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Embracing Complexity in Research

on Neurodevelopmental Conditions and Mental Health

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Executive Summary

Background

Neurodevelopmental conditions (NDCs) 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.

- **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 co-ordination 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.

Introduction

Neurodevelopmental Conditions and Mental Health

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 (commonly referred to as intellectual disabilities in research), attention deficit hyperactivity disorder (ADHD), attention deficit disorder (ADD), social communication disorders, Tourette's, dyslexia, dyspraxia, Down syndrome, and many more. Up to 16% of children and adolescents have NDCs (Zablotsky et al., 2019), though this figure is widely disputed, and it has been suggested actual prevalence rates are far higher due to under or mis diagnosis of NDCs.

Although NDCs are diverse, they share common characteristics – being a lifelong neurodivergence[2], emerging in childhood, and often with overlapping areas of difficulties, such as in general development, communication and language, social inter-relatedness, motor coordination, attention, activity, behaviour, mood, and sleep (Gillberg, 2010; Thapar et al., 2017). While it is common for people with NDCs to have more than one, most research studies, systems, services, and policies are set up to only look at one NDC at a time (Alexander et al., 2021; Gillberg, 2010; Pauc, 2005). For example, a selection bias against participants with learning disabilities has been indicated in autism research (Russel et al., 2019).

In practice, this siloed approach means many people with NDCs and their families may not receive timely – or even appropriate – support. For example, there is significant overlap between autism, learning disability and epilepsy, and epilepsy is a leading cause of early death in autistic people with learning disabilities, a group who are often resistant to traditional epilepsy treatments (Bolton et al., 2011; Croen et al., 2015; Harper et al., 2019; Pickett et al., 2011; Robertson et al., 2015; Royal College of Psychiatrists, 2017; Sansa et al., 2011; Tunchman & Rapin, 2002; Viscidi et al., 2013). However, in a review of over 1,400 global treatment trials for epilepsy, none had included autistic people (see Harper et al., 2019). Those at greatest risk are typically excluded from research that could otherwise reduce those risks.

There is significant overlap between NDCs and mental health. For example, research indicates children and adolescents with NDCs are at increased risk of experiencing mental health problems (Alexander et al., 2021; Kumar et al., 2016; Lai et al., 2019; Larson et al., 2011; Maïano et al., 2018; Rydzewska et al., 2019). Yet, we still know relatively little about preventing and treating mental health conditions in this group, and they are frequently excluded from research, especially those with multiple NDCs. Typically, mental health research focuses on people with a single NDC, such as a diagnosis of autism or learning disability. While this research can help us to understand mental health within a specific NDC, this does not reflect the reality that most people with NDCs have more than one, potentially limiting the applicability of research to people with overlapping conditions. For example, in Cameron et al.'s (2020) systematic review of research on psychological interventions for depression in children and adolescents with learning disabilities and/or autism, none of the studies identified had

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[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.

[2] Neurodivergence is defined as *"divergence in mental or neurological function from what is considered [neuro] typical"* (Lexico, 2021), such as autism, dyslexia, dyscalculia, epilepsy, hyperlexia, dyspraxia, ADHD, and so on. Neurodiversity acknowledges and embraces the diversity of human brain and minds.

included children who were autistic and had a learning disability – all participants either were autistic without a learning disability or had a learning disability but not autism, indicative of a selection bias against participants with learning disabilities in autism research (Russel et al., 2019).

While high rates of co-occurring mental health and NDCs may be attributed to various factors, it is clear mental health is a challenge that spans across NDCs. Research spanning across multiple NDCs and mental health may better reflect the real world. Therefore, it is imperative for research and practice to embrace complexity across NDCs and mental health. However, researchers may experience challenges conducting studies across NDCs and mental health, such as recruiting participants across different NDCs, accounting for differences in varying communication abilities and methods (e.g., body language, facial expressions, speech, signs, symbols, pictures), and accounting for variation in presentation of mental health conditions, to name a few. Furthermore, this is an extremely broad area covering a range of research fields (e.g., psychiatry, psychology, pharmacology, genetics) across identifying, preventing, and treating mental health conditions in people with NDCs.

Embracing Complexity

Led by Autistica, Embracing Complexity is a coalition that brings together 61 NDC and mental health organisations[3] acknowledging the overlap in NDCs, and working together to tackle key co-morbidities and improve diagnosis, services, and research across NDCs (Embracing Complexity website, 2020).

The need for a more joined-up approach to neurodiversity is a large part of why Embracing Complexity was set up. Since their launch in May 2019, Embracing Complexity have been calling for a more joined-up approach acknowledging the overlap of NDCs, to help people with NDCs achieve the best outcomes (Autistica, 2019; Cerebra, 2019). At the start of this project, Embracing Complexity had published two key reports:

1. **Embracing Complexity: Towards New Approaches for Supporting People with Neurodevelopmental Conditions** (Embracing Complexity, 2019), sharing the lived experience of over 500 people with NDCs and families, highlighting the barriers people with NDCs face in diagnosis, services, and research and calling for improvements in these areas.

