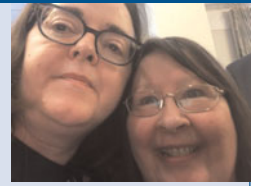


Editorial

The role of psychiatry in championing positive life outcomes for children and adults with neurodevelopmental disorders and their families

Yvonne Newbold and Mary Busk



Summary

Children and adults with neurodevelopmental disorders make up an estimated 10% of the population. Addressing health inequalities and poorer life outcomes is essential to deliver better quality care. Two parent-carers working in national roles in England suggest ways to increase understanding and work together in coproduction to achieve this.

Keywords

Neurodevelopmental disorders; families; inequalities; anxiety; trauma.

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Yvonne Newbold (pictured right) is a member of the NHS Assembly and mother to 26-year-old Toby who has autism with profound and multiple learning disabilities as well as many other neurodevelopmental comorbidities. He also has a history of challenging behaviour, which was extremely violent for the latter half of his childhood and beyond. She now runs Newbold Hope, a small organisation which is working with families and with statutory services staff who care for children with both a neurodevelopmental disorder (NDD) and violent and challenging behaviour. She never wants another family to have to live with daily violence from their own child for as long as she did. In the 3 years since she has been doing this work, through a series of webinars, workshops, online support and other resources, there are now several hundred children who are no longer physically violent towards others, and who are now happier, calmer and with much more hopeful futures ahead of them. She has also been working with a UK research team on a qualitative study looking at the impact on families from this sort of violence from a child who also has an NDD. **Mary Busk** (pictured left) is a Family Carer Adviser in the Children and Young People Team in the Learning Disability and Autism Programme in NHS England and Improvement. Before this role, she recognised the need for the education, health and social care systems to listen to and work with parent-carers. She cofounded the National Network of Parent Carer Forums and was involved in writing the new legislation in England for children and young people with special educational needs and disabilities that became law in 2014. She also coproduced research priorities to improve the health of children and young people with neurodisability and other diagnoses, including the long-term conditions and childhood disabilities, which is part of the community services data-set. She has three children one of whom, Alex, has autism, a sensory processing disorder, a severe learning disability, expressive and receptive language disorders and Ehlers-Danlos, hypermobility type. He also had avoidant/restrictive food intake disorder, which took many years to work through with great care and support from a specialist out-patient service. She has spent most of her son's 20 years advocating to have his needs understood and met, working through multiple crises and ensuring he has a good quality of life.

established for patients with diabetes, far too often those with an NDD fall through the cracks of complex health, education and care systems, with devastating results. This deepens health inequalities and leads to poorer life outcomes.

We know from Contact's *Caring More than Most Report* (2017) that families of disabled children in England experience greater poverty and are more likely to live in single parent households than families with non-disabled children.² Studies from around the world^{3,4} have highlighted stress and resilience in parents of children with NDDs. Reports during Coronavirus disease 2019 (COVID-19) showed a disproportionate impact on people with disabilities and their families.

Anxiety

Although there is some understanding of challenging behaviour, violence in children with NDDs has been historically underacknowledged. In the UK, the largest funder of health and care research, the National Institute for Health Research (NIHR) has commissioned new studies to develop the evidence base about treating anxiety among those with NDDs. In our experience, people with NDDs can find their environment and other people to be very confusing. This can make them feel unsafe, anxious and frightened. Every person with an NDD has a unique profile, including sensory, communication and social issues that will have an impact on how well they cope in any situation. Identifying these factors and addressing them to help the person cope better is essential for lowering the heightened anxiety levels that can cause behaviour to become challenging.

However, mental health services are not always commissioned to treat anxiety in autism. Additionally, children and young people may not have the right understanding of, and support for, the different aspects of their NDD, including the necessary communication aids at home and at school. The issue is made far more difficult as they may not appear outwardly either to have an NDD or a disability that is recognised by the Equality Act 2010, as in the case of autism and an intellectual disability (also known as learning disability in UK health services). In the face of an invisible disability, they and their families are very often blamed for any challenging behaviour that often happens because reasonable adjustments have not been made to enable the person to function at their best.

People with a neurodevelopmental disorder (NDD) and their families can often feel like the poor relation as far as physical and mental health is concerned. We are two mothers with first-hand experience of how traumatic things can become when the right services cannot be accessed. We see what happens when families reach crisis. We also get to see many of the lost opportunities along the way when, if someone had stepped in, or things had been done differently or someone had listened to what was being said, a significantly more positive outcome may have been achieved. We are delighted to be asked to write for this issue, and our hope is that it may lead to greater understanding and collaboration between practitioners and families.

According to *Embracing Complexity* people with one or more of this group of disorders make up an estimated 10% of the population, which is roughly double the number of people who are living with diabetes.¹ Yet whereas care pathways are long-

Trauma

It can take several years for a parent-carer to successfully navigate a complex system to secure an appointment for mental health services. By the time they do parent-carers are most likely to be traumatised and exhausted, not just by challenges in their daily lives, but also by the judgement, blame and shame that other people project onto them. (A parent-carer means 'a person aged 18 or over who provides/intends to provide care for a disabled child for whom the person has parental responsibility' – Children and Families Act 2014.)

