Chapter

Rethinking Autism Assessment, Diagnosis, and Intervention Within a Neurodevelopmental Pathway Framework

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Abstract

The neurodiversity paradigm is reshaping how we understand, use language, interpret and undertake research, and support autistic people and those with related neurodevelopmental differences across the lifespan. Multi-disciplinary teams are seeking new ways to operationalise deficit focussed diagnostic criteria, to reflect the preferences of autistic people and the wider neurodiversity movement. In this chapter, we explore what the neurodiversity paradigm could mean in practice and how to reconcile the position that autism is a difference not a deficit and therefore individuals do not need to be "fixed" or "cured," with the continued importance of timely diagnosis and the very real impact on participation, engagement, and wellbeing of autistic individuals and their families, within the environments of home, education, community, employment, and care. We present work underway to move from "single condition" pathways to neurodevelopmental pathways and new approaches which consider co-occurring conditions in a single process, involve autistic people as partners and value differences.

Keywords: autism, neurodevelopmental pathways, assessment, diagnosis, intervention

1. Introduction

Internationally recognised diagnostic criteria for Autism Spectrum Disorder (ASD) are provided in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5) [1] and the International Classification of Diseases, Eleventh Revision (ICD-11) [2], under a newly included category of "neurodevelopmental disorders," which are lifelong and not episodic mental health conditions. The behaviourally defined criteria continue to be "impairment" or "deficit" focused and diagnostic terms use the language of "disorder," which might be considered to be at odds with social models of disability, realistic medicine, and the neurodiversity paradigm [3].

There is clear evidence that different neurodevelopmental conditions defined as they are currently, usually co-occur and overlap [4] and it is often the combination

of individual profile or "neurotype" together with the environment, that determines support needs rather than diagnosis. One consequence of this development in diagnostic criteria, is that it supports the shift in clinical practice, away from a "single condition" focus towards "neurodevelopmental" pathways [5] and a diversification of our approach to assessment, diagnosis, and intervention.

From the historical point when autism began being diagnosed [6], the single-condition approach has been positive in raising the profile and need for autism assessment. It has led to the development of accessible and focussed, evidence-based clinical guidelines [7]; together with evidence about what leads to effective and efficient pathways [8] and accessibility of professional learning frameworks and resources to help multi-disciplinary teams develop shared and specialist skills and to learn from experiences of those waiting for and taking part in assessment [9].

The challenges with a single condition approach at this point are: firstly, it limits what is considered in an assessment and clinicians tend to find what they are looking for. With the binary option of "is it autism or not?," we fail to identify important neurodevelopmental differences or diagnoses, out with our current lens. Secondly, even where we do not find autism but suspect another condition, for example, ADHD, the individual must rejoin a new waiting list and see a new set of people, who often ask very similar questions, with a similar binary focus.

As services evolve towards the adoption of a "neurodevelopmental" approach [5] which sets out with different questions and a different underlying philosophy, there is a need for practical tools and an iterative process of evaluation in partnership with neurodivergent people.

2. Evolving paradigms

Evolving paradigms support changes in the way we think, question, communicate, and act. The reality is that there is overlap, complexity, and nuance in how core theories are applied in practice.

Medical model paradigms broadly focus on "within-person" disease, disorder, or disability. Autism research within this paradigm has mostly been led by non-autistic people and outcome measures are usually skills based rather than focussed on the preferences of the individual. This model has been criticised by many within the autistic community for being deficit focussed, so that observed and reported "signs" are seen as pathologised and the focus of intervention is on "treatment" or "cure" of the person who has this "functional impairment" problem [10]. The model has also underpinned valuable scientific development in understanding the genetic, neurodevelopmental, and cognitive explanations for the differences we see in individuals [11]. Often for people with ADHD, the medical model of "treatment" is still sought after and reported to be effective in improving outcomes.

