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OPINIONS & PERSPECTIVES

Research on adults with autism spectrum disorder: Roundtable report

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The prevalence of autism spectrum disorder (ASD) in adults is estimated to be at least 1% (Brugha et al., 2011), yet almost all ASD research focuses on children. Adult intervention studies, in particular, are few in number and poor in quality (Bishop-Fitzpatrick, Minshew, & Eack, 2013), and support networks for adults with ASD are much more limited and of a far lower standard than for children (Taylor & Seltzer, 2012). Around half of all adults are rated as having a poor or very poor outcome (Howlin & Moss, 2012), with social independence and integration remaining very limited, even when compared with other groups of individuals with disability (Roux et al., 2013).

It is within this context that a 1-day meeting was convened at The University of Sydney, Australia, in August 2013, to discuss the current state of research on adults with ASD and to identify priorities for future research. The discussion was updated in August 2014 in light of recent publications. Participants were clinicians and/or researchers in the fields of ASD or intellectual disability, from a range of disciplines, including occupational therapy, social work,

psychology (cognitive, developmental, clinical, and social), child and adult psychiatry, psycholinguistics, disability research and policy, and providers of specialist services for children and adults with ASD. The following commentary summarises the principal issues raised, identifies gaps in current knowledge, and highlights potential research priorities.

1. Why is there a need to focus on *adults* with ASD?

Although diagnostic and intervention services for children with ASD have improved considerably over recent decades, there is a dearth of adequate provision for adults. The lifetime costs of the disorder are considerable and are estimated to be greater than the costs of heart disease, cancer, and stroke combined (Buescher, Cidav, Knapp, & Mandell, 2014). As life expectancies increase across most of the world the numbers of individuals with ASD surviving into old age will also rise significantly.

2. Why is there a need to focus on adults with ASD?

Although many of the concerns related to growing old with ASD are common to individuals with other developmental or mental health problems, there are factors that differentiate this group from others with chronic disability (cf. Henninger & Taylor, 2013; Levy & Perry, 2011). First, cognitive levels are highly variable, ranging from profound impairment to superior intelligence. Second, with age, the severity of symptoms characteristic of ASD tends to improve, often markedly (Anderson, Liang, & Lord, 2014; Howlin, Moss, Savage, & Rutter, 2013), and a very small minority may no longer show any obvious signs of ASD in adulthood (Anderson et al., 2014; Fein et al., 2013). Thus, in general, adults with ASD do not show patterns of frequent relapses or steady decline in functioning over the years (Orinstein et al., 2014); instead, functional ability can improve steadily with age, although the lack of ASD-specific services for adults severely limits opportunities to develop their skills and competence levels.

3. Current gaps in knowledge

3.1. *Diagnosis and assessment*

Although there now exists a number of well-validated instruments available for confirming diagnosis in children with ASD (cf. Bolte & Diehl, 2013), their value with adults is less well established. Some new instruments for diagnosing ASD in adults are being developed (Eriksson, Andersen, & Bejerot, 2014; Ritvo et al., 2011), but there is a lack of reliable and valid adult measures, either for confirming diagnosis or for assessing intervention outcomes.

3.2. *Factors affecting outcome*

Recent reviews (e.g., Anderson et al., 2014; Henninger & Taylor, 2013; Howlin et al., 2013; Levy & Perry, 2011; Magiati, Tay, & Howlin, 2012) document variable trajectories of adults with ASD. Even among individuals of normal IQ, outcome is highly variable: a very small minority is described as having “optimal outcomes” (Anderson et al., 2014; Fein et al., 2013; Orinstein et al., 2014), but others remain severely impaired (e.g., Howlin et al., 2013). Almost nothing is known about the factors that determine outcome. Although cognitive and communication skills clearly have some impact, there is a lack of information on the role of other characteristics such as social competence, early ASD severity, personality and

temperament, or physical and mental health. The long-term impact of external factors including family stress, cultural or ethnic background, social support networks, or access to specific interventions or educational programs as children is also unknown. Claims that early intensive interventions can result in savings of many millions of dollars over subsequent decades (e.g., Chasson, Harris, & Neely, 2007) are unsupported by any direct evidence, and although there is some evidence that access to behavioural interventions may be helpful, Orinstein et al. (2014) found no association between long-term outcome and intensity of early intervention. Similarly, although there is a growing emphasis on the importance of helping children with ASD succeed in integrated school settings, the long-term impact of specific educational programs, especially in secondary schools and in tertiary education, remains largely unexplored.

