



Media Release

Massive row over NDIS autism eligibility gobbledygook

A major dispute broke out between two autism advocates: they both described the NDIA's eligibility criteria for autistic people as "gobbledygook", but they are at odds over who said it first.

Bob Buckley, Convenor of *Autism Aspergers Advocacy Australia*, claims Ms Louise Davies, Deputy Chief Executive Officer from *Autism SA*, was clearly first to call the NDIA's criteria "gobbledygook". But Ms Davies says Mr Buckley was first (see http://a4.org.au/node/794).

Currently, clinicians diagnose Autism Spectrum Disorder (ASD) according to formal terms given in either

- the *Diagnostic and Statistical Manual for Mental Disorders*, 5 th edition (2013) which is usually called the DSM-5 (not the DSM-V as used by the NDIA previous editions were known as DSM-IV from 1994 and DSM-IV-TR from 2000), or
- the World Health Organisation's *International Classification of Diseases*, 10th edition (1996) which is usually known as the ICD-10.

Diagnostic criteria for autism-related conditions in the ICD-10 are aligned with the DSM-IV and DSM-IV-TR. The WHO is working on an ICD-11; it is not known whether it will follow the DSM-5. The terms and their relationships with each other are shown at http://a4.org.au/ASDformal.

The NDIA describes NDIS eligibility for autistic people in two NDIS documents: 1) <u>Early Intervention</u> <u>Requirements</u>, and 2) <u>Disability Requirements</u>. The NDIA's eligibility criteria (see below) do not make sense ... even to experts.

- Both documents use the term, "autism". "Autism" is not a term used in formal diagnosis.
- "Autism Spectrum Disorder" singular is the name of the diagnosis in the DSM-5 (2013). The NDIA's *Early Intervention* criteria use the term "Autism spectrum disorders" plural which is an ill-defined term used to mean all or some of the Pervasive Developmental Disorders category described (formally) in the ICD-10 and the previous DSM-IV (1994) and DSM-IV-TR (2000).
- The NDIA's *Disability* criteria mention Level 2 and Level 3 severity as if there is a single severity rating with a DSM-5 diagnosis of ASD. The DSM-5 introduced severity ratings; they are not part of the current ICD-10 and superseded DSM-IV (pre-2013) diagnoses that most autistic people have. A DSM-5 ASD diagnosis may/should have two separate severity ratings, not one as the NDIA's criteria imply/suggest.

"So far, the NDIA has shown a poor understanding of ASD", Mr Buckley says. "From the beginning, they severely underestimated the number of autistic people ... and many of the NDIA's gatekeepers, their service planners, show little or no knowledge or experience of autistic people and their needs."

"The NDIA's eligibility criteria for ASD appear confusing for even NDIA staff" Ms Davies said.

Data show people with ASD are >30%, the biggest category of primary disability in the NDIS (see http://a4.org.au/node/1027). Almost 50% of NDIS participants in the South Australian NDIS trial have ASD.

"The number of people diagnosed with severe or profound disability due to ASD doubles every 5 years. The growing numbers are a serious challenge for Governments", Mr Buckley says.

The relevant Ministers in the Commonwealth Government have not met with national peak advocacy organisations for ASD since the LNP Government was elected two years ago.

Disagreement between the Commonwealth and South Australian Governments over the number of people with disability, such as the number of NDIS participants with ASD, is delaying final agreement to deliver the scheme (see http://a4.org.au/node/1038). "Delay makes autistic children miss out on essential services" Mr Buckley said.

The NDIS trials have been underway for more than two years, but the NDIA has yet to engage properly with ASD-related stakeholders. The NDIA is engaging with stakeholders for Intellectual Disability (see http://www.ndis.gov.au/news/news-intellectual-disability-ref-grp) ... it needs to engage with ASD stakeholders.

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Annex

from Operational Guideline - Access - Early Intervention Requirements

see http://www.ndis.gov.au/access-early-intervention-requirements (accessed 14/9/2015)

List C – Permanent Impairment/Early intervention, under 6 years – no further assessment required

Synonyms for conditions are also shown (e.g. condition/synonym/synonym)

- 1. Conditions primarily resulting in Intellectual/learning impairment
 - Intellectual disability
 - Global Developmental Delay
 - Autism Spectrum Disorders (diagnosed by a specialist multi-disciplinary team, pediatrician, psychiatrist or clinical psychologist experienced in the assessment of Pervasive Developmental Disorders/Autism Spectrum disorders, and assessed using the current Diagnostic and Statistical Manual of Mental Disorders (DSM-V) diagnostic criteria)
 - ◆ Autism
 - Asperger's disorder
 - ◆ Childhood disintegrative disorder
 - ◆ Pervasive developmental disorder not otherwise specified /Atypical autism

2. ...

from Operational Guideline - Access - Disability Requirements

see http://www.ndis.gov.au/access-disability-requirements (published 1/9/2014, accessed 14/9/2015)

List A – Permanent impairment/functional capacity – no further assessment required

- 1. **Intellectual disability** diagnosed and assessed as moderate, severe or profound in accordance with current DSM criteria (e.g. IQ 55 points or less and severe deficits in adaptive functioning)
- 2. **Autism** diagnosed by a specialist multi-disciplinary team, pediatrician, psychiatrist or clinical psychologist experienced in the assessment of Pervasive Developmental Disorders, and assessed using the current Diagnostic and Statistical Manual of Mental Disorders (DSM-V) diagnostic criteria as having severity of Level 2 (Requiring substantial support) or Level 3 (Requiring very substantial support)
- 3. ...