Within a social paradigm or social model of disability, there is a rejection of the deficit model and recognition of the relationship between the environment and individuals. Since the 1970s, the "biopsychosocial model" has underpinned clinical practice within mental health services [12]. Diagnostic assessment includes consideration of the physical and social environment (e.g., home, education, employment, community environments, and the attitudes and actions of people in them) and how these result in a positive or negative impact on people with neurodevelopmental differences. Strengths and differences in thinking style are recognised, although the focus may still be on problems arising and autism may still be described from the view

of observers rather than the autistic person's experience. Within this model, there is acknowledgement that autistic masking [13] and/or supportive environments may result in less obvious presentation and an adapted approach to diagnostic assessment is applied. Interventions may involve people around the autistic person making changes rather than "fixing" the person. Outcomes reported may relate to skills, participation, functioning, or quality of life but may have arisen from neurotypical "societal norms." Measurement of factors and outcomes important to autistic people and their families can also be considered. In line with this paradigm, Autism and ADHD clinical guidelines [14–17] now recommend environmental modifications as a first line of intervention.

One interpretation of this model from a professional perspective can be that diagnosis does not matter because the focus should be on supporting needs identified, with the assumption that this will happen. Consequently, the power over who decides whether diagnosis matters or not lies with professionals. People may end up waiting until they hit a crisis before diagnosis is considered necessary or receive inappropriate supports which do not fully account for an understanding of the importance of diagnosis for identity or other understanding of neurodevelopmental differences. This way of thinking is criticised by some autistic people who share their experience that diagnosis can be transformational and barriers to accessing diagnostic assessment exacerbate stress.

3. The neurodiversity paradigm

The clinical application of the neurodiversity paradigm [18] is still in its infancy but has the potential to provide an important additional layer to the social model. From just one academic publication including the word "neurodiversity" in 2010, there were 33 in 2020 [11] and we can foresee an escalation of this field. Practice based on this paradigm offers subtle but important differences in language, mindset, and actions. The following perspective is that of neurotypical authors who are practitioners and researchers seeking to understand what needs to change and how we could play a role in that change through understanding and actions.

3.1 Nothing about us without us

A vital shift is the involvement of neurodivergent people in setting priorities, for research, service provision, and individual support, and in balancing power between professionals and those who might be seen as "neurominorities." Historical research evidence that has previously been seen as robust, is now being questioned with the lens of this paradigm. What we view as evidence-based practice requires re-evaluation in relation to its acceptance to neurodivergent communities. Future research in this paradigm will include autistic people as leaders and partners, at all stages, from setting the research priorities and questions [19] to delivery and reporting of research [20]. Future development of assessment tools and supports or interventions will be centred around perspectives and experiences of neurodivergent people.

3.2 Language and mindsets matter

Preferred language and terminology in relation to autism and other neurodevelopmental conditions is to some extent culturally determined and continue to evolve

[21]. In English-speaking countries, research highlights a preference for "identity first" language and reference to "autistic people," however a review of Dutch people, reported a preference for person first language—referring to "people with autism" [22]. In our own community in Scotland, autistic people have shared with us how important their autistic identity is and how much language matters [23]. The neurodivergent people we spoke to expressed a range of preferences and told us that it is important to ask people about their preferences, particularly in professional relationships. However, it is not just the language people use but the mindset behind it that matters. The neurodiversity paradigm encourages professionals to find out about and be mindful of neurodiversity-affirming language and approaches in all interactions. Application of a neurodiversity-affirming approach is currently a new and emerging concept in research and practice [24].

3.3 Difference not deficit

Within the neurodiversity paradigm, autistic or neurodivergent identity is understood as a welcome and important part of a neurodiverse society. People are seen as different, not impaired or disordered and this will require a big shift in the language we use in assessment tools, processes, and diagnostic reports. As the next iterations of DSM and ICD are a few years off, clinicians are trying to translate deficit focussed criteria into strengths focussed language in assessments, conversations, written reports, and information provided. It is possible to describe the same actions, responses, and preferences that define what it means to be autistic or neurodivergent, with a new lens. Outcome measures used to define success can start with this new lens of "what is important to autistic individuals and the autistic community?"