2. **Embracing Complexity in Diagnosis: Multi-Diagnostic Pathways for NDCs** (Embracing Complexity, 2019), highlighting services which have implemented pathways to diagnose multiple NDCs simultaneously in children, aiming to reduce the long waiting lists and multiple referrals people with NDCs often face to get right diagnoses.

During this project Embracing Complexity launched their briefing **COVID Complexity: Learning from lockdown to support those who think differently** (Embracing Complexity, 2021), sharing the lived experience of 160 people with NDCs, relatives and carers during the COVID-19 pandemic and implementation of lockdown measures, highlighting why the post-pandemic world must do more to support all people with NDCs.

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[3] See Appendix A for a full list of current members. An up-to-date list of members can be found on the Embracing Complexity website at https://embracingcomplexity.org.uk/about-us.

Emerging Minds

Emerging Minds is a research network set up to bring together researchers, charities, and other organisations to address important mental health research questions. The Emerging Minds network aim to reduce the prevalence of mental health problems experienced by children and young people and tackle four research challenges (Emerging Minds website, 2020):

1. **The big question:** Implementing effective promotion of good mental health, prevention, and early treatment at scale amongst children.
2. **Embracing complexity:** Meeting the needs of children with **intersecting needs** to promote good mental health, prevent, and tackle problems early. Intersecting needs includes children with NDCs, special educational needs, communication challenges, physical health conditions, behavioural difficulties, and children who are not in school, or at risk of being excluded.
3. **Voices, power, and attitudes:** Amplify young people's voices and change societal attitudes in ways that positively impact on mental health.
4. **Supporting the supporters:** Enabling family members, friends, and settings to promote good mental health, prevent, and overcome problems.

Emerging Minds is committed to supporting early career researchers through their funded cross sector placement scheme, bringing together early career researchers and third or public sector organisations for a three-month period (or longer part-time) to complete a research project that will make a difference to children and young people’s mental health (Emerging Minds website, 2021).

Emerging Minds provided the funding for this research project, which fits in with their key research challenge **embracing complexity**, described above.

Embracing Complexity in Research on Neurodevelopmental Conditions and Mental Health: Our Research Project

The purpose of this research project was to explore barriers and opportunities in transdiagnostic research on NDCs and mental health, with the aim of facilitating the completion of future research spanning across multiple NDCs and mental health. To achieve this, the key activities in this project included:

- Reviewing research priorities relevant to NDCs and identifying areas of research which are of importance across multiple groups of people with NDCs.
- Identifying barriers and enablers of transdiagnostic research through interviews with the research community and exploration of pre-existing research initiatives.
- Identifying a network of researchers and organisations interested in future research collaboration across NDCs and mental health.

By identifying barriers and opportunities in transdiagnostic research and starting discussions with the research community, Embracing Complexity can begin to tackle challenges to conducting research that span across NDCs and mental health. Strengthening links across researchers, particularly those who specialise in different NDCs, will enable more effective sharing of knowledge and best practice. Taking a strategic approach is likely to be key enabling research in this area, which will ultimately lead to better outcomes for people with NDCs.

To ensure we were able to achieve our aims within this small-scale, time-limited project, we developed a logic model to guide the project (see **Figure 1**). Logic models are a visual representation of the relationship between a project's resources, activities, outputs, and identified outcomes, in relation to key stakeholder groups. They are a useful tool to develop a shared understanding of a project and are a working document that are updated iteratively to reflect changes as a project develops.

Figure 1 – Embracing Complexity Research Project Logic Model

Context: Embracing Complexity brings together organisations working to improve the lives of people with neurodevelopmental conditions (NDCs) to think differently about how to campaign, fund research, and offer support, in order to improve lives faster, more efficiently and more effectively

Aims: To build Embracing Complexity's research influence and facilitate future transdiagnostic research across NDCs and mental health

Inputs

- Funding from Emerging Minds Research Network (University of Oxford) for 3-month project
- Supervision from Embracing Complexity Lead and Chair (based at Autistica)

Processes

Activities

- Review research priorities across NDCs
- Identify barriers and opportunities in trans-diagnostic research
  - Interview researchers
  - Explore pre-existing research and initiatives
- Identify network of researchers and/or research organisations interested in future collaborations
- Establish Special Interest Research Group
- Write up findings
- Disseminate findings

Outputs

- Emerging Minds blog
- Mental Elf blog
- Report highlighting findings:
  - Shared themes across NDC research priorities
  - Barriers and opportunities to transdiagnostic research
- Lay summary
- Infographics
- Presentation of findings

Stakeholders

- People with NDCs
- Family members and friends
- Embracing Complexity members
- Emerging Minds network
- Professionals at the intersection of NDC and mental health:
  - Charities
  - Practitioners
  - Researchers
  - Research directors
  - Research funders
  - Policy makers

Outcomes

- Increased awareness of the importance and need for transdiagnostic research across NDCs and mental health
- Increased understanding of the barriers and opportunities in transdiagnostic research across NDCs and mental health
- Establish a network of researchers and organisations interested in future collaborations
- Facilitate future transdiagnostic research

Assumptions: To improve the lives of people with NDCs, research should cross diagnostic boundaries and recognise the complexity of people's lives

External factors: Current context, impact of COVID-19 on member organisations, research landscape, funding, service provision, etc.