3.3. *Effectiveness of adult-based interventions*

Recent systematic reviews highlight both the small numbers and low quality of most adult intervention studies (Lounds Taylor et al., 2012; National Institute for Health and Care Excellence [NICE], 2013). The United Kingdom’s (UK) NICE clinical guidelines were unable to recommend any specific type of treatment, although programs based on behavioural principles were rated positively and certain interventions, such as social skills or leisure programs, were also considered to show benefits. Specialised supported employment schemes, too, appear to be beneficial (Mavranzouli et al., 2014). However, adults with ASD are usually accommodated within generic services for individuals with intellectual disability. These services are rarely able to take into account ASD-specific requirements, and there are no data on the cost-effectiveness of the various interventions, support programs, residential or day provision currently provided to adults with ASD.

3.4. *Co-occurring problems in adulthood*

3.4.1. *Mental health problems: Identification, causes, and treatment.* Accurate estimates of psychiatric difficulties among adults with ASD are compromised by the lack of validated measures to identify mental health problems in this group. People with ASD may interpret questionnaire items in a very different way from other individuals. Their capacity to report on personal mood states is also likely to be impaired as a consequence of difficulties in self-awareness (Williams, 2010). Although figures for rates of mental health problems in this group vary widely

(from 20 to > 75%; Joshi et al., 2013; Mannion, Brahm, & Leader, 2014; Mazzone, Ruta, & Reale, 2012), data on the *types* of mental health problems experienced are more consistent, with difficulties related to anxiety, depression, and obsessions/compulsions being frequently reported. Diagnoses of schizophrenia and bipolar disorder are much less frequent. Although some reports suggest that suicide rates are high, there are no reliable data on incidence.

There are some indications that factors related to social isolation or loss (e.g., lack of work and/or leisure activities, problems in leaving home, coping with the demands of college or further education, difficulties in finding and maintaining work, loss of family members, changes in care or support staff, etc.) may influence the onset of mental health problems (e.g., Hutton, Goode, Murphy, Le Couteur, & Rutter, 2008), but there are currently no systematic data that address this issue.

The lack of evidence-based treatments in this group is a further problem. Pharmacological or psychological interventions commonly used with individuals with mental health problems have not been trialled with adults with ASD (NICE, 2012). Although there are some positive reports on the effectiveness of CBT for children and adolescents with ASD (see Ho, Stephenson, & Carter, 2014), these interventions have not been tested on adults.

Finally, anecdotal evidence suggests that many adults with ASD and mental health problems have difficulty accessing mental health services. This may be a consequence of these services being provided by professionals with limited knowledge of ASD (Underwood, McCarthy, & Tsakanikos, 2010).

3.4.2. Forensic problems. Despite suggestions in the media, and occasionally in the scientific literature, that individuals with ASD are more likely to commit serious crimes (Scragg & Shah, 1994), rates of offending among individuals with ASD are actually *less* than in the general population (Ghaziuddin, 2013; King & Murphy, 2014). However, if problems with the criminal justice system do arise, these can be very difficult to deal with. There is little knowledge about the needs or difficulties of individuals with ASD among those working in the criminal justice system (including judges, prison psychiatrists, wardens, etc.). Crucially, too, in-prison treatments that rely on group interaction, social understanding, and empathy are not designed for people with ASD.

3.4.3. Physical illness. Little is known about the physical health of adults with ASD. Although high rates of chronic gastrointestinal problems are reported in children (Mazurek et al., 2013), the

long-term effects of these or other difficulties is almost entirely unresearched. There are some indications (albeit from small samples) that mortality rates are significantly higher than in the general population, with the most common causes of death being respiratory failure, heart problems, and seizures (Bilder et al., 2013). The presence of epilepsy is also associated with cognitive decline in adulthood and higher rates of behavioural problems (Howlin, Savage, Moss, Tempier, & Rutter, 2014).

3.4.4. Other developmental disorders. Rates of ASD are significantly elevated among individuals with other genetic or developmental disorders (Zafeiriou, Ververi, Dafoulis, Kalyva, & Vargiami, 2013). Here, too, almost nothing is known about the trajectories into adulthood, or response to intervention among individuals with both ASD and another specific disorder (e.g., fragile X syndrome, foetal alcohol syndrome disorders, etc.).

3.5. Older adults

Demographically, it is evident that the numbers of elderly people with ASD will increase significantly over the next few decades. However, among descriptive studies of adult cohorts, the average age tends to be around 30 years, and we know almost nothing about the ageing process in older individuals. Although the available evidence suggests that the low quality of life in ASD persists in elderly individuals (van Heijst & Geurts, 2015), we do not know whether this group is more or less prone to cognitive decline than others or which areas of skill remain intact and which are more likely to show decline.