3.4 Does diagnosis matter?

With the understanding that we live in a neurodiverse society and that diversity is to be welcomed—a key question is then why do we need diagnosis at all? The reason is that autistic people tell us that it does matter, whether diagnosed early in childhood [25], or in adulthood [26]. In societies constructed to provide resources to meet needs according to diagnosis, lack of diagnosis is an immediate barrier to accessing support and information. Even where legislation and policy advise that no support is diagnosis dependent, diagnostic labels are a shorthand for understanding the types of adaptations and supports in the present environments and importantly when there is a transition to a different level of independence, autonomy, or life stage, where demands placed on the person change. Further key benefits of diagnosis are self-understanding or identity and access to peers with shared experience [27].

Although some would argue that diagnoses can be stigmatising, it is clear that stigma and discrimination happen anyway in societies lacking in acceptance and understanding of diversity. Individual differences are there anyway, and it is not the diagnosis that makes people different. The decision and power about whether or not to disclose diagnosis in different contexts, should lie with the individual [28].

3.5 If it's just a difference why is support needed?

Within this paradigm, it is acknowledged that being a neurominority in a largely neurotypical world can still lead to difficulties for individuals at different times in life. This might be a direct difficulty in daily life or indirectly in response to masking or

camouflaging [13] to try to fit in. Difficulties described might arise with, for example, sensory processing, feeling overwhelmed, being able to use communication to express the range of things you want to say, understanding or predicting social expectations, being able to initiate, plan and organise or responding to disrupted expectations or unpredictable situations. When a difficulty is experienced, a key difference is that this is understood in the context of the 24 hour environment and in the context of neurotype. When a person is no longer described as having "challenging behaviour" but their actions, responses, distress, and stress are understood, we are better placed to meet individual needs.

4. Neurodevelopmental pathways

The neurodiversity paradigm and neurodevelopmental pathways are different constructs in development. Each can inform but is not dependent on the other.

Chris Gillberg and researchers in Sweden have highlighted the co-occurrence of neurodevelopmental conditions and advocated a neurodevelopmental and multi-disciplinary approach for more than a decade [4, 29], this is now beginning to be applied more widely in Scotland. Care pathways are applied internationally as a way of planning and delivering individualised support to specified groups of people through multidisciplinary team working [30]. Within the last decade, evidence has become available to inform standards and practice in pathways for assessment and diagnosis of autism in children and adults [8, 9, 31].

4.1 Children and young people

As services evolve, there is a move in Scotland towards developing neurodevelopmental pathways and service providers have a need for evidence-informed guidance. In 2021, the Scottish Government National Autism Implementation Team published the first children's neurodevelopmental pathway guidance in the UK [5] and the Scottish Government published a national neurodevelopmental specification: principles and standards of care [32]. In 2022, 50% of children's health board areas in Scotland are implementing neurodevelopmental pathways and the other 50% are undertaking work to move in this direction, in partnership with education and social care partners, with the aspiration of taking an integrated approach to support according to need before, during and after diagnosis.

4.2 Adults

The adult service context in Scotland is quite different and there is currently no formal adult neurodevelopmental pathway guidance. The development of adult autism services has taken place in intellectual disability and adult mental health services [33]. Within these services, co-occurrence of autism and ADHD is recognised but services are not always planned in partnership with neurodivergent people, they may not be "neurodevelopmentally informed" nor do they give routine consideration of other co-occurring neurodevelopmental conditions. Demand for provision often exceeds capacity to meet needs.

Under-ascertainment of adults with ADHD and a dearth of services has been highlighted [34]. A feasibility study was undertaken in response to this challenge [35]. It makes recommendations that neurodevelopmental approaches be developed

through a stepped care model [36]. Stepped care approaches are used within mental health services to deliver care in a range of settings depending on needs, risk, and complexity [37]. New ways of working with a broader multidisciplinary team have the potential to deliver services more suited to neurodivergent people. Practitioners leading change in adult neurodevelopmental pathways need access to evidence-informed approaches, professional learning, and resources.

We give consideration below to the ways a neurodiversity paradigm could inform future pathways for children and adults.