Research Priorities Across Neurodevelopmental Conditions and Mental Health

Research priorities are topics, questions, or uncertainties that are deemed important to investigate through further research, building on the current knowledge and evidence base. Research priority setting is described as '*A collective activity for deciding which uncertainties are most worth trying to resolve through research; uncertainties considered may be problems to be understood or solutions to be developed or tested; across broad or narrow areas*' (Sandy Oliver, see Nasser & Crowe, p.1).

The importance of conducting "patient-orientated" research, defined as *'the design and conduct of research that respects and focuses on the priorities and outcomes relevant to patients'* (Jun et al., 2015, p.2), is growing substantially.[4] In the UK, James Lind Alliance (JLA) research priority setting partnerships were established to address evidence of a mismatch between the research being conducted and what patients and health professionals want to be researched (for an overview, see Crowe et al., 2015). JLA priority setting partnerships bring together a range of stakeholders, including patients, carers, clinicians, and researchers to identify and prioritise uncertainties or questions for research through a series of engagement activities (e.g., surveys, interviews, workshops) to inform research agendas (Conwan & Oliver, 2013; Crowe et al., 2015; Jun et al., 2015).

In addition to JLA priority setting partnerships, other research priority-setting activities have been reported to establish priority areas for research topics. These vary significantly in terms of methodology and patient or public involvement, such as academic commentaries or opinion articles, expert consultations, reports of researcher or clinician-based workshops, surveys with various stakeholders, Delphi studies synthesising and obtaining consensus across stakeholder groups (see Hasson et al., 2000), and the Child Health and Nutrition Research Initiative (CHNRI) systematic approach to research priority setting (see Rudan et al., 2008). Generally, methods including extensive reviews of pre-existing research and integrating the views of various stakeholders, namely those with lived experience, are perceived as the "gold-standard" for establishing research priorities.

While the total number of research priorities set ranges considerably depending on the methods used and the topic of interest, typically around 10 top research priorities are set. There is also substantial variation in the specificity of research priorities – some cover extremely broad areas of research, whereas others formulate highly specified research questions, for example following the PICO format (P: Population or problem, I: Intervention, C: Control or comparison, O: Outcome of interest; see Aslam & Emmanuel, 2010).

Identifying Research Priority Setting Exercises

To enable the identification of research areas of importance shared across NDCs, a review of research priority setting partnerships or exercises relevant to NDCs was completed. This included searching priority setting partnership websites (e.g., JLA), academic databases (e.g., Web of Science) and general search engines (e.g., Google) to identify all relevant literature (e.g., peer-reviewed research publications and grey literature reporting research priority setting partnerships or exercises). In addition to searches, several researchers and NDC

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[4] The term 'patient' has been used in this context due to an initial focus on research on medical conditions.

organisations were contacted to enquire about other relevant research priority setting activities, in addition to social media posts.

Due to the evolving nature of research priorities and the importance of context, we were interested in research priorities set within the past 12 years (from 2008 onwards). Although Embracing Complexity is based in the UK, research priorities from other countries were included. Due to the broad nature of NDCs and the diverse range of relevant research fields (e.g., education, health, social care, psychology, psychiatry), various terms are used under the broad umbrella category of "neurodevelopmental conditions" (NDCs). Therefore, a range of broad and specific NDC terms were used in our searches to identify research priority exercises (see **Appendix 2**).

Overall, we identified 41 research priority setting partnerships or exercises directly relevant to NDCs (see **Table 2** for the full list). In addition, a few ongoing research priority setting exercises were identified, such as the child neurological conditions priority setting partnership, for which the top ten unanswered research questions in paediatric neurology are anticipated to be established by October 2021 (British Paediatric Neurology Association website, 2021). Furthermore, a systematic review of autism research priorities was identified, summarising research priorities across seven autism research priority setting studies (Roche et al., 2020). This was not included in the current review as no new research priorities were established and the studies Roche et al. (2020) reviewed were included in our review.

Following the completion of this review, the International Society for Autism Research (INSAR) published research priorities on suicide prevention in autistic people in April 2021 (INSAR, 2021). They conducted two systematic reviews, consulted with more than 1,000 autistic people and those who support them, and conducted seven workshops in the UK, USA, and Netherlands to identify and prioritise the top 10 issues for suicide prevention in autistic people.

