

Embracing Complexity



Time to think differently

Conversations Not Assumptions – 30 June 2022
Embracing Complexity Special Interest Research Group

Catch up on the webinar

- Webinar info, slides and recordings
<https://embracingcomplexity.org.uk/news/conversations-not-assumptions-sirg-webinar-on-mental-health>
- Watch back on Facebook: <https://fb.watch/dZB5gFzXYw/>
- Milo's film: <https://youtu.be/FcYqnY4fMGs>

What is neurodiversity?

- Around 10-15% of individuals meet diagnostic criteria for one or more neurodevelopmental conditions (NDCs), including autism, ADHD, and various motor and learning difficulties.
- Neurodiversity views NDCs not as disorders, but as the expressions of the broad variation that exists among all people in the way our minds and brains function. The everyday challenges experienced by neurodivergent people are often a product of the social environment in which they live.
- In a broad sense, neurodiversity could encompass certain mental health conditions.
- This view emphasises not just challenges, but also strengths and what neurodivergent people can contribute to our society.

Why is this important?

- Links between neurodevelopment and mental health: NDCs and mental health conditions often co-occur and may be seen under the same umbrella. People with the same condition and across different conditions may have very different profiles.
- Developing coping strategies and resilience: Focusing on both difficulties and strengths unique to each individual can help tailor coping strategies and adjustments to the environment.
- Getting the right treatment and support: Shifting away from aiming to “fix” specific difficulties and towards making the environment more inclusive.

- Avoiding poor outcomes: Both NDCs and mental health conditions need to be closely monitored together over time, in order to offer timely support and prevent poor outcomes in those most likely to experience them.
- Directing research: The neurodiversity framework is having a strong impact on research, with more and more researchers looking at NDCs beyond individual categories using so-called transdiagnostic approaches.

Overlapping and co-occurring conditions

- Individual NDCs such as autism, ADHD, epilepsy and cerebral palsy have been found to overlap. A Norwegian study led by Pal Suren (see below) found that 17.3% of autistic people also had ADHD, and 11.2% also had epilepsy.
- The high degree of overlap between autism and ADHD is likely due to their shared features, such as social differences and struggles with executive function. However, there are subtle differences.
- The overlap can create complexities in diagnosis and support. It is only in the most recent iteration of the DSM that autism and ADHD can be diagnosed together. Studies have shown that existing ADHD scales are much less effective in identifying ADHD symptoms in autistic children, and vice versa. There is little research on how to support people with both conditions.
- NDCs also commonly overlap with mental health conditions. 7 in 10 autistic children also have a mental health condition such as anxiety, depression or obsessive-compulsive disorder (OCD).
- These high rates of mental ill-health are partly due to struggling to fit in or make sense of the world, stigma and discrimination, and having fewer resources and support to develop coping skills.
- Roughly 1 in 5 women with anorexia are autistic. Recently, more attention has been paid to Avoidant/Restrictive Food Intake Disorder (ARFID), which was introduced to the DSM in 2013 and the ICD-11 earlier this year. ARFID is characterised by avoiding certain food or food groups entirely, and differs from other restrictive intake disorders in that it is not driven by body image. It is possible that some autistic people diagnosed with anorexia actually have ARFID, or both.

Drivers of mental ill-health in neurodivergent people

- There are a wide range of factors driving mental ill-health in this group, including socioeconomic, biological and environmental factors – see the diagram on the slides for details.
- Genetics may also be a factor. For example, ADHD is highly heritable, and is linked to dysfunction in the transfer of dopamine – low levels of which are associated with a number of mental health conditions.
- Diagnosis and treatment of mental health conditions in neurodivergent people is made more difficult by the numerous possible drivers and co-occurring

conditions. Many are calling for more personalised approaches, focusing on individual minds.

Avoid making assumptions

- Many young people with NDCs try and mask their neurodivergent traits; a recently completed study found that this group also report masking mental health difficulties.
- Many characteristics of NDCs overlap or look like symptoms of mental health conditions. For example, difficulty concentrating and restlessness are characteristics of ADHD, but also features of depression.
- In looking for signs of mental health difficulties, look for change in these characteristics from what is typical for that person – if an autistic person has always avoided social contact, this may not be cause for concern, but if they were previously very social this could be a sign of mental health difficulties.