5. Assessment

There is a need for the development of evidence-based neurodevelopmental and neurodiversity-affirming assessment tools for children, adolescents, and adults.

5.1 Diagnostic tools

Tools recommended in single-condition clinical guidelines for identification and diagnostic assessment of autism (e.g., ADOS and ADI-r) [38] and even tools designed to take a neurodevelopmental perspective (e.g., ESSENCE) [4], all use the deficit focussed language of diagnostic criteria. There are no self-report tools recommended for young people or adults that use neurodiversity-affirming language. We hope that this is something that changes in the next decade and that in future, clinicians can map the conversations we should be having to criteria in a robust way.

5.2 Assessment approaches

There are some approaches to contextual assessment and planning which are not standardised or mapped to diagnostic criteria but may have a better fit within the neurodiversity paradigm. They consider individual preferences, factors facilitating participation and engagement in naturally occurring environments. Some examples of these are:

The SCERTS framework [39], which can be applied in a neurodiversity-affirming way but is not designed as a diagnostic tool. A key element of the assessment is the consideration of "within child" developmental stage, together with assessment of "transactional supports" which are the things people around the child do and the adjustments put in place in the environment or learning materials. The focus is on the child being able to do things, when the adults do particular things and not on "fixing the child" or their "behaviour." Predictability and desirability in everyday environments are used to support emotional regulation and social communication.

The Person in Context tool [40] was developed with neurodivergent people and is designed to gather information about how an individual experiences aspects of themselves without reference to context and then with consideration of experiences in different environments.

Peter Vermeulen's "Autism Good Feeling Questionnaire" [41] can be used through a structured conversation with an autistic person to find out what is most likely to make them happy. This approach helps "flip the narrative" within a neurodiversity paradigm.

The School Participation Questionnaire [42] supports teachers to consider the ways a child participates and inclusive environmental supports in place to facilitate active engagement.

Our literature review did not identify published or standardised neurodiversity-affirming assessment tools and we do not know of clinical guidelines which have reviewed or recommended such tools. This is clearly an area in need of development.

6. Interventions and supports

In a systematic review of research priorities of the autistic community, Roche et al. [19] identified the request for research that will lead to real-world changes in the daily lives of the autism community. Neurodiversity-affirming approaches are not yet widely defined and researched but health and education professionals and allies are interested in how to take these on board. It is clear that there is no single approach or intervention for all autistic or neurodivergent people in all contexts. Aspects of different approaches may be relevant at different times and the neurodiversity paradigm offers a new perspective in decision-making.

There is research evidence of the benefits of inclusive environments in naturally occurring environments of education, employment, and home but what makes them neurodiversity affirming is as much about appropriate and informed choices and how the approach is used, as it is about which approaches work. The following examples are a selection of commonly reported "interventions" and supports, recommended in clinical guidelines. We provide examples of ways they can be considered from the perspective of a neurodiversity paradigm. This is by no means a complete list and we would advise that practitioners can reflect on any approach used currently in a similar way.

6.1 Behaviour focussed interventions

Outdated "fix the person" interventions are rejected by the neurodiversity movement [43] and by professional allies working within the neurodiversity paradigm. The negative view of behaviourist or behaviourally focussed approaches is widely known [44]. As Amy Laurent highlights, within a neurodiversity paradigm, "Compliance is not the goal" [45]. New goals do not seek to use external rewards to encourage people to mask and do things they find distressing but rather seek to provide intrinsically motivating experiences to reduce distress. Even commonly used interventions like Cognitive Behavioural Therapy recommended in clinical guidelines [15] can be re-evaluated within the neurodiversity paradigm. They can clearly benefit some people in some circumstances but are problematic when offered as the only option to people who might benefit from other types of support. Until there is better evidence about acceptability to the autistic community and potential risks, they should be used with caution [46], due to a lack of autism and neurodevelopmentally informed knowledge amongst CBT practitioners and the lack of alternatives to psychological therapies being offered.

6.2 Parent-mediated interventions

Parent-mediated interventions are recommended in autism clinical guidelines [14, 16]. Rather than seeking to "fix the child" they can support parents and carers to better understand their child's developmental stage and preferences. Such interventions are applied in naturalistic settings and have been found to reduce parent and family stress and improve communication experiences for autistic individuals [47].