Table 2 – NDC Research Priority Setting Exercises

Topic for Research Priority Exercise	Group/Author	Year	Number of Research Priorities
Autism	JLA	2016	25
Learning Difficulties	JLA	2018	24
Childhood Disability	JLA	2015	25
Neurodevelopmental Disorders	JLA	2017	20
Epilepsy	Wales Epilepsy Research Network	2009	12
Neuro-oncology	JLA	2015	25
ADHD Treatments	SBU	2014	10
Learning Disabilities - SLT	RCSLT	2019	88
Developmental Language Disorder - SLT	RCSLT	2019	60
Rehabilitation and Disability	NHS England Clinical Reference Groups	2018	3
Neurosciences	NHS England Clinical Reference Groups	2018	3
Autism - Mental Health	Benevides et al.	2020	5
Developmental Disabilities	Tomlinson et al.	2014	30
Autism	Frazier et al.	2018	20

Traumatic Brain Injury	Nadler et al.	2018	12
Mental and Neurological Health	Khandelwal et al.	2009	46
Epilepsy	Kwan et al.	2015	14
Epilepsy	Kelley et al.	2009	14
Epilepsy	Gray matters	2008	6
Down Syndrome	Sinclair et al.	2019	10
Augmentative and Alternative Communication	O'Keefe et al.	2009	19
Complex Communication Needs	Light & McNaughton	2012	5
Brain and Spine Cavernous Malformations	JLA	2016	10
Intellectual Disabilities - Palliative Care	Tuffrey-Wijne et al.	2016	30
Neurology and Psychiatry - Sleep	Bassetti et al.	2015	24
Children and Youth with Special Health Care Needs	Coller et al.	2020	73
Cerebral Palsy	McIntyre et al.	2009	23
Autism - Sleep	Pavlopoulou & Dimitriou	2019	7
Autism	Pellicano et al.	2014	17
Autism	Gotham et al.	2015	29
Autism - Interventions/Supports	Gotham et al.	2015	9
Autism - Older People	Warner et al.	2019	11
Autism - Older Adults	Piven et al.	2011	6
Fetal Alcohol Spectrum Disorders	Schölin et al.	2020	5
Autism - Early Research	Fletcher-Watson et al.	2017	14
Autism - Transition and Employment	Nicholas et al.	2017	12
Autism - Transition	Shattuck et al.	2018	12
Autism - Anxiety	Vasa et al.	2018	9
Neurodevelopmental Disorder - Psychiatry	Alexander et al.	2020	19
Fetal Alcohol Spectrum Disorder	Finlay-Jones et al.	2020	45
Tourette Syndrome	Tourettes Action	2018	10

Notes: JLA = James Lind Alliance, SBU = Swedish Agency for Health Technology Assessment and Assessment of Social Services, RCSLT = Royal College of Speech and Language Therapists, SLT = Speech and Language Therapy.

Most of the NDC research priority setting partnerships or exercises were condition specific (e.g., autism, learning disability, epilepsy, ADHD), however, some covered multiple conditions (e.g., childhood disability, neurodevelopmental disorders, neurosciences). As shown in the graph below (**Figure 2**), the majority (n=13 of NDC research priority exercises) were on autism, followed by epilepsy (n=4), learning/intellectual disabilities (n=2) and neurodevelopmental disorders (n=2). Within the autism research priority setting exercises, several were on a specific area within autism research, such as mental health, anxiety, sleep, transition, employment, childhood, and adulthood.

Figure 2 – Topics of NDC Research Priority Setting Exercises

Considerable variation was present in the methods used to identify research priorities. Several were JLA research priority setting partnerships and therefore brought together a range of stakeholders to identify and prioritise research questions through a series of engagement activities. Others identified research priorities through engagement activities, such as completing surveys or workshops with stakeholder groups. A few were based on researchers' or practitioners' perspectives on what future research is needed, without clear involvement of the perspectives of other stakeholders.

In addition to the NDC research priorities, 44 other research priority setting partnerships of relevance to NDCs were also identified, such as research priorities for various therapy professions (e.g., occupational therapy, speech and language therapy, physiotherapy), allied health professionals, social work, mental health, and other related conditions (see **Appendix 3** for a full list).

Synthesising Research Priorities Across Exercises

Specific research priorities were extracted from each of the priority setting partnerships or exercises and input into a single database in Microsoft Excel. As research priority setting partnerships can cover a broad range of research areas due to the involvement of various stakeholder groups (e.g., people with NDCs, families or carers, various professional groups, clinicians, researchers), all research priorities were included in our analysis rather than the top 10 research priorities only, as this may miss the broad range of research areas included. The specific number of research priorities for the exercises ranged from 3 to 88 (**see Table 2,** above).

In order to identify overlapping areas of importance, a coding scheme was specifically developed for this purpose, to group similar research priorities together across multiple priority setting partnerships and exercises (see **Table 3,** below). Using this framework, specific research priorities for all of the NDC research priority setting exercises were coded in Microsoft Excel. The coding scheme was iteratively updated throughout the coding process to ensure it captured the broad range of research areas reflected, with input from the Embracing Complexity team and steering group, consisting of key individuals from core member charities in the coalition.

