

Feedback from the Australian Advisory Board on Autism Spectrum Disorders

Australian Bureau of Statistics Discussion Paper –

2015 Survey of Disability, Aging and Carers

The AABASD is pleased to have been given the opportunity to provide feedback on the content of the 2015 Survey of Disability, Aging and Carers (SDAC). Below are some comments in relation to the ABS Discussion Paper:

- **Re: Coverage of persons living in gaols or correctional institutions and crisis and homeless accommodation (Page 2)**
 - Information on the number of people with Autism Spectrum Disorder (ASD) or suspected as having ASD who are living in gaols or correctional institutions would be very useful. Anecdotally, it is suspected that people with ASD are over-represented in gaols or correctional institutions. However, there are currently no Australian studies on this topic and there have been conflicting results in studies completed overseas (Mouridsen, 2012).
 - It would also be helpful to know whether or not people with ASD or suspected as having ASD are often using crisis and homeless accommodation, to determine whether or not people with ASD are over-represented in this group.

- **Re: Diseases and conditions will be classified in accordance with the *International Classification of Diseases* (currently ICD-10). (Page 3)**
 - In the case of ASD, it would be more appropriate to use the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) (2013), as these are the diagnostic criteria used in Australia.

- **Re: Defining activity limitations (Page 3)**
 - AABASD supports the suggestion that the core activities (mobility, communication and self-care) should be broadened to take account of profound/severe limitations in other activities such as self-management or learning (Page 3). Activities that are particularly problematic for people with ASD include self-management, particularly self-regulation of behaviour and organisation of daily tasks.

- **Re: Longitudinal information (Page 4)**
 - AABASD supports the collection of longitudinal data, as we currently have very limited information on the long-term outcomes of children with ASD.

- **Re: Identification of Disability (Page 8)**
 - In addition to 'difficulty learning or understanding', it might be useful to include other cognitive difficulties that affect the capacity to live independently e.g.,
 - Memory difficulties
 - Concentration difficulties

- Difficulties with planning and organisation
 - Difficulties making complex decisions that affect the person's future
- **Re: Need and Receipt of Assistance (Page 10)**
 - It may be less time consuming to ask about the person's need for assistance in different contexts e.g.,
 - Looking after themselves at home (e.g., dressing bathing, eating, cooking, housework)
 - Looking after themselves in the community (e.g., transport, shopping, banking)
 - Managing independently at school or other educational facility
 - Managing independently in the workplace
- **Aids (page 12)**
 - Some forms of aids have not been mentioned (e.g., aids for written communication, aids for memory and organisation)
- **Participation in Social and Community Activities (Page 12)**
 - It would be useful to have some comparative data about the time use of people with a disability as compared to those without disability
 - It may be useful to ask about time spent doing nothing or time engaging in solitary passive leisure pursuits (e.g., watching TV), as anecdotally, it seems that people with disabilities (including those with ASD) spend a lot of time not engaged in any meaningful activity or not engaging in activities with other people. As a result they can be very bored and lonely. This can have a negative impact on their quality of life and mental health.
 - AABASD supports the suggestion that there is a need to capture more information about environmental factors such as experience with attitudes, social norms and customs.
- **Patient experience (Page 13)**
 - People with ASD often experience co-morbid mental health difficulties (Lugnega et al., 2011), but anecdotally, mental health services provide limited or inadequate services for people with ASD. This may be because mental health clinicians attribute the mental health difficulties of people with ASD to their autistic symptoms, or because they lack skills and experience in the ASD field.
 - Further questions about barriers that people with disabilities encounter when accessing mental health services would therefore be welcomed.
- **Participation in Education (Page 14)**
 - Further information on unmet needs for assistance in education and type of educational institution would be useful.
 - Students with ASD are over six times more likely to underachieve academically, and demonstrate significantly more emotional and behavioural difficulties than their typically developing peers (Ashburner *et al.*, 2010). The Australian Bureau of Statistics (2009) found 82% of children with ASD to be 'having difficulty' at

school, principally in the areas of learning, communicating and social integration. Research from the UK suggested that they are much more likely to be suspended or excluded (Batten, 2005) and that parents of students with ASD are more likely than parents of students with other disabilities to resort to home schooling because of serious concerns about their child's unhappiness and the inability of schools to cater for their child's needs (Parsons and Lewis, 2010). In the experience of AABASD staff, there are similar issues in Australia.

- **Participation in Employment (Page 15)**

- AABASD supports the suggestion to capture more details about unmet need for assistance within employment settings, and include recall questions for persons in selected age groups about their labour force participation experience since leaving school.
- Recent Australian studies have found the level of unemployment among people with high functioning ASD to be around 45-50% (Autism Spectrum Australia, 2012, Neary, 2012). Of those who were employed, the majority had unskilled jobs. More than 50% of Queensland parents of young adults with ASD reported that their adult son or daughter was dissatisfied with his or her employment status, while 85% of parents perceived their sons and daughters as capable of higher level employment (Neary, 2012). As young people with high functioning ASD do not have an intellectual impairment, it is reasonable to expect that they should be able to access employment. Their parents perceived the main barriers to gaining employment to be poor social skills (31%) and poor interview skills (30%) (Neary, 2012).

- **Assistance provided to main recipient (Page 19)**

- In relation to the categories of tasks in which carers provide assistance, it is suggested that 'cognitive/emotional support' be separated into two categories as 'cognitive support' and emotional support' are quite different.

- **Respite care (Page 20)**

- It would be useful to know if the carers consider the respite services that are available meet their needs.
- The behavioural rigidity and resistance to change of people with ASD can make accommodating them in respite facilities a challenging prospect. Where families are able to access respite services, their children often respond to the change in routine, environment and carers, by refusing to go to the respite facility or by exhibiting significant distress and maladaptive behaviours. Greater flexibility in the range of available respite services is therefore required. For example, in-home respite options would enable children and adults with ASD to be cared for in familiar environments with familiar routines, and would therefore reduce the incidence of challenging behaviours.

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