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Changing the story: How diagnosticians can support a neurodiversity perspective from the start.

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Changing the story: How diagnosticians can support a neurodiversity perspective from the start

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Caregivers usually reach out to professionals because they are concerned about their child's behaviour or development. Their much beloved child does not seem to act the way other children do. Parents of autistic children, prior to that child's diagnosis, will have likely noted their child's delays in reaching typical developmental milestones, more frequent or intense behavioural dysregulation, and have general concerns around their child appearing 'different' (Crane et al., 2018). They may worry that their parenting choices are to blame for child's difficulties.

Parents often feel intense distress akin to grief after their child receives an autism diagnosis (Abbott et al., 2013; Mulligan et al., 2012). Sinclair's (2012) iconic essay, *Don't Mourn for Us*, recognizes that many parents feel such grief because of their 'shattered expectations'. This grief is further fueled by the 'stories of autism' crafted for families by both professionals and popular media. The diagnostic entity of autism is a subjective construct used by society to interpret and categorize behaviour, affect and ways of thinking – a sort of story or narrative (Duffy & Dorner, 2011). The way we share this diagnostic story with families will guide their thinking about 'how to accommodate and respect autistic children – and how to love them . . . Or they help autistic[s] . . . understand themselves, [and learn] how to get on in a world of neurotypicals' (Hacking, 2009, p. 502). Dominant autism narratives, including those shared by the diagnostician at the initial diagnosis, will be heard and internalized by families, autistic children and society as a whole.

Until recently, the diagnosis of autism has been framed from a deficit-based perspective as seen in diagnostic manuals such as the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM*-5; American Psychiatric Association, 2013) and the *International Classification of Diseases, 11th Revision* (*ICD-11*; World Health Organization, 2008), as well as theories that describe autism as fundamentally characterized by central deficits in social motivation (e.g. Chevallier et al., 2012), or other skills. Not only genetic (e.g. Bailey et al., 1995), but also environmental (e.g. Christensen et al., 2013) literature on the *aetiology of autism* frames challenges as deficits rooted in the autistic person. The result is that the medical model has created stories of autism in which 'autistic people are inherently inferior to nonautistic people, . . . [that autistics] lack something fundamental to being human, . . . and that autism is something to be fixed, cured, controlled or avoided' (Bottema-Beutel et al., 2020, p. 8). Solely deficit-framed descriptions often miss the strengths that can be associated with autism. While autistic children often have more challenges than neurotypical children, the overall well-being of autistic children and their families is harmed when we frame autism in terms of deficits alone.

An alternative framing could, as soon as the family begins the diagnostic process, use a strengths-based approach (Urbanowicz et al., 2019) and draw on the idea of neurodiversity (Singer, 1999; Walker, 2012). Neurodiversity proponents believe that human neurological diversity is valuable (Armstrong, 2010) and that an individual has a disability because of a complex interplay between the physical, cognitive and emotional traits of that individual and the characteristics of their physical and social environments. While neurodiversity proponents and autistic advocates acknowledge autism's disabling aspects, they also push back against society's often overly restrictive and prescriptive notions of 'normal' and celebrate *autism* as an inseparable and often positive part of their identity (Milton & Sims, 2016).

The recent push to authentically include autistic voices in all phases of the research process (e.g. Fletcher-Watson et al., 2019) along with the concurrent acknowledgement that self-determination is critical to building a positive quality of life for autistic people (e.g. Weiss & Burnham Riosa, 2015) have been paralleled by increasing adoption of collaborative and family-centred models, which both tend to emphasize strength-based approaches to developing meaningful intervention goals and strategies. However, it is critical that diagnosticians, who are often one of the first to frame autism for families, consider moving away from the medical model's deficit-based story to a more balanced, neurodiversity-framed view of autism (Crane et al., 2018).

Telling a neurodiversity-aligned 'story of autism' – one that highlights both strengths and challenges from the start – will improve the families' experience of the diagnostic process, especially if the diagnostician highlights 'ways to

help children with autism to grow and thrive' (Anderberg & South, 2021, p. 12). This positive framing may improve parents' experience of the diagnostic process by

> . . . strengthening self-esteem and increasing positive thinking about the assessment process; making parents feel that their parenting has been worthwhile; reducing feelings of failure; undermining negative beliefs that parents hold (e.g. thinking they may be somehow to blame); and increasing trust between parents and professionals. (Crane et al., 2018, p. 3766)

Parents experience more positive emotions about an autism diagnosis when providers increase their positivity, warmth, respect and confidence (Anderberg & South, 2021). A strengths-based approach to share developmental and diagnostic information can change the way parents view their autistic children, which in turn change the way autistic children view themselves, leading to greater empowerment in adulthood (Urbanowicz et al., 2019).

