

LD Senate: Case for LD and ASD terms being used in a distinctly and non-interchangeably

Author: Dr Martha Laxton-Kane, Consultant Clinical Psychologist along with members from the LD Senate. 2024

Context

The use of the terms Autism Spectrum Disorder (ASD) and Learning Disability (LD) have in more recent years become synonymous with the two groups increasingly being used interchangeably. This is being seen in a number of areas from commissioning posts to references in the literature. Whilst this may be useful and convenient from some perspectives it is presenting with a fundamental issue: it gives the impression that people with LD and people with ASD are the same, with the same challenges, issues and needs. It is not entirely clear how this has come about but it is our view that this is absolutely not the case.

This short paper sets out the case for no longer using ASD and LD interchangeably and covers the following key areas:

- Diagnoses
- Prevalence
- Needs
- Interventions
- Service Organisation

Identification

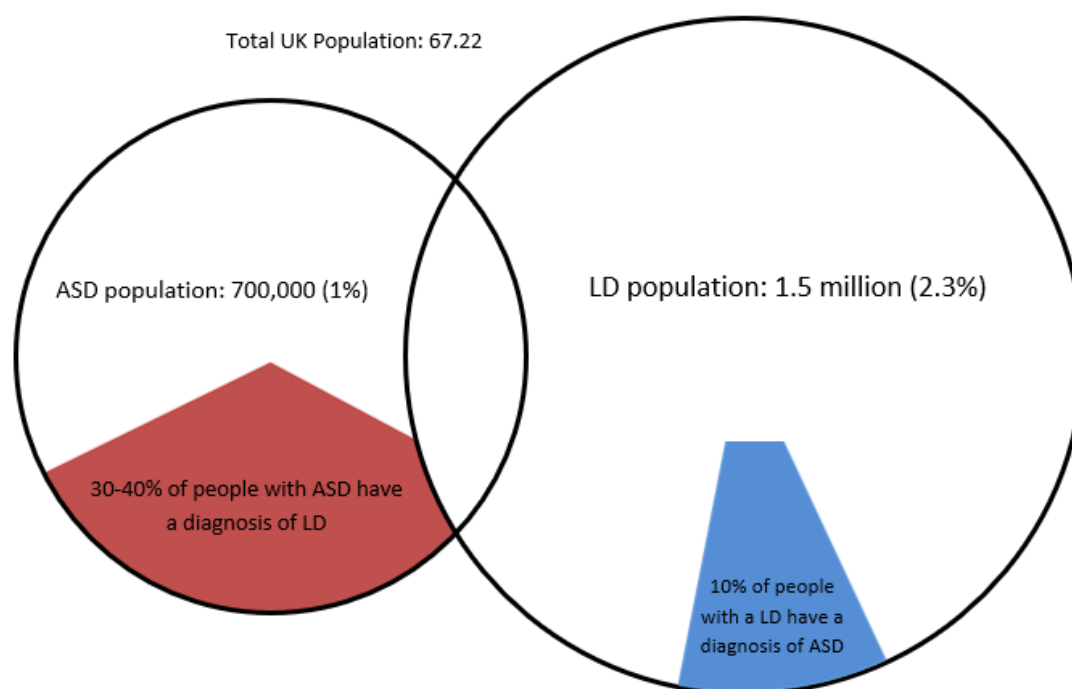
One way in which people with LD or ASD are identified is through diagnostic criteria. Whilst we are not advocating that such assessments are necessary it is useful to compare the criteria. The main elements of each 'official diagnostic criteria' are quite different. The appendix gives the official diagnoses according to DSM5 for both ASD and LD. It is acknowledged that ASD is being increasingly seen under the neurodiversity spectrum that includes other presentations such as ADHD.

A diagnosis of ASD includes impairments in social communication abilities and restricted and repetitive behaviours. By contrast the main focus for a Learning Disability is about significant impairments of cognitive ability (with an IQ below 70) as well as impairments in functional skills. Both are lifelong. As a consequence of quite different diagnostic criteria the process of diagnoses involves a fundamental different approach.

In addition to the 'diagnoses', co-morbidities and the overall profile are also quite different. Co-morbidities with ASD are much more around other neurodevelopmental problems e.g. ADHD and psychiatric diagnoses especially OCD and anxiety and there is increased suicide risk and distressed behaviours including substance misuse. By contrast the average number of other co-morbidities that someone with a learning disability has, is 11 ranging from specific system problems to sensory loss such as vision or hearing deficits (Kinnear et al 2018). Additional health needs are much more prevalent in people with learning disabilities.