Barriers to support

- There are many barriers along the pathway to mental health support for neurodivergent people – including recognition of need, identification, and the provision of support – see the diagram on the slides for more details.
- Neurodivergent people often have difficulty identifying and sharing their own emotional states (alexithymia), which can make it difficult for them to recognise emotional or mental health needs.
- It can be especially difficult for people with communication challenges, such as people with severe or profound and multiple learning disabilities, to share their emotions.
- Diagnostic overshadowing is when people attribute all of a person's behaviours or emotions to a diagnosis they already have. This might mean assuming a person is acting or feeling a certain way because they are neurodivergent, rather than because of a physical or mental health condition. This can mean conditions are missed. For example, many autistic women are initially diagnosed with a personality disorder or similar mental health condition, which leads to further delay in identifying autism.
- As a society, we can hold fixed views on what mental health looks like. This means we might assume a neurodivergent person spending lots of time alone is unhappy, rather than because they need time alone to process the world around them. We might assume a neurodivergent person who smiles a lot is happy, when this may be a learned social behaviour or stimming.
- People often encounter difficulties accessing and navigating complex services. Parents often report battling to get mental health support for their neurodivergent child, services working alone rather than together, variation in services based on where they live, and extremely long waiting lists.

- There are many things we can do to remove barriers – such as supporting families with information or help with phone calls and forms, increasing collaboration between services, teaching professionals about the overlap between NDCs and mental health conditions, developing diagnostic tools for mental health conditions with neurodivergent people, and increasing government funding for services.

What can we do differently?

- Notice the signs: The child may “show” their state of mind rather than tell. They may be eating or sleeping less, aggressive, withdrawn or losing interest in things they used to enjoy. Perhaps a parent might notice they are just not themselves.
- Assessment: If we just look at symptoms, we may miss the cause. For example, aggression or withdrawal could be due to illness, lack of routine, change of staff, frustration, bullying or lack of coping skills. In many cases, it is the environment that needs to be changed.
- Ensure access to mental health services: Ask how best to communicate, such as using visuals, Talking Mats or sign language. Use clear, straightforward, unambiguous language. Offer shorter or longer sessions, and supports such as social stories. Be open to a different setting, such as home or online. Some children may not want to engage directly, and trust can take time to build.
- Around 25%-40% of autistic children are minimally verbal or non-speaking; communication may present differently. People with learning disabilities more generally are often overlooked when considering neurodiversity access.
- Stronger links between frontline and services: Preventative work can potentially have a big impact. Continuity of care into adulthood and across services is needed to prevent young people being “lost” at crucial points.

Parent/carer mental health

- Parents of autistic children are twice as likely to have mental health conditions. This may be partly genetic.
- Good parental mental health is also important for the health and wellbeing of children – so carer support is crucial for the wellbeing of all.

Key links

- Webinar feedback survey: <https://www.smartsurvey.co.uk/s/AA1XLU/>
- Embracing Complexity website: <https://embracingcomplexity.org.uk/>
- Emerging Minds website: <https://emergingminds.org.uk/>

