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CLINICAL REFLECTION

Future clinical priorities in neurodevelopmental disorders: an international perspective

Ashok Roy, Meera Roy & Henal Rakesh Shah

Ashok Roy is a consultant psychiatrist and Associate Medical Director with Coventry and Warwickshire Partnership NHS Trust, working in Psychiatry of Intellectual Disability at Brooklands Hospital, Birmingham, UK. **Meera Roy** is a consultant psychiatrist with Worcester Health and Care NHS Trust, Worcester, UK. **Henal Rakesh Shah** is a consultant psychiatrist in the Department of Psychiatry at Topiwala National Medical College, Mumbai Central, Mumbai, Maharashtra, India.
Correspondence Email: ashok.roy@covwarkpt.nhs.uk

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SUMMARY

In this reflection we summarise the various obstacles to accessing healthcare encountered by people with neurodevelopmental disorders (intellectual disability, autism and attention-deficit hyperactivity disorder) with and without mental health problems. We outline different service models from around the world, ranging from the person centred to the institutional. Finally, we suggest ways of addressing some of the problems identified, including a model of integrated care involving intellectual disability, neurodevelopmental and mental health services that would better serve this population.

KEYWORDS

Attention-deficit hyperactivity disorder; autism spectrum disorders; intellectual disability; service models and workforce; neurodevelopmental disorders.

People with neurodevelopmental disorders such as intellectual disability, autism and attention-deficit hyperactivity disorder (ADHD) have higher prevalence rates of coexisting mental and physical health problems than the general population and these contribute to a lower life expectancy. Despite their additional health needs, these populations find it difficult to access appropriate healthcare.

Obstacles to services

Although increasing awareness and advocacy have raised the profile of neurodevelopmental disorders, a common obstacle is late recognition. A child with a neurodevelopmental disorder can be labelled 'mischievous' or 'lazy', often failing to receive timely diagnosis and treatment. Another cause of delay in diagnosis is that family physicians, psychiatrists and paediatricians do not always having the skills to diagnose these disorders and make the necessary referrals. This can lead to diagnostic overshadowing, as the individual's symptoms are attributed to a mental illness rather than a coexisting but undetected neurodevelopmental disorder.

At a population level, basic epidemiological data are often lacking, making planning for policy and intervention a challenge (Bitta 2017). Lack of adequate, affordable and accessible services and professionals is a common obstacle. People in urban areas may have access to facilities, but in smaller communities and rural areas there can be problems with access. In most low- and middle-income (LAMI) countries, there is an inadequate number of general mental health professionals, with very few psychiatrists with expertise in neurodevelopmental disorders.

Another obstacle is the absence of standardised tests to reach a diagnosis. This is more marked where tests in local languages are not available. Difficulties in communication and social interaction, poor concentration and impulsivity, and abnormalities in sensory perception and processing can reduce engagement with services, thus delaying diagnosis and provision of treatment and support, leading to a poor quality of life and excessive carer burden.

Common models of service provision

A spectrum of service provision for people with intellectual disabilities in different countries is summarised in Table 1 (Roy 2022). This table suggests a worldwide trend in which people with neurodevelopmental disorders are increasingly cared for in the community. Although the will is there to reduce segregation to enable them to take their place in the society, they are low among competing health priorities and need governmental support, so that progress can feel slow.

The prevalence of neurodevelopmental disorders is higher in LAMI countries and in many of them these populations are served by mainstream mental health services, often without any training for staff or adjustment in mental healthcare to allow for the additional needs that they have. For example, staff may not understand that people with autism spectrum disorder may need information written down as they have poor auditory recall or that those with ADHD have attention problems.

In some countries there are specialist services, although there is a risk of segregation. Specialist services can be:

- community based, with trained professionals providing vocational rehabilitation, independent living, education, recreational activities, social skills training, sexuality education, etc.
- volunteer based, where volunteers trained in evidence-based interventions work with family networks under specialist supervision
- consultation based, through visiting expert psychologists, psychiatrists and therapists
- centre based, where expert teams provide services to those who can access them.

Even if services are available, ignorance, cost and stigma may deter parents. Interventions for children are usually based in schools; it is essential that health and education services work together, especially mental health services, to enable early detection and intervention for better outcomes (Patel 2013).

Priorities for the future

Services for people with neurodevelopmental disorders are now being given greater priority. The World Psychiatric Association Action Plan 2020–2023 (Javed 2020) coincides with a much-needed focus on the mental health needs of people with neurodevelopmental disorders.