To be clear, we are not advocating for a Pollyannaish approach that discounts the parents' emotions surrounding the diagnosis, especially their fears about the real challenges faced by autistic children. However, the discussion does not need to be solely negative. Neurodiversity advocates have a practical focus on the endpoint of promoting autistic people's quality of life (Robertson, 2010). To this end, the diagnostician can help parents reframe negative messaging while reassuring parents that they will learn how to harness the strengths of both their child and themselves to promote the well-being of their family. Similarly, instead of presenting early intervention as a means by to 'fix' or 'cure' their autistic child, it can be framed as a way for parents to better understand how their child learns and how they can build positive environments to support their child's needs and growth (Armstrong, 2010).

Neurodiversity proponents' focus on well-being contrasts with attempts to meet potentially unattainable and often unwanted goals, such as 'normalization'. Focusing on 'normalization' as the goal of intervention for autistic youth can have serious negative consequences. Compensation and masking strategies, also known as camouflaging, are often used by individuals with and without autism in an effort to blend into their social surroundings by mimicking the behaviour of others and, in the case of autistic individuals, suppressing autistic traits (Hull et al., 2020). Although these strategies can be used to improve social relations and academic/professional success, hiding one's autistic identity can be costly in terms of stress and anxiety, decreased well-being and an increased prevalence suicidal ideation (Hull et al., 2020; Milton & Sims, 2016).

We would like to offer a few suggestions for diagnosticians who are sharing a diagnosis of autism with families. We believe it is imperative for assessors to have training and support in how to communicate assessment results with families in a meaningful, respectful and supportive way. We also refer the reader to some recent articles for additional thoughts about how to support families during an initial diagnosis, both related to a strengths-based approach and other issues such as preparing families for the disclosure and providing support for navigating the service system after a diagnosis (see Abbott et al., 2013; Anderberg & South, 2021; Mulligan et al., 2012):

1. *Remember that 'words are powerful'* (Donaldson et al., 2017). The way the diagnostician tells the 'story of autism' makes a difference. Consider the terms used to describe a child and the diagnosis of autism from a neurodiversity perspective (see Bottema-Beutel et al., 2020, for more in-depth discussion). For example, instead of using the word 'deficit', try 'area of challenge/difficulty'; instead of co-morbid, try 'co-occurring'; and for very young children, consider using 'high probability' of autism, rather than 'at-risk'. These seemingly subtle changes in vocabulary communicate to families that their child is more than a label and that their child is still the same child that came to the clinic with them prior to the diagnosis.
2. *Partner with parents during disclosure* (Anderberg & South, 2021). Ask parents how they are feeling about receiving a diagnosis and what they already think and know about autism. This will help identify where parents may need more information and support. They will also need information about autism, about why their child fits with this diagnosis and what to do next. This may be a shift for many diagnosticians who are not trained in this process and currently rarely engage in shared agenda setting (Mule et al., 2021).
3. *Set a positive and warm tone* (Anderberg & South, 2021; Crane et al., 2018). A warm and positive clinician can mitigate parents' emotional reactions after disclosure and help them identify strengths in their owns skills as parents and in their children. Get to know the child and family and provide feedback in an empathetic and respectful way to acknowledge parent concerns and feelings while also sharing strengths.
4. *Be honest and remain hopeful* (Mulligan et al., 2012). We must balance discussion of strengths with acknowledgement of a child's needs – in terms of both learning (such as intellectual disabilities) and the environment (such as a need for additional structure). Parents came to the assessment because of concerns, and ignoring those concerns may leave parents feeling unheard and undervalued. Challenges can be acknowledged in context of a whole child with strengths and weaknesses that can be harnessed or supported.

5. *Consider how intervention/treatments are presented*. Many families receive an autism diagnosis for their child and immediately begin a journey of seeking more and more hours of intervention to 'cure' their children. While beginning intervention early is certainly important, data do not support the idea that highly intensive, highly structured intervention will promote 'recovery' (see Pellecchia et al., 2019). Rather than talking about recovery, discuss intervention as a way to increase adaptive skills and promote quality of life. Early autism intervention research has become more naturalistic and child friendly while remaining highly effective at increasing communication and supporting social interactions and play that build on a child's strengths and interests rather than 'curing' them.
6. *Consider intersectionality*. Diagnostic disclosure should be done in using culturally responsive and sensitive practices. Depending on their culture, families may have a history of negative interactions with health care providers and a general mistrust in the system (Moseley et al., 2007) or may feel undervalued or unheard by medical professionals – especially if their initial concerns were not taken seriously. Autism may be stigmatized in certainly cultures, which may necessitate even more care in how the diagnosis is disclosed and whether parents blame themselves for their child's differences (Stahmer et al., 2019).
7. *Address caregivers' support needs*. Parents of autistic children often experience greater stress than parents of neurotypical children (Keenan et al., 2016). Caregivers often experience a lack of support, negative judgements and affiliate stigma from friends, family and the community at large along with added financial burden (Papadopoulos et al., 2019). Given all of these impacts, many parents may urgently need support and validation. We do not believe there need be any conflict between encouraging positive views of autism and recognizing the challenges that caregivers face in our society.

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