We have not identified any which explicitly state that they are positioned within a neurodiversity paradigm, however, some existing programmes take a child-led, relationships focussed approach rather than a behaviourist, or reward-based approach. They could be delivered in a neurodiversity-affirming way, particularly those that take account of sensory, play, and communication preferences, motivation, and support parents to understand how to adapt communication and naturally occurring opportunities to meet their child's needs [48]. Within these programmes, a neurodiversity-affirming approach honours autistic communication, recognises the communicative intent behind echolalia, never forces eye contact or touch and values passions and self-regulation actions, such as stimming.

6.3 Supporting social communication

Social skills interventions are criticised for positioning neurotypical responses and actions as correct and encouraging masking of natural and authentic ways of being for neurodivergent people. This in turn can reduce mental well-being [13]. Within the neurodiversity paradigm, there can be an acknowledgement that autistic people in a neurotypical world may need help to understand social actions and expectations in day to day environments. However crucially, there should be no expectation that neurodivergent people adopt neurotypical behaviours. The onus for changing lies with the neurotypical majority. Awareness and nuanced understanding of "double empathy" changes the way we think about autistic communication styles being different and not wrong [49]. Do we need to stop supporting all autistic people in understanding social expectations because historical methods are problematic? or do we need to reconsider why and how we do this?

Most interventions recommended in clinical guidelines [50] are based on evidence gathered without reference to the neurodiversity paradigm or the views of the autistic community [51]. A recent systematic review of 26 social skills intervention studies published in the past 20 years, highlighted that only 4 involved autistic people in their design and less than half sought feedback from participants [52]. This study highlights the importance of applying evaluation of social validity in future evidence reviews and reports of whether interventions are recommended.

Some researchers and intervention developers are seeking to update historical practice, to reflect the neurodiversity paradigm, respect neurodiversity, and acceptability of approaches to supporting social understanding to the neurodivergent community. For example, authors of the PEERS programme [53] and Social Thinking Methodology [54] have taken explicit steps to reflect their awareness of and support for neurodiversity affirming ways of applying approaches to support social understanding for those who wish to engage in these approaches, without the expectation that autistic people adopt a neurotypical communication style. As with CBT, it is possible that these approaches have something to offer in facilitating autonomy and confidence in aspects of social interaction in the neurotypical world, for some people, if they can be used in ways which value neurodivergent communication preferences and thinking styles as different, not wrong.

Over time, we anticipate partnerships between autistic and non-autistic people can support access to a nuanced and shared understanding, a difference not deficit mindset and neurodiversity affirming adaptations and supports in naturally occurring environments of home, school, further education, work, and in the community.

6.4 Visual supports

Developmentally relevant visual supports [55] also come recommended in clinical guidelines [14–16]. These are good example of an approach that can be applied flexibly and which can be implemented through a medical, social, or neurodiversity paradigm.

One more controversial type of visual support for communication amongst the autistic community is The Picture Exchange Communication System or PECS [56]. It has been reported to be effective for autistic people, in providing a means of expression which does not rely on speech or pointing but the use of ABA methods to support communication is problematic within the neurodiversity paradigm. The question for speech and language therapists and teachers is—do we need to stop using Picture Exchange as a communication support, if we want to work within a neurodiversity paradigm? Or can we modify the way we support people to understand and be motivated to use picture exchange when it is developmentally relevant for them? Is it enough to change the focus from only requesting objects, to also adding socially and personally motivating and useful language, like people's names and verbs? Should we adapt the games we use to introduce and practice picture exchange, to ensure they are intrinsically desirable rather than coerced or prompted? There is work ahead to revisit the outcome measures used, so that they focus on outcomes valued by autistic people.