Early detection and screening

Normed standardised instruments for assessing intellectual functioning and adaptive behaviour that are considered the gold standard for use in neurodevelopmental disorders are not universally available (Lemay 2022). This gap may be filled by the ICD-11 behavioural indicators for disorders of intellectual development included in the World Health Organization's new Clinical Descriptions and Diagnostic Requirements (CDDR, formerly Clinical Descriptions and Diagnostic Guidelines) for ICD-11 mental, behavioural and neurodevelopmental disorders. An international field study of the CDDR's behavioural indicators reported that they had excellent inter-rater reliability, good to excellent concurrent validity and good clinical utility, making them particularly useful in identifying individuals with neurodevelopmental disorders in settings where specialised services are unavailable (Lemay 2022).

People presenting with behavioural problems should be screened for autism and ADHD, as failure to do so can lead to people being wrongly diagnosed and receiving inappropriate treatment, resulting in poor outcomes.

TABLE 1 Strengths, weaknesses, opportunities and challenges of service models in various countries, with reflections

Country	Service model	Strengths	Weaknesses	Opportunities	Challenges	Reflections
Sweden, Norway	Bespoke	Person centred	Expensive	Supports human rights	Difficult to provide universally	Person centred but often not affordable, funded through taxation
Russia and previous Soviet republics	Defectology, now gradually moving to community care	Safety net across the lifespan	Segregated from mainstream	Could become more integrated over time	Needs sustained investment	Service transition is slow and person centredness is all but absent
Greece, Spain, UK	Post-institutional community-based services	Person-centred care in the community	Healthcare is insufficiently integrated	Greater integration could improve physical and mental health	Competing demands from other healthcare priorities	Complex process to drive simultaneous integration and personalisation
Low- and middle-income countries	Reliant on non-governmental organisations (NGOs) and families	Person often remains in the family home	Little support for families, with high reliance on NGOs and charities	Possibility of developing family-centred services	Low priority among other healthcare services	Will need governmental support through policies and resources

Workforce training and development

Raising awareness of intellectual disability and neurodevelopmental disorders can be a challenge because of the lack of standardised approaches and the acknowledgement of the different roles that professionals and care staff have in providing treatment and support to this population. Core capabilities frameworks for healthcare workers supporting people with intellectual disability or autism provide an opportunity to develop high-quality role-specific training (Department of Health and Social Care 2019; Skills for Health 2019). A reasonable adjustment required in mainstream services is patient prioritisation by clinicians with knowledge and understanding of autism. The autism competency framework (Department of Health and Social Care 2019) lists the range of capabilities that psychiatrists and other professionals need to have. With the changing curriculum of medical education and increased emphasis on competency-based curricula, future physicians and paediatricians might be better trained. Schoolteachers are often the first to notice that something is amiss with a child. However, their training may not have included early identification and intervention for neurodevelopmental disorders. Strengthening teachers' training for early detection and intervention is another opportunity to overcome delays. Mental health problems and neurodevelopmental disorders, whether coexisting or occurring independently, can be overlooked as diagnoses in adults as health professionals may be untrained in or unaware of these conditions. Trained and appropriately skilled professionals could lead the workforce transformation required to make reasonable adjustments to mainstream services needed to improve outcomes for people with mental health problems, neurodevelopmental disorders or both.

An integrated all-age service model

Effective services need to be configured to care for three populations with overlapping needs. These are people with mental health problems, people with neurodevelopmental disorders and people with both. Such services require the support of professionals with special expertise. This is possible in a model with mental health services working in partnership with neurodevelopmental services, where all staff have a high level of awareness of mental illness and neurodevelopmental conditions and some staff provide specific expertise to assess and treat individuals requiring the support of both services. An integrated all-age service would cater for the three populations – those with mental health problems, those with neurodevelopmental disorders and those with both.

An integrated or interlinked service would allow for the training of groups of staff in the skills needed to deal with comorbidities. In most countries, it would be necessary for mainstream mental health services to work collaboratively with smaller and more specialised intellectual disability services and with neurodevelopmental services. The smaller more specialised services would be able to provide consultation and advice for patients with complex needs and provide training and supervision for generic staff. The need for multidisciplinary and, in certain cases, interprofessional teams could establish comprehensive nodal services with connections to downstream centres. In an international context, especially after the COVID-19 pandemic, the role of technology and teleservices has been highlighted. Developing systems to integrate these aspects could lead to the provision of more seamless and accessible care.

Conclusions

Challenges from the patient perspective include difficulties with early detection, service access and stigma. From the clinician perspective the predominant challenges are training and partnership working. From the service perspective the challenge is developing a multifaceted approach with more accurate measurement of the size of the population with mental health problems, neurodevelopmental disorders or both, screening and early detection, workforce training and development, implementation of integrated and co-produced services and research into effectiveness.

These measures will go some way to reducing the health inequalities endured by these groups of people. Future research needs to build evidence for implementing low-cost, evidence-based strategies for early detection and intervention.

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Declaration of interest

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