families were able to distinguish patterns of employment/PSE. In this sample, employment in the community or participating in PSE was relatively common; two-thirds were working independently or in college at some point in the 12-year study. However, fewer than 25% consistently maintained these activities over time. A number of different behaviors of the adults with ASD (such as autism symptoms, behavior problems, daily living skills) distinguished those who were never in independent employment/PSE from those who were at least sometimes participating in these activities. Importantly, about one-third of men in this sample were employed or in PSE at each study time point, but none of the women were consistently engaged in these activities. Although research focused on helping adults with ASD get jobs or start PSE programs is important, our findings suggest that we also need a better understanding of how to support adults with ASD in a job or PSE program, once it has been obtained. We also need a greater understanding of the unique needs of females with ASD in adulthood.

Title: Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data

Authors: Gotham, Marvin, Taylor, Warren, Anderson, Law, Law and Lipkin
DOI: 10.1177/1362361315583818

Lay abstract: Through a voluntary online survey, information was gathered from 255 self-reporting adults with autism spectrum disorder (ASD) (aged 18–71), and from the legal representatives of 143 other adults with ASD (aged 18–58) whose level of functioning or other circumstances necessitated legal guardianship. This paper first reports adult outcomes for individuals with ASD across this wide range of functioning. Second, it summarizes
priorities for future ASD research from the perspective of adults with ASD and their legal guardians. Although the self-reporting group had much higher rates of employment, marriage/partnership, and independent living than are typically seen in ASD outcome studies, they remained underemployed and had strikingly high rates of co-occurring disorders. In both the self-reporting and legally-represented groups, the reported outcomes and priorities both indicate the need for more adult research on life skills, treatments, co-occurring mental and physical health conditions, and vocational and educational opportunities. Other highly rated research priorities included improving public services, health care access, and above all, public acceptance of adults with ASD. The majority of the self-reporting adults were women (64%) and/or individuals first diagnosed with ASD as adolescents or adults (73%), and thus findings from this group may not generalize to other high-functioning ASD samples. We suggest that both research and public policy around ASD will benefit from incorporating information from the unique perspectives of adults with ASD and their families.

Title: Still stressed but feeling better: Well-being in autism spectrum disorder families as children become adults

Authors: Pozo and Sarriá
DOI: 10.1177/1362361315583191

Lay abstract: Parents of individuals with autism spectrum disorder (ASD) face multiple challenges and demands that can compromise their well-being. The transition to adulthood and adulthood itself have been identified as times of particular stress for parents. Some studies, however, show improvements in the well-being of mothers of adolescents and young adults with ASD. This article presents a study of Spanish parents (51 mothers and 51 fathers) of 102 individuals with ASD. The aim was to examine parental well-being (evaluated based on stress, anxiety, depression and psychological well-being) in three groups of parents: adults, adolescents and young children with ASD. The results showed differences in parental well-being depending on the life stage of their children. Although parental stress and psychological wellbeing levels were similar across the groups, depression and anxiety were lower in parents of adolescents or adults (compared with parents of young children). In addition, the results revealed that the most important factor influencing parental well-being was how parents perceived situations. This was evaluated based on parents’ “sense of coherence”; parents with a strong sense of coherence showed a feeling of confidence that their life events were comprehensible, meaningful and worthy of engagement and that they had the resources to cope with the demands of these events. These findings are discussed in relation to how parents adapt over the life span and the implications for interventions in families with children with ASD.

Title: The health status of adults on the autism spectrum

Authors: Croen, Zerbo, Qian, Massolo, Rich, Sidney and Kripke
DOI: 10.1177/1362361315577517

Lay abstract: Children with autism spectrum disorders (ASD) often have other medical and psychiatric illnesses. However, very little is known about the general health status of adults with autism. The objective of this study was to describe the frequency of psychiatric and medical conditions occurring in a large and diverse population of adults with autism spectrum disorders in the US. We examined the electronic medical records of 1507 adults with an ASD diagnosis and compared them to the medical records of 15,070 adults without an ASD diagnosis who received healthcare at Kaiser Permanente (www.kaiserpermanente.org) in Northern California from 2008–2012. We found that the rates of all major psychiatric disorders including depression, anxiety, bipolar disorder, obsessive compulsive disorder, schizophrenia, and suicide attempts were significantly higher in adults with autism than adults without autism. In addition, nearly all medical conditions were significantly more common in adults with autism, including immune conditions, gastrointestinal problems, sleep disorders, seizure, obesity, dyslipidemia, hypertension, and diabetes. Rarer conditions, such as stroke and Parkinson’s disease, were also significantly more common among adults with autism. Future research is needed to identify specific social factors, health care access issues, and biological factors that may explain the higher rates of psychiatric and medical conditions among adults on the autism spectrum.