6.5 Intervention and support in naturally occurring environments

A disproportionate number of exclusions and anxiety-related absence from school affect autistic learners [57, 58], and in the UK only 22% of autistic people are in employment [46]. Naturally occurring environments of school, further education, or work have not always met the needs of autistic people [59–61], however relevant adjustments in physical and social environments have the potential to be powerful interventions within a neurodiversity paradigm. Within this paradigm difference and diversity are expected and daily environments are designed to be inclusive; people in these environments are the agents of change, through adapting their own assumptions, expectations, and communication and modelling neurodiversity-affirming words and actions.

What can employers and educators do? A key issue arising in conversations with autistic people is the need for access to high-quality professional learning, which is co-created with autistic people, to support practitioners to put neurodiversity-affirming ways of working into practice. Recognised approaches might include: taking an anticipatory approach rather than reacting when things go wrong; recognising, valuing, and celebrating a wide range of strengths and achievements; considering individual needs to feel well-regulated in structured and unstructured times (e.g., needs for quiet spaces, movement needs, needs for information and avoidance of disrupted expectations and knowing that good things should just happen); finding meaningful ways for autistic people to feel listened to and to have their experiences and preferences taken into account. In schools, this might be involving young people in planning to meet their needs. In the workplace, this might be providing opportunities to reflect on what's going well and whether there are reasonable adjustments the autistic individual would like.

In school settings, the biggest reason for challenges arising is the mismatch between an individual's developmental stage and expectations of others. We can

consider how to make learning meaningful, so that individuals see the point in what they are expected to do. Adults can look for ways to infuse the day with predictable and desirable experiences. For example, instead of using rewards to encourage a child to remain seated in assembly, the adults can consider sensory and communication preferences and adapt assembly to make it intrinsically enjoyable, so that the individual wants to stay. Teams can reflect on language and mindsets in relation to distress. Instead of talking about "behaviour that is challenging," consider how situations are experienced by the individual, which explains their responses and actions.

While environmental modifications are recommended and may be well understood in some professional groups, there are practitioners working in more medical or biopsychosocial paradigms who remain uncertain of how to support people to access this support. There is a need to prioritise research about approaches set in naturally occurring environments, to give clarity to what works, for whom in what circumstances, and what is valued by autistic people.

7. A neurodiversity-affirming professional and ally

Neurodivergent people and professional allies are engaged in thought and debate about how to evolve mindsets and practice, reflecting on how neurotypical people can work positively in partnership with neurodivergent friends, family, and people at work and in our community. We propose that a neurodiversity-affirming approach:

- is based on listening to individuals and their preferences
- provides developmentally relevant support for understanding and expression
- seeks to understand differences rather than labelling deficits
- does not focus on fixing the person or making them perform in a neurotypical way
- prioritises approaches designed and developed in partnership with neurodivergent people
- takes account of elements of the physical and social environment that can be adapted and made inclusive
- honours communication, sensory, and play/leisure preferences
- understands the preferences for predictability or other aspects of daily life
- recognises the need for processing time and safe spaces
- recognises difficulties experienced and seeks to address these in partnership with the individual and their family
- offers access to timely diagnostic assessment
- enables opportunities to engage with a community of people with shared interests and experiences

- encourages stimming and safe self-regulation strategies
- uses neurodiversity affirming language and mindsets and normalises conversations about diversity and difference
- flips the narrative to celebrate the value of a neurodiverse society
- focusses on opportunities for meaningful participation and active engagement in day to day life

8. Conclusion

We conclude this chapter on a hopeful note. The neurodiversity paradigm is here to stay and we have foundations to build upon, to develop an evidence base led by and developed with the autistic and neurodivergent community. Researchers and practitioners have reported a range of elements core to neurodiversity-affirming practice. There is a real desire for change and a need for practical, evidence-informed guidance, tools, and resources for students, new practitioners, and people in leadership roles. By thinking in a neurodevelopmentally informed way, individuals of all ages, with all neurotypes can be better understood and many adjustments could become second nature. The complex shift from single-condition approaches to neurodevelopmental pathways is happening and is only possible because it is built upon several decades of evolution in how we think about and understand autism and other neurodevelopmental differences from the medical, social, and neurodiversity perspectives.

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Conflict of interest

The authors declare no conflict of interest.

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