Where appropriate, research priorities that covered multiple areas were coded to more than one research area. For example, one of the autism research priorities identified in Shattuck et al. (2018) was: '*The changing phenomenology of autism and how it influences service needs as individuals transition into adulthood*'. This was coded as two research priority areas – '*Understanding NDCs*' and '*Supporting people with NDCs – service provision*' due to the overlapping relevance to these research areas.

Overall, there were 847 specific research priorities across the 41 NDC research priority setting exercises identified. Due to overlaps, the research priorities were coded a total of 1,318 times.

Table 3 – Coding Scheme for Research Priority Areas

Research Priority Areas	Description
Recognition and identification of NDCs	Research relating to the recognition or identification of NDCs (e.g., early signs, screening, assessment, diagnosis, identification methods) and related service provision.
Supporting people with NDCs	Research on support approaches, interventions, services, and outcomes for people with NDCs, including support for co-occurring NDCs and other conditions. This area was further sub-grouped into: physical health, mental health, speech and language, social, employment, education or academic, psychoeducation, developmental or functional, sensory, forensic, sleep, behavioural, service provision, and other or generic support.
Families or carers	Research on families and carers of people with NDCs (e.g., supporting family members and carers, understanding their needs, collaboration with families)
Professionals	Research on professionals working within NDCs (e.g., professionals' knowledge, skills, practice, training, development, collaboration between professionals).
Wider community	Research relating to the wider community (e.g., public awareness and understanding of NDCs, societal and cultural attitudes and perceptions of NDCs).
Causes or prevalence	Research on the causes or prevalence of NDCs or co-occurring NDCs.
Understanding NDCs	Research on developing understanding of NDCs (e.g., exploring the experiences of people with NDCs, their needs, daily life).
Other	Any other research areas.

Key Research Priority Areas Across Neurodevelopmental Conditions

Overview

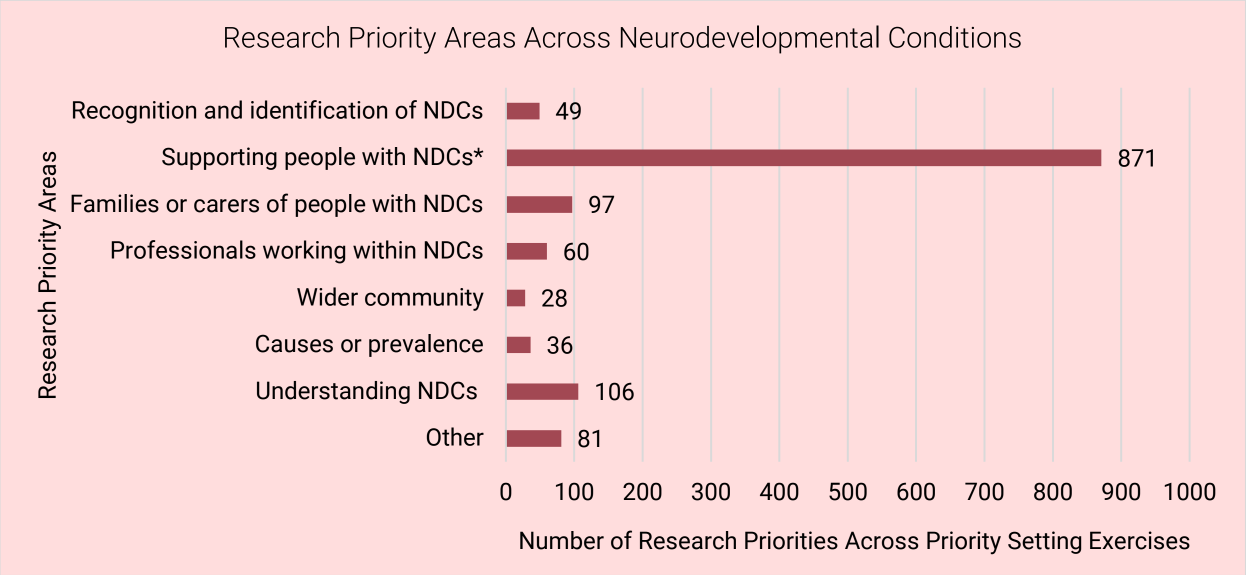
The key research priority areas across the NDC research priority setting exercises were supporting people with NDCs (n=871 research priorities), understanding NDCs (n=106), research on families or carers of people with NDCs (n=97), research relating to professionals working within NDCs (n=60), research on the recognition or identification of NDCs (n=49), the causes or prevalence of NDCs (n=36), and research relating to the wider community (n=28). In addition, there were research priorities that covered other research areas (n=81). For an overview, see **Table 4** and **Figure 3.** A breakdown of how research priorities were coded for each NDC research priority setting exercise is provided in **Appendix 4**.