Title: “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum

Authors: Nicolaidis, Raymaker, Ashkenazy, McDonald, Dern, Baggs, Kapp, Weiner and Boisclair
DOI: 10.1177/1362361315576221

Lay abstract: Studies have noted important gaps in healthcare services for adults on the autism spectrum. Our goal was to obtain an in-depth understanding of
autistic adults’ experiences with healthcare and their ideas for improving the care they receive. Our research used a community-based participatory research approach, where academic researchers, autistic adults, family members, and healthcare providers serve as equal partners on the research team. We conducted interviews with 39 autistic adults and 16 family members and disability services professionals who have supported autistic adults in healthcare settings. Participants expressed a wide range of satisfaction with healthcare, but what differentiated positive and negative experiences almost always related to the interplay among patient-, provider-, and system-level factors. Participants identified numerous patient-level, autism-related factors that impact healthcare interactions, including verbal communication skills, atypical non-verbal communication, sensory sensitivities, challenges with body awareness (e.g. differentiating pain or other sensations), slow processing speed, and challenges with organization. These patient-level factors interacted with provider-level factors such as providers’ knowledge about autism in adults, incorrect assumptions about individual patients, willingness to allow written communication, use of accessible language, openness to providing other accommodations (e.g. turning off fluorescent lights), and skill in appropriately incorporating supporters. Finally, participants’ healthcare experiences could not be separated from the larger context in which they lived and received care. These system-level factors included the availability of supporters, complexity of the healthcare system, accessibility of healthcare facilities, and stigma about autism. Further efforts are needed to empower patients, adequately train providers, increase the accessibility of the healthcare system, and decrease discrimination.

**Title: Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study**

**Authors:** Moss, Howlin, Savage, Bolton and Rutter

**DOI:** 10.1177/13623613155858916

**Lay abstract:** Some studies of mental health in adults with autism have suggested that the majority of individuals experience very high rates of psychiatric problems. Others, however, report considerably lower rates. We explored difficulties related to mental health in 58 adults with autism (10 females, 48 males; mean age 44 years) whom we have followed up since they were children. In childhood all had a non-verbal intelligence quotient (IQ) in the average range. Assessments of mental health were based on a measure used in previous studies of adults with autism and their families (the Family History Schedule). Reports from parents or other carers indicated that many adults (44%) had good mental health. However, 28% had experienced mild to moderate difficulties; 23% had severe problems and 5% very severe psychiatric difficulties. Depression was the most commonly reported problem. Twenty-two adults were also able to report on their own mental health. Many reported no mental health problems, but around a quarter reported mild to moderate difficulties and almost one third had severe or very severe mental health problems. Most problems were related to anxiety, depression and/or obsessive-compulsive symptoms. Ratings of poor mental health were not associated with gender, severity of autism in childhood or IQ, but individuals with the poorest mental health scores tended to have poorer social outcomes and to show more severe autism symptoms in adulthood. The study revealed the difficulties of accurately assessing psychiatric problems in adults with autism and the need for more autism-specific measures of mental health.

**Title: Predictive validity of self-report questionnaires in the assessment of autism spectrum disorders in adults**

**Authors:** Sizzo, Horwitz, Teunisse, Kan, Vissers, Forceville, Van Voorst and Geurts

**DOI:** 10.1177/1362361315589869

**Lay abstract:** There is a need for accurate tools, such as questionnaires, that can assist in the assessment of adults who want to know if they have an autism spectrum disorder (ASD). We wanted to examine how well three adult questionnaires could predict ASD in an early stage of the assessment process. In order to do this we asked 210 adults who were referred to one of six outpatient centers in the Netherlands, to complete the Ritvo Autism Asperger Diagnostic Scale (RAADS-R, 80 questions) and two short versions of the Autism Spectrum Quotient (AQ, with 28 and 10 questions, respectively). These adults subsequently followed the standard diagnostic process, after which 139 of the 210 adults received a diagnosis of ASD and 71 adults received another diagnosis. In addition we asked 63 people from the general population to complete the questionnaires. We analyzed the results and found that the questionnaires correctly predicted ASD in 80% of the 139 adults who really did have ASD. However, the questionnaires incorrectly predicted that 50% of the 71 adults who did not have ASD actually did have ASD. There was no significant difference in how well the three instruments could predict ASD diagnoses. The results suggest that diagnosing ASD cannot rely on questionnaires alone but still requires proper diagnostic interviews, conducted by trained clinicians.
Title: Offending profiles of individuals with autism spectrum disorder: A study of all individuals with autism spectrum disorder examined by the forensic psychiatric service in Norway between 2000 and 2010