Prevalence

Figure 1: Ven diagram of ASD and LD populations in UK (office for national statistics 2020)



Of the ASD population 30-40% will have a LD and of the LD population 10% will have ASD. These figures are from the office for National Statistics (2020). We would therefore estimate that the percent of the population that have both is in fact only 0.023-0.036%. Therefore the actual of overlap between ASD and LD is actually very small as a portion of the general population and in particular in comparison to the number of people who have ‘just learning disability’ or ‘just ASD’.

Brugha et al (2018) looked at representative estimates of the prevalence of autism in adults of all ages and ability. They concluded that ‘few adults with autism have intellectual disability; however, autism is more prevalent in this population’. They gave an estimated overall 1.1% prevalence of Autism in England.

We accept that there has been suggestions across different services and groups that the 1.1% prevalence rate of ASD may in fact be higher, however we are basing these calculations on known indicators. Even if these markers or prevalence rates are slightly different.

	Total	LD	ASD	LD with ASD
Population	67.2 million	1.5 million	700,000	245000 (ASD to LD) 150000 (LD to ASD)
Percentage of total population	100%	2.3%	1%	0.023 – 0.036 %

Needs

The different profiles (as outlined above in the identification section) of people with ASD compared to people with LD lead to different needs. People with a learning disability have a lot of physical health co-morbidities and sensory losses and therefore over their lifespan will need specific proactive physical health care to reduce their risk of avoidable mortality, rates of which are unacceptably high as referenced by LeDeR. For people with ASD, due to the higher prevalence of mental health problems compared to the general population, there is an over representation of the ASD population in mental health services. More than 7 in 10 people with ASD have a mental health problem (Autistica 2022).

In LD there is more likely to be a need to consider independence in the context of ongoing long term support due to impairments in functional skills and health needs. This may range from support with housing, finances, daily living skills to support with health and social care. The range of support that people with ASD may need is perhaps more likely to be much more far ranging, including increased likelihood of mental health needs, whilst of course not diminishing the challenges. Whilst more ongoing and intense support may be required for those with a diagnosis of ASD and LD, those without LD may need more episodic support.

Interventions

Both Scottish and English guidelines on best practise (SIGN and NICE) separate out the terms 'learning disability' from 'ASD' with a number of specific papers focused on different areas of health care.

One key area that is common in all interventions for people with ASD and also people with LD is the need to work with the environment including the actual physical environment, awareness training for professionals, adapting communication etc. However for many areas the nature of the adaptations maybe quite different. Whilst communication adaptations may be required for both groups (including being more literal, visual and clear), for people with LD there may also be a need to use extra additional communication aids such as PECS, Makaton etc and concentrate on a select amount of key words due to a more impaired communication skills. Supporting communication in people with ASD is more likely to focus on making concepts more concrete, understanding nuances and social rules. The importance of understanding social rules is really important and key for people with ASD, whereas for LD we might look more about developing functional skills.

For ASD there is a lot of research to support the challenges that people face in everyday life (see Autistica, SIGN 145 and NICE CG142 and CG170) and but the evidence into actual mental health interventions lacks a strong evidence base (NICE guidelines for mental health often refer to people within the general population, not inclusive of ASD). Conversely there is more evidence for mental health interventions for people with learning disabilities about what works and what doesn't work (see NICE CG170).

As a consequence of some of the different needs for support and intervention, staff awareness and training will be quite different. For example, in a school setting the skills required to support a young person with a learning disability who can use 10 verbal words and PECS is going to be very different compared to supporting a teenager with ASD in a mainstream school who is taking their GCSEs.

Service Organisation

Historically services were organised by learning disability teams within healthcare (e.g. community learning disability teams). ASD specific services were not historically present. However the rise in diagnosis, awareness and spotlight on ASD has led to a huge increase in dedicated services, particularly ASD assessment services. The additional support of media has almost had the effect of more focus on Autism services and there are now many dedicated voluntary and community services. Nationally there is enormous demand for ASD assessments but little demand for assessments in LD, especially in children's services. Services and commissioning is focusing on mental health for which there is a big spotlight (e.g in England, Building the Right Support, 2022).