Table 4 – Key Research Priority Areas Across NDCs

Research Priority Areas	Total Research Priorities	Research Priority Setting Exercises[1]
Supporting people with NDCs[2]	871	41
Understanding NDCs	106	31
Families or carers of people with NDCs	97	20
Professionals working within NDCs	60	19
Recognition and identification of NDCs	49	17
Causes or prevalence	36	17
Wider community	28	18
Other	81	21

Notes: [1]This is the total number of research priority setting exercises that included research on this area (out of a total of 41) [2]There were several sub-groups within 'Supporting people with NDCs'. An overview of these sub-groups is presented in **Table 5** and **Figure 4**.

Figure 3 – Research Priority Areas Across NDCs



*There were several sub-groups within 'Supporting people with NDCs'. An overview of these sub-groups is presented in **Table 5** and **Figure 4**.

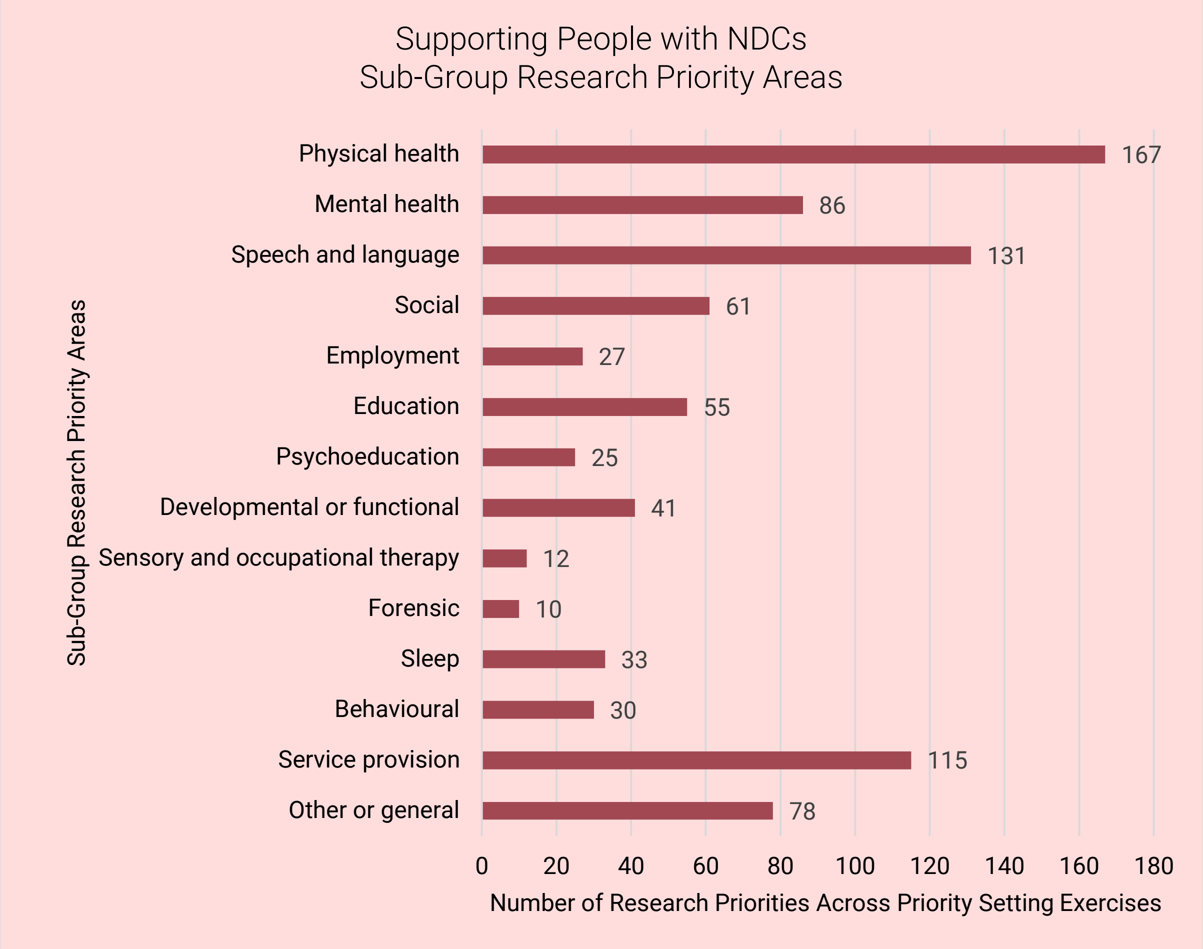
The research priority area ‘supporting people with NDCs’ had several sub-group areas, the most common were physical health (n=167 research priorities), speech, language and communication (n=131), mental health (n=86), social (n=61), education (n=55), developmental or functional (n=41), sleep (n=33), behavioural (n=30), employment (n=27), psychoeducation (n=25), sensory or occupational therapy (n=12), and forensic (n=10). Furthermore, there were research priorities related to service provision (n=115) and other or general support (n=78). For an overview of sub-groups within supporting people with NDCs, see **Table 5** and **Figure 4.**

