

Embracing Complexity in Research on Neurodevelopmental Conditions and Mental Health: Executive Summary

Background

Neurodevelopmental conditions (NDCs)¹ are lifelong conditions which affect the brain and influence how people think, perceive the world, and interact with others, such as autism, learning disabilities, attention differences, Tourette's, dyslexia, dyspraxia, and many more. Although NDCs are diverse, they often share common characteristics and challenges. For example, people with different NDCs are at increased risk of experiencing mental health problems.

While it is common for people with NDCs to have more than one, most systems, services, policies, and research is set up to only look at one NDC at a time. Research spanning across multiple NDCs is likely to better reflect the real world, therefore it is imperative for research and practice to embrace complexity across NDCs, especially regarding mental health. However, this is not currently standard practice in neurodevelopmental research, and researchers experience various challenges conducting studies across NDCs and mental health (e.g., obtaining research funding, designing accessible research that accounts for communication differences, recruiting participants, working across disciplines).

Methods

In this project we: a) reviewed research priorities relevant to NDCs to identify overlaps in important research areas across NDCs, b) explored barriers and opportunities in transdiagnostic research through interviews and exploration of current research, and c) established a network of researchers and organisations interested in future research collaboration across NDCs and mental health. The aim was to facilitate future research spanning across NDCs and mental health.

Findings

Key findings include:

- **Mismatch between established research priorities and research being conducted.** The most prominent area of research identified as a priority across NDCs was around supporting people with NDCs (e.g., physical health, communication, mental health, social supports, education, and so on). However, research being conducted on NDCs does not appear to reflect this as a priority, with the majority of funded or published research focusing on other topics, such as research on causes, neuroscience, biology, and genetics. Clearly, research on supporting people with NDCs is much needed. Other frequent research priority areas shared across NDCs included research on understanding people with NDCs, supporting families or carers of people with NDCs, and supporting professionals working with people with NDCs.

¹ A note on language choices – in this report we use the term “people with neurodevelopmental conditions/ people with NDCs” based on consultation with charities and experts by experience involved in Embracing Complexity. There is currently no research on preferred language across this very large and diverse group of people and we acknowledge that this language may not be preferred by everyone represented in the report.

- **Awareness and understanding about the overlap of NDCs.** Another key finding was a perceived lack of understanding about the overlap between NDCs and neurodevelopment amongst researchers and research funders, partly related to research and clinical silos. A shift towards conceptualising neurodevelopment broadly, moving away from pre-defined diagnostic labels, towards “neurodevelopmental needs”, may be beneficial. This would require buy-in from various researchers across NDC specialisms, disciplines, research funders, and research publishers. It would be beneficial to bring together researchers from various silos to explore this in further detail.

Recommendations

Neurodevelopmental research is in urgent need of infrastructure to improve data and informatics across diagnostic boundaries. One-time grants to individual projects are insufficient for developing shared infrastructure that would increase efficiency and coordination of research activity. Investing in this infrastructure now could save money in the long term by avoiding duplication – and more importantly, improve outcomes for people with a wide range of NDCs. Based on this project, strategic investment in research on NDCs and mental health could include:

1. **Bringing together researchers from across research silos.** Bringing researchers together will enable sharing of information and knowledge, considering which next steps are needed for future research spanning across NDCs, and developing research collaboration and partnerships.
2. **Enabling transdiagnostic comparisons.** The evidence base for supporting people with NDCs must be usable across diagnostic boundaries. Cataloguing existing research cohorts, particularly those with open access, could kickstart multiple comparative studies across NDCs. Identifying a set of core measures to include in neurodevelopmental studies, as is already done in mental health, would enable researchers to more easily compare different groups.
3. **Exploring neurodevelopmental registries.** In many areas of health research, patient registries have greatly accelerated the process of “matching” studies with would-be participants. People with NDCs and their families are often keen to take part in research, but such a registry would require major investment. NHS bodies could routinely offer the opportunity to join the registry at the point of diagnosis or as part of a support pathway – particularly when there is a lack of well-evidenced relevant support available.
4. **Funding research based on research priorities established.** There is a clear mismatch between the topics of research conducted across NDCs and research priorities established by priority setting partnerships. Research funders should be funding research based on priorities established by research setting partnerships, explicitly those including active participation of communities the research relates to (i.e., people with NDCs, families or carers, professionals or practitioners, researchers and/or policy makers).

5. **Improve awareness and understanding about the overlap of NDCs.** Increasing awareness and understanding about the overlap between NDCs is much needed, especially amongst researchers and research funders. Exploring feasible ways of conducting pan-neurodevelopmental research and will be beneficial to promote this as an approach.
6. **Ensuring research is inclusive and accessible.** Lastly, and perhaps most importantly, it is crucial to ensure future research is inclusive and accessible to people with a range of neurodevelopmental needs. Continuing to focus on easier-to-reach populations excludes marginalised people from research. Due to the increased complexity of conducting truly accessible research accounting for neurodevelopmental diversity, research funders need to consider accessibility.

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