Parent-carers learn very quickly to be careful about openly discussing their child's behavioural challenges. There is very limited understanding of NDDs and challenging behaviour among the wider population. It is not uncommon for a parent to be shunned by their family, friends and neighbours, and to be scorned by other parents at the school gate. There is little training available for staff regarding challenging behaviour in children with NDDs. This means many parent-carers can be wrongfully blamed, with an incorrect focus on the parent-carer's parenting skills. Yet the parents that we meet, many of them already at or beyond crisis point, are truly remarkable, facing daily situations that most people could barely imagine. Their levels of resilience in the face of long-term and relentless adversity are often exceptional and this group of families could, through future research, offer a much deeper understanding of why some people appear to cope better than others through difficult times.

Parent-carers are the very best resource their child will get. They generally have a deep and holistic understanding of their child. They also have to advocate for those who have no voice to ensure that their voice is heard, but it can feel as if nobody listens and that they are seldom believed. Instead, society vilifies them and blames them for their child's behaviour. Parent-carers are very often traumatised, and re-traumatised, by the frustrations of trying to access services. Children with an NDD also run a high risk of becoming traumatised themselves because of too many negative experiences that may be related to their disability, including much higher rates of school exclusion and bullying⁵ than their neurotypical peer group.

Communication

Parent-carers know that every year without the right help and support in the community (from health, education or social care) their child is becoming increasingly anxious and coping less well. The distress this can cause may mean that challenging behaviour is intensified, which is often the child's way of communicating these negative feelings and emotions. This can be further compounded by an inability of others to understand the child's communication needs, which can also lead to significant distress. Parent-carers know that, without help, this is likely to lead to their child having contact with the criminal justice system or to a long admission in an in-patient mental health setting. Adults with NDDs are significantly overrepresented in our prison population, and this group of parents can see the writing on the wall. They are terrified of the future.

Inequalities

Every child and every adult deserve to live a happy and productive life that is filled with hope for the future. Children who are living long term with severe anxiety will struggle to learn. Writing off 10% of the population just because of the lack of the right services to meet

their needs is unacceptable. The evidence base for medication and psychological interventions for children are also very limited, as highlighted by systematic reviews and relevant National Institute for Health and Care Excellence guidelines. However, parent-carers already know a lot about which interventions can work, so the lack of an evidence base should not prevent the provision of practical help and support. Referrals to allied health professionals who are able to support a greater understanding of both a child's sensory and their communication needs can be very helpful.

Getting it right in childhood is about much more than simply avoiding an adulthood of lost opportunities. We know there is a higher use of psychotropic medication in this group, where no mental illness is diagnosed. We know that children with autism are 28 times more likely than neurotypical children to experience suicidal ideation or attempts.⁶ We know that 79% of adults with autism report having a mental health problem at some point in their lives.⁷ We know that too many people with an intellectual disability die too young from preventable reasons, including inequity of access and poor quality of care.

Working together

It is essential to find ways for practitioners and families to work together so we generate a greater understanding. Together we could shape commissioning, service delivery and the research landscape, to make a real difference. INCLUDE is a national project in the UK and is part of a larger equality, diversity and inclusion programme within the NIHR. *Working Well Together* from the National Collaborating Centre for Mental Health provides evidence and tools to enable coproduction⁸ – working and involving people and families directly as equals – in mental health commissioning. Coproduction is also essential for the realisation of personalisation, or the process by which people with disabilities, physical health or mental health needs receive support tailored to their individual needs and wishes. This is at the heart of the ambitions for improving care in England through the NHS Long Term Plan⁹ (<https://www.england.nhs.uk/2014/08/personalised-resource/>).

In recent months, we have seen innovative new commissioning models with the rolling out of the NHS-led Provider Collaborative Programme in England. Will these new models of care be evidence based, coproduced and evaluated to better support a child and their parent-carers? This has so much potential, and with leadership and contributions from psychiatry and others, what they promise to deliver in terms of improved care and better life outcomes can be achieved. Existing policies in England including Care Education and Treatment Reviews (CETRs) are there to help deliver more timely care and support across education, health, care and housing for children and adults with NDDs and their families (<https://www.england.nhs.uk/learning-disabilities/natplan/>).¹⁰ These help avoid crises, institutionalisation and inappropriate admissions to in-patient settings. Please be allies to parent-carers in this work. Please commit to working in coproduction, both strategically, to create new pathways of care close to home, and individually, to provide high-quality, person-centred care for each child, adult and their families in their community. A proactive and powerful alliance between clinicians and parent-carers will lead to improved life outcomes and to increased satisfaction and shared understanding.

We would like to see a future when all practitioners can see beyond a child's apparent 'volatile and out-of-control' behaviours, when they understand the complex challenges a child faces, and when they know how to play a part in improving their life outcomes. For example, actively listening to them, recommending a CETR, signposting information, or being willing to advocate within local systems, including with commissioners, for what is needed for that child and

their family. A kind word of encouragement can make a huge difference too. Let us work together to ensure that the care in place for children and adults with NDDs creates positive life outcomes for them and their families. Working together, we know this is possible.

Declaration of interest

None.

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