Table 5 – Supporting People with NDCs Sub-Group Research Priority Areas

Support Sub-Group Areas	Total Research Priorities	Research Priority Setting Exercises[1]
Physical health	167	30
Speech, language and communication	131	11
Mental health	86	29
Social	61	21
Education	55	21
Developmental or functional	41	21
Sleep	33	5
Behavioural	30	14
Employment	27	10
Psychoeducation	25	13
Sensory and occupational therapy	12	6
Forensic	10	5
Service provision[2]	115	24
Other or general	78	25

Notes: [1] This is the total number of research priority setting exercises that included research on this area (out of the total 41) [2] This includes service provision for people with NDCs not covered by the above sub-groups

Figure 4 – Supporting People with NDCs Sub-Group Research Priority Areas



Supporting people with NDCs

The most prominent research priority area (n=871 research priorities) was research into support approaches, interventions, and services for people with NDCs, including current support and practice, developing and evaluating support (e.g., effectiveness, efficacy, outcomes), implementing supports, service provision and delivery, and access to support. This included support for co-occurring conditions, such as co-occurring NDCs, physical health and mental health conditions. This was split into several sub-groups (described below), as it was the most comprehensive research priority area. This research area emerged in each of the 41 NDC research priority setting exercises included in this review.

Example research priorities (see further examples in **Appendix 5**):

- *'Which early interventions are effective for children and young people with learning difficulties, at what ages and stages are they best introduced and what are the long-term outcomes?'* – Learning Difficulties (JLA, 2018)
- *'How can system navigation be organized in a manner that enables coordinated services and supports across the lifespan for individuals with neurodevelopmental disorders and their families?'* – Neurodevelopmental Disorders (JLA, 2017)

Physical health

Overall, 167 research priorities covered physical health care support or services for people with NDCs, including various health care treatments and supports (*e.g., medication, physical therapies, physiotherapy, diet, surgery, medical devices, physical activity, exercise, continence programmes, radiotherapy, postural management, dentistry, orthotics, end of life care, complementary and alternative therapies, immunology, preventative health care, annual health checks*), health care outcomes or indicators, and health care service provision (e.g., implementation and provision of health services and systems, access to health care, accommodations for NDCs). Overall, 30 of the 41 NDC research priority setting exercises included research on physical health support (see **Appendix 4**). Example research priorities (see further examples in **Appendix 6**):

- *'Medication choice in people with coexisting conditions'* – Neurodevelopmental Disorders (JLA, 2017)
- *'Investigation of health care self-advocacy strategies and potential barriers to effective health care self-advocacy for autistic people'* – Autism – Older People (Warner et al., 2019)
- *'What are the most efficient ways of training health care workers to reduce the discrimination faced by people with developmental disabilities in health care systems?'* – Developmental Disabilities

Speech, language and communication

There were 131 research priorities on speech, language, and communication support, including the provision of speech, language, and communication services or support for people with NDCs. Overall, 11 of the 41 NDC research priority setting exercises included research on the speech, language, and communication support (see **Appendix 4**). This review included several exercises specific to speech, language, and communication needs, such as priority setting for developmental language disorder (RCSLT, 2019), learning disabilities (RCSLT, 2019), augmentative and alternative communication (O'Keefe et al., 2009), and complex communication needs (Light & McNaughton, 2012).

For example (see further examples in **Appendix 6**):

- *'Provision of speech interventions for people with learning disabilities across UK-wide SLT services'* – Learning Disabilities – SLT (RCSLT, 2019)
- *'What is the utility and effectiveness of easy read and pictorial information provided to people with moderate and severe ID?'* – Developmental Disabilities (Tomlinson et al., 2014)
- *'Design a new generation of innovative AAC systems that are truly responsive to the needs and skills (motor, sensory perceptual, cognitive, linguistic) of children with CCN; that are easy to use; that are appealing; and that offer powerful communication options across environments.'* – Complex Communication Needs (Light & McNaughton, 2012)

Mental health

There were 87 research priorities covering mental health support, primarily research on improving the mental health and well-being of people with NDCs (e.*g., general and tailored mental health interventions such as cognitive behavioural therapies, psychological support, general well-being support, improving quality of life*) access to mental health support (e.g., service availability, variation), factors that impact mental health, and the identification of mental health conditions in people with NDCs. Overall, 29 of the 41 NDC research priority setting exercises included research on mental health support (see **Appendix 4**).