There is a growing trend to group the two groups together. As an example the NHS long term plan refers to one of their 13 areas as being 'Learning Disability and Autism'. This is also reflected in some commissioning posts that are responsible for LD and ASD. There is also the Learning Disabilities and Autism Programme (LDAP) in place to ensure that actions are put in place to reduce health inequalities and improve health outcomes.

The Scottish Government responded to this LD Senate Statement giving a comprehensive overview of their position. Below are some key aspects:

The Scottish Government does not use Autism and Learning Disability interchangeably and agrees that they should not be used interchangeably.

Our Towards Transformation Plan, published in March 2021, is a joint plan for Autism and learning/intellectual disability. It recognises that although the issues and solutions can, and will, be different, there is also often common ground, including around the challenges and barriers people face. This includes things like stereotyping.

We have also committed to bringing forward a Learning Disability, Autism, and Neurodiversity Bill to help support human rights for these groups and to undertake scoping work around the potential role of a commissioner to ensure that people's rights are respected and protected.

The Welsh Government response to this LD Senate Statement:

"Welsh Government has separate policy priorities for autism and other neurodevelopment conditions and for learning disability, although we acknowledge there will be some who will have co-existing LD and ND, where the holistic needs of the individual should be taken into account. We do have a dedicated learning disability and neurodevelopmental conditions policy team, taking a different strategic approach for each area, we published an updated Learning Disability Strategy earlier this year, which was co-produced with people with an LD to ensure actions reflected their identified priorities. We have also had an autism strategy and in 2021 published statutory guidance on the delivery of autism services, we are also rolling out an ND improvement programme aimed at improving services for autism, ADHD and Tourettes initially from the range of ND conditions. Strong feedback from our LD and ND communities is clear that the identity and needs of neurodivergent people and people with learning disabilities should not be conflated as their life experiences and needs can be very different."

Conclusion

Despite a fundamental difference in diagnostic criteria and the assessment process, there is approximately only 0.023-0.036% of people (based on census data) in the general population who will have both a diagnosis of both LD and ASD. There are many significant differences in the level and type of needs and interventions for people with ASD and LD yet the terms have been used increasingly interchangeably. This may be due to convenience or poor understanding or for another reason.

We acknowledge that there is some overlap in areas for support needed such as working with the environment and supporting communication skills but the actual content of this is quite different. We would therefore argue that fundamentally people with LD and people with ASD have their own needs and should be considered as separate groups. If we pull together two streams of funding for people with different needs then we risk disadvantaging both groups (for example missing the significant physical health needs of people with LD or significant mental health needs of people with ASD). We need to protect the needs of both groups.

Whilst we acknowledge that there are opportunities to be had for joint and close working at times, both groups of people are likely to encounter varied, different and significant challenges throughout their life and for this reason our view is that terms should not be used interchangeably.

Recommendation

The two groups of people with Learning Disability and people with Autistic Spectrum Disorder should not commonly be referred to interchangeably in National Health Service forums (planning, commissioning, services) in order to protect the individual and sometimes unique needs of each of the groups.

References

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APPENDICES

ASD Diagnoses:

*The DSM-5 made some key changes to autism diagnosis. There's now **a single diagnosis of autism spectrum disorder** that replaces the different subcategories that were used previously.*

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity: Severity is based on social communication impairments and restricted repetitive patterns of behaviour. (See table below.)

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behaviour. (See table below.)

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

- **With or without accompanying intellectual impairment**
- **With or without accompanying language impairment**
 - (Coding note: Use additional code to identify the associated medical or genetic condition.)
- **Associated with another neurodevelopmental, mental, or behavioural disorder**
 - (Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioural disorder[s].)
- **With catatonia**
- **Associated with a known medical or genetic condition or environmental factor**

Learning Disability Definition:

DSM-5 defines intellectual disabilities as neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living. The DSM-5 diagnosis of ID requires the satisfaction of three criteria:

1. Deficits in intellectual functioning—“reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience”—confirmed by clinical evaluation and individualized standard IQ testing ([APA, 2013](#), p. 33);
2. Deficits in adaptive functioning that significantly hamper conforming to developmental and sociocultural standards for the individual's independence and ability to meet their social responsibility; and
3. The onset of these deficits during childhood.

(American Psychiatric Association, 2013)

Reference: American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.