At present, many older individuals with ASD, who do not have severe intellectual disability or severely challenging behaviours, remain at home supported largely by their ageing parents (Howlin et al., 2013). What will happen when this “invisible” network of carers is no longer available is a source of great anxiety to both older adults with ASD and their parents. There is no research into models of care that are appropriate for older adults with ASD; no information on how current services (already increasingly overstretched) for the elderly will be able to cope with individuals with special needs.

3.6. ASD in subgroups

3.6.1. Minority groups. Two recent reviews of interventions for children with ASD or other neurodevelopmental disabilities (Kasari & Patterson, 2012; Norbury & Sparks, 2013) highlight the many biases in such studies, particularly biases of language,

cultural background, and socioeconomic status. These concerns apply equally to adult studies.

3.6.2. *Females.* Remarkably little is known about ASD in females (Kirkovski, Enticott, & Fitzgerald, 2013). Although the ratio of males to females diagnosed with ASD is typically around 4 to 1 (Frazier, Georgiades, Bishop, & Hardan, 2014), there are suggestions that females may be diagnosed later (Begeer et al., 2013) or underdiagnosed because of their relatively superior social and communication skills (Dworzynski, Ronald, Bolton, & Happé, 2012; Zwai-genbaum et al., 2012). Thus diagnostic systems for adult females may be even less satisfactory than for adult males. Some research also indicates that social outcomes for females tend to be less positive overall than for males (e.g., Howlin et al., 2013). Response to treatment may also differ. However, these conclusions remain uncertain because of the very small numbers of women included in most studies.

3.6.3. *Individuals with “savant skills”.* Among individuals with ASD of all levels of cognitive ability there exist some with specific islets of ability that are far superior to those found in the general population (memory, music, or computing ability tend to be most commonly identified). However, few individuals prove able to use these skills in ways that promote social inclusion or higher employment levels (Howlin, Goode, Hutton, & Rutter, 2009). Conversely, the world of work has little capacity to identify and make use of these skills. How these gifts could be developed to result in greater personal, practical, and economic benefits is yet another area that warrants further research.

4. Public policy issues

There has been little development of public policy regarding service delivery for adults with ASD. In Australia, the government introduced the Helping Children with Autism package in 2007, but this is explicitly restricted to those under 13 years of age (Australian Government Department of Social Services, 2014). More recently, Australia has launched a National Disability Insurance Scheme, and international experience has documented a number of challenges in successfully implementing such schemes for adults with mental disorders in general, including ASD (Salvador-Carulla & Einfeld, 2014). In the United States, the Combating Autism Act was passed in 2006 (The White House, 2006). The Act provides substantial funding for biomedical research, surveillance, and early intervention, but

no specific provisions for adults. In contrast, the UK Autism Act 2009 (The National Autistic Society, 2013) explicitly requires development of an adult autism strategy to support the needs of adults with ASD. As far as we are aware, the UK is unique in passing such legislation, although, unfortunately, there is no additional funding provided to ensure that the recommendations are adequately fulfilled.

5. Recent initiatives

For the vast majority of individuals with ASD the services necessary to support them through adulthood are unavailable or inadequate. There has been little research so far to indicate the most cost-effective strategies to guide service provision. However, increasing recognition of this problem has led to a number of recent initiatives. These include the Autism-in-Older Adults Working Group in North Carolina (Piven, Rabins, & Autism-in-Older Adults Working Group, 2011), the Ontario Working Group on Mental Health & Adults with Autism Spectrum Disorder (<http://www.adultasd.ca/>), the collaboration between AGE Platform Europe and Autism-Europe (Autism Europe, 2012), and the adult stream of the Australian Cooperative Research Centre for Living with Autism Spectrum Disorders (<http://www.autismcrc.com.au/>).

It is to be hoped that the establishment of evidence-based interventions will be the product of these much-needed endeavours.

Conclusion

Gaps abound in research, policy, and service delivery in relation to adults with ASD. The very limited available information indicates that far too many individuals experience poor outcomes during adult life. This situation is unacceptable for individuals, distressing for families, and a lost opportunity for a positive contribution to society.

Researchers must generate the knowledge to enable effective, evidence-informed policies and services to be developed. The way forward involves action on multiple fronts: the development of better diagnostic and assessment methods for adults; research on trajectories throughout adulthood, including longitudinal studies, factors that affect adult trajectories, and the long-term effects of interventions in childhood; systematic study of identification, causes, and treatment of co-occurring problems during adulthood; and a focus on issues related to subgroups of adults with ASD. Recent

collaborations formed to address this issue offer reason to be optimistic the challenge can be met.

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