Resources and reading shared in the webinar

- What is neurodiversity? <https://www.geniuswithin.org/what-is-neurodiversity/>

- Autism Spectrum Disorder, ADHD, Epilepsy and Cerebral Palsy in Norwegian Children: <https://bit.ly/3Rk0jEU>
- Learning About Neurodiversity in Schools (LEANS) – resource pack for teachers aimed at mainstream primary pupils: <https://www.ed.ac.uk/salvesen-research/our-projects/learning-about-neurodiversity-at-school>
- Edinburgh Psychoeducation Intervention for Children and Young People (EPIC) – booklets for understanding neurodevelopmental difficulties: <https://www.ed.ac.uk/clinical-brain-sciences/research/epic-edinburgh-psychoeducation-intervention>
- EPIC blog (suitable for parents and teachers): www.epic-information.com
- SameHere scale (to educate on talking about feelings and educating young people): <https://samehereglobal.org/continuum/>
- Oxford CAMHS resources: <https://www.oxfordhealth.nhs.uk/camhs/carers/>
<https://www.oxfordhealth.nhs.uk/camhs/carers/resources/>
- Know Your Normal – Ambitious about Autism (autism and mental health): <https://www.ambitiousaboutautism.org.uk/what-we-do/connecting-young-people/youth-led-toolkits/know-your-normal>
- Right from the Start toolkit – Ambitious about Autism (recognising autism): <https://www.ambitiousaboutautism.org.uk/sites/default/files/toolkits/right-from-the-start-toolkit-ambitious-about-autism.pdf>
- Autistic Mutual Aid Society (AMASE) website and resources: <https://amase.org.uk/> <https://amase.org.uk/resources/mhguide/>
<https://amase.org.uk/mhsummary/>
- School related anxiety (aimed at Scotland but principles are applicable anywhere): <https://www.thirdspace.scot/wp-content/uploads/2020/08/NAIT-Anxiety-Related-Absence-Guidance-2020.pdf>
- Embracing Complexity report on improving research infrastructure: <https://embracingcomplexity.org.uk/news/new-report-on-improving-research-across-conditions>
- Altering Dynamics of Autonomic Processing Therapy (ADAPT): A novel, targeted treatment for reducing anxiety in joint hypermobility: <https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-021-05555-4>
- Organisations providing advice on rights in education and how to access those rights
 - IPSEA – for advice on children’s rights and how to challenge decisions: <https://www.ipsea.org.uk/>
 - Coram – for legal advice on children’s rights: <https://childlawadvice.org.uk/>

Other reading and research on neurodivergence and mental health:

- Eating disorder or disordered eating? Eating patterns in autism: <https://www.autism.org.uk/advice-and-guidance/professional-practice/avoidant-eating>
- ARFID, autism and anorexia: <https://www.thelondoncentre.co.uk/disorders-read-more/arfid-and-autism>
- Untangling the ties between autism and obsessive-compulsive disorder: <https://www.spectrumnews.org/features/deep-dive/untangling-ties-autism-obsessive-compulsive-disorder/>
- How to tell if you have autism, OCD, or both: <https://www.stairwaytostem.org/how-to-tell-if-you-have-autism-ocd-or-both/>
- Differentiating between Asperger's and OCD: <https://iocdf.org/expert-opinions/expert-opinion-aspergers-and-ocd/>
- Six ideas about how to address the autism mental health crisis: <https://journals.sagepub.com/doi/full/10.1177/13623613211067928>
- A blind spot in mental healthcare? Psychotherapists lack education and expertise for the support of adults on the autism spectrum: <https://doi.org/10.1177/13623613211057973>
- Serving the underserved: How can we reach autism families who systemically miss out on support? <https://journals.sagepub.com/doi/10.1177/13623613221105389>
- Mental health experiences of young autistic adults in England: <https://journals.sagepub.com/doi/10.1177/1362361318757048>
- Psychiatric disorders in children with autism: <https://pubmed.ncbi.nlm.nih.gov/18645422/>
- Comparing autism and OCD within a compulsive and repetitive trait framework: <https://hydra.hull.ac.uk/assets/hull:17929a/content>
- Investigating restrictive eating disorders in autistic women: <https://link.springer.com/article/10.1007/s10803-020-04479-3>
- Towards a treatment for intolerance of uncertainty in young people with autism: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5676830/>
- Sensory, emotional and cognitive contributions to anxiety in autism: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5258728/>
- Anxiety disorders and sensory over-responsivity in children with autism: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2980623/>
- Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults: <http://eprints.gla.ac.uk/250774/1/250774.pdf>
- 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality: <https://journals.sagepub.com/doi/10.1177/1362361318816053>
- Mental health problems in youths with intellectual disability: Need for help and help-seeking: <https://pure.eur.nl/en/publications/mental-health-problems-in-youths-with-intellectual-disability-nee>