Authors: Helverschou, Rasmussen, Steindal, Søndanaa, Nilsson and Nøttestad

DOI: 10.1177/1362361315586171

Lay abstract: Individuals committing the most serious crimes or those who behave very strangely during arrest or interrogative interview are examined by forensic experts. The experts write a report describing the offender’s background and diagnoses, the offence they are accused of, their explanation of the offence, and the evaluation of the individual’s accountability. These forensic psychiatric examinations are conducted to avoid situations in which individuals with mental health problems are punished or sentenced to prison. This study examined the characteristics of adults with autism spectrum disorder (ASD) who have undergone a forensic psychiatric examination and explored any relationships that existed between the diagnosis and the offence. The reports we studied described 41 men and 7 females. ASD was diagnosed quite late in these individuals (average age = 25 years). Further, 22 of the 48 cases were diagnosed with ASD for the first time by the forensic experts. Reviewing these reports further, we found that the educational level and employment status of these individuals was low. Family networks were close but social networks outside the family were limited. The majority had additional psychiatric disorders and most offenders knew their victims. Similar to other offenders, the examined individuals constitute a vulnerable group but there were important differences. Unlike most others who commit criminal acts, the majority of the individuals in this study showed no evidence of substance abuse, they had close relationships to their victims, and were willing to confess to the accused crime. No clear association between the characteristics of ASD and the criminal act were identified but in most cases ASD characteristics (such as obsessions) appeared related to the motive for the offence.

Title: Further understanding of complex information processing in verbal adolescents and adults with autism spectrum disorders

Authors: Williams, Minshew and Goldstein

DOI: 10.1177/13623613155586171

Lay abstract: More than 20 years ago, Minshew and colleagues proposed the Complex Information Processing model of autism. According to this model, autism involves a range of general deficits including impairments in motor skill, complex memory, complex language, concept formation (identifying common features of objects or categories), and reasoning. This is coupled with intact or superior performance in the areas of attention, simple memory, simple language, visuospatial skills (processing visual information and where that information is) and rule-learning. Even though autism is diagnosed on the basis of behaviors, it is a brain-based disorder characterized by the networks that integrate information across the brain processing information inefficiently. Studies indicate that individuals with autism can organize information into already identified concepts; however, they have difficulty creating new concepts to handle information that does not clearly fit into an already known concept. This weakness leads to difficulties when the amount of information that needs to be processed increases. A recent study demonstrated that this relative weakness in ‘conceptual reasoning’ had a negative impact on adaptive functioning (i.e. how well individuals are able to cope with everyday demands and how independent they are) in children and adults with autism. In this current study, we provide further evidence of the difficulty that relatively older adolescents and adults with autism have with conceptual reasoning. We also provide evidence that this difference in conceptual reasoning differentiates them from age and ability-matched typical individuals better than their differences in language. For verbal adults with autism, language may serve as a compensatory mechanism for learning. However, even more developed language skills cannot overcome an inherent weakness in concept formation/reasoning that makes information processing challenging for individuals with autism as task demands increase.

Title: The use of eye-tracking to explore social difficulties in cognitively able students with autism spectrum disorder: A pilot investigation

Authors: Hanley, Riby, Carty, McAteer, Kennedy and McPhillips

DOI: 10.1177/1362361315558076

Lay abstract: The difficulties experienced by people functioning on the autism spectrum do not disappear with age – it is a lifelong developmental condition. Although many people with autism develop sophisticated ways of coping and compensating for their difficulties, social demands often prove to be barriers to success in education and with relationships, even for those who are cognitively able. Research has shown how people with autism attend to the social world differently, particularly to people and faces. We used eye-tracking techniques to measure this important social behaviour, exploring attention during social interaction in cognitively able adults, and how it is linked to social awareness. The participants in this study...
were University students with an autism spectrum disorder (ASD) and typically developing (TD) students from the same University and thus they were all of a similar level of ability. During the interaction, students with ASD looked less at the conversational partner’s eyes and more at their mouth than TD students. Importantly, while 63% of TD participants reported thinking they were deceived about the true nature of the interaction, only 9% of ASD participants picked up this subtle social signal. We argue that understanding how these differences in social attention manifest during interaction is important, particularly for understanding the social difficulties experienced by adults with ASD on a daily basis. This is particularly important given the growing number of adults with ASD who are attending higher level education, for example at University, and who may be particularly susceptible to drop-out due to the demands of coping in situations where social awareness and companionship may be crucial.

**Title:** Group social skills interventions for adults with high-functioning autism spectrum disorders: A systematic review

**Authors:** Spain and Blainey

**DOI:** 10.1177/1362361315587659

**Lay abstract:** Social skills interventions are commonly offered to children and adolescents who have a diagnosis of autism spectrum disorders (ASD). While there is evidence to suggest that these are useful for reducing social and communication difficulties, little is known about whether these interventions are also effective for adults with ASD. This paper reviewed the evidence available for social skills intervention groups for adults with high-functioning ASD (i.e. who do not also have an intellectual disability). Five studies were identified from a literature search and were included in this review. We found that the interventions differed in terms of the number of sessions offered, the topics covered, and the way in which information was presented to participants. We also found a number of limitations in the way that studies were conducted, making it difficult to compare the approaches. However, taken together, the evidence suggests that social skills groups may be beneficial for adults with ASD, such as through increasing knowledge and understanding of social situations, improving social functioning, and reducing loneliness. Social skills groups may also help to reduce co-occurring anxiety and depression in adults with ASD.