Medical Xpress

New autism diagnosis guidelines miss the mark on how best to help children with developmental problems

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Credit: Gustavo Fring from Pexels

The first national guidelines for diagnosing autism were released for public consultation last week. The report by research group Autism CRC was commissioned and funded by the National Disability Insurance Scheme (NDIS) in October 2016.

The NDIS has taken over the running of federal government early intervention programs that provide specialist services for families and children with disabilities. In doing so, they have inherited the problem of diagnostic variability. Biological diagnoses are definable. The genetic condition fragile X xyndrome, for instance, which causes intellectual disability and development problems, can be diagnosed using a blood test.

Autism diagnosis, by contrast, is imprecise. It's based on a child's behaviour and function at a point in time, benchmarked against age expectations and comprising multiple simultaneous components. Complexity and imprecision arise at each stage, implicit to the condition as well as the process. So, it makes sense the NDIS requested an objective approach to autism diagnosis.

The presumption of the Autism CRC report is that standardising the method of diagnosis will address this problem of diagnostic uncertainty. But rather than striving to secure diagnostic precision in the complexity and imprecision of the real world, a more salient question is how best to help children when diagnostic uncertainty is unavoidable.

What's in the report?

The report recommends a two-tiered diagnostic strategy. The first tier is used when a child's development and behaviour clearly meet the diagnostic criteria.

The process proposed does not differ markedly from current recommended practice, with one important exception. Currently, the only professionals who can "sign off" on a diagnosis of autism are certain medical specialists such as paediatricians, child and adolescent psychiatrists, and neurologists. The range of accepted diagnosticians has now been expanded to include allied health professionals such as psychologists, speech pathologists and occupational therapists.

This exposes the program to several risks. Rates of diagnosed children may further increase with greater numbers of diagnosticians. Conflict of interest may occur if diagnosticians potentially receive later benefit as providers of funded treatment interventions. And while psychologists and other therapists may have expertise in autism, they may not necessarily recognise the important conditions that can present similarly to it, as well as other problems the child may have alongside autism.

The second recommended tier of diagnosis is for complex situations, when it is not clear a child meets one or more diagnostic criteria. In this case, the report recommends assessment and agreement by a set of professionals – known as a multidisciplinary assessment. This poses important challenges:

- Early intervention starts early. Multidisciplinary often means late, with delays on waiting lists for limited services. This is likely to worsen if more children require this type of assessment.
- Multidisciplinary assessments are expensive. If health systems pay, capacity to subsequently help children in the health sector will be correspondingly reduced.
- Groups of private providers may set up diagnostic one-stop shops. This may inadvertently discriminate against those who can't pay and potentially bias towards diagnosis for those who can.
- Multidisciplinary assessments discriminate against those in regional and rural areas, where professionals are not readily available. Telehealth (consultation over the phone or computer) is a poor substitute for direct observation and interaction. Those

> in rural and regional areas are already disadvantaged by limited access to intervention services, so diagnostic delays present an additional obstacle.

A diagnostic approach reflects a deeper, more fundamental problem. Methodological rigour is necessary for academic research validity, with the assumption autism has distinct and definable boundaries.

But consider two children almost identical in need. One just gets over the diagnostic threshold, the other not. This may be acceptable for academic studies, but it's not acceptable in community practice. An arbitrary diagnostic boundary does not address complexities of need.

We're asking the wrong question

The federal government's first initiative to fund early intervention services for children diagnosed with autism was introduced in 2008. The Helping Children With Autism program provided A$12,000 for each diagnosed child, along with limited services through Medicare.

The Better Start program was introduced later in 2011. Under Better Start, intervention programs also became available for children diagnosed with cerebral palsy, Down syndrome, fragile X syndrome and hearing and vision impairments.

While this broadened the range of disabilities to be funded, it did not address the core problem of discrimination by diagnosis. This is where children who have equal needs but who for various reasons aren't officially diagnosed are excluded from support services. Something is better than nothing, however, and these programs have helped about 60,000 children at a cost of over A$400 million.

Yet the NDIS now also faces a philosophical challenge. The NDIS considers funding based on a person's ability to function and participate in life and society, regardless of diagnosis. By contrast, entry to both these early intervention programs is determined by diagnosis, irrespective of functional limitation.

While funding incentives cannot change prevalence of fragile X syndrome in our community (because of its biological certainty), rates of autism diagnoses have more than doubled since the Helping Children with Autism program began in 2008. Autism has become a default consideration for any child who struggles socially, behaviourally, or with sensory stimuli.

Clinicians have developed alternative ways of thinking about this "grey zone" problem. One strategy is to provide support in proportion to functional need, in line with the NDIS philosophy.

Another strategy is to undertake response-to-intervention. This is well developed in education, where support is provided early and uncertainty is accepted. By observing a child's pattern and rate of response over time, more information emerges about the nature of the child's ongoing needs.

The proposed assessment strategy in the Autism CRC report addresses the question, "does this child meet criteria for autism?". This is not the same as "what is going on for this child, and how do we best help them?". And those are arguably the more important questions for our children.

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