Example research priorities (see further examples in **Appendix 6**):

- *'Why are children and young people with learning difficulties more likely to experience mental health problems?'* – Learning Difficulties (JLA, 2018)
- *'Are counselling/psychological strategies (e.g. talking therapies) effective to promote the mental health of children and young people with neurodisability?'* – Childhood Disability (JLA, 2015)
- *'To develop objective measures of anxiety'* Autism – Anxiety (Vasa et al., 2018)

Additional mental health research priorities are reported in INSAR's (2021) research priorities on suicide prevention in autistic people, which was published after the completion of this review.

Social

There were 61 research priorities on social support and services for people with NDCs, including support for social skills or relationships and social care services (*e.g., community support, residential support, practical home assistance, travel assistance, short breaks*). Overall, 21 of the 41 NDC research priority setting exercises included research on the social support (see **Appendix 4**).

For example (see further examples in **Appendix 6**):

- *'What are the most effective ways to support/provide social care for autistic adults?'* – Autism (JLA, 2016)
- *'Which interventions are most effective to help individuals with neurodevelopmental disorders improve their social skills and develop and maintain social relationships?'* – Neurodevelopmental Disorders (JLA, 2017)
- *'What are the positive and negative effects of supported conversation?'* – ADHD Treatments (SBU, 2014)

Education

There were 55 research priorities on education or academic support (e.g., school support or provision, specialist teachers or teaching assistants, education programmes or interventions, curriculum access, education outcomes, educational attainment) for people with NDCs. Overall, 29 of the 41 NDC research priority setting exercises included research on education support (see **Appendix 4**).

For example (see further examples in **Appendix 6**):

- *'How can educators and multi-disciplinary teams be better trained to provide individualized education for and accommodate children with neurodevelopmental disorders to ensure optimal outcomes?'* – Neurodevelopmental Disorders (JLA, 2017)
- *'determine the best teaching methods for developing reading and writing skills in people who use AAC'* – Augmentative and Alternative Communication (O'Keefe et al.,2009)
- *'How can schools support students with FASD?'* – FASD (Finlay-Jones et al., 2020)

Developmental or functional

There were 41 research priorities on support for people with NDCs focused on development or functioning across the lifespan (e.g., general developmental support, early intervention, support to optimise functioning and independence, life skills training). Overall, 21 of the 41 NDC research priority setting exercises included research on developmental or functional support (see **Appendix 4**).

For example (see further examples in **Appendix 6**):

- *'Which strategies are effective in helping children and young people with learning difficulties live independent lives, including during times of transitions?'* – Learning Difficulties (JLA, 2018)
- *'Developmental and behavioral interventions'* – Autism (Frazier et al., 2018)
- *'Would early intervention, eg, tummy time, creeping, and crawling, enhance my child's development?'* – Down Syndrome (Sinclair et al., 2019)

Employment

There were 27 research priorities on employment or vocational support for people with NDCS. Overall, 10 of the 41 NDC research priority setting exercises included research on the employment support (see **Appendix 4**). For example (see further examples in **Appendix 6**):

- *'Impact of training on SLCN for employers when considering the experiences of a person with learning disabilities who is seeking employment/ currently employed'* – Learning Disabilities – SLT (RCSLT, 2019)
- *'What are the barriers to employment that exist for people with CP?'*– Cerebral Palsy (McIntyre et al., 2009)
- *'In the area of employer capacity, subthemes consisted of the need to proactively engage employers and multisectoral industries and in turn, better link potential employers with people with ASD who are able and willing to work. The need to create long-term supports for individuals with ASD for sustained employment was highlighted'* – Autism - Transition and Employment (Nicholas et al., 2017)

Sleep

There were 33 research priorities on sleep support for people with NDCs. Overall, 5 of the 41 NDC research priority setting exercises included research on sleep support (see **Appendix 4**). For example (see further examples in **Appendix 6**):

- *'What is the long term safety, effectiveness and sustainability of behavioural strategies and/or drugs (e.g. melatonin) to manage sleep disturbance in children and young people with neurodisability (outcomes include time to onset, duration, and reducing impact on family)?'* – Childhood Disability (JLA, 2015)
- *'Interventions to obtain adequate sleep are expected to promote neuroplasticity and cognitive processes during rehabilitation after brain damage and during cognitive behavioural therapies'* – Neurology and Psychiatry – Sleep (Bassetti et al., 2015)
- *'gather data on sleep medication and use of different sleep related strategies'* – Autism – Sleep (Pavlopoulou & Dimitriou, 2019)

Behavioural

There were 30 research priorities on behavioural support for people with NDCs, including specific behavioural interventions or strategies (e.g., Applied Behaviour Analysis, Positive Behavioural Support) and general support for "challenging behaviour" or behaviour described as challenging. Overall, 14 of the 41 NDC research priority setting exercises included research on behavioural support (see **Appendix 4**). For example (see further examples in **Appendix 6**):

- *'Which interventions best help individuals with neurodevelopmental disorders develop emotional and behavioural regulation (including increasing impulse control and reducing compulsive behaviour)?'* – Neurodevelopmental Disorders (JLA, 2017)
- *'How best can we scale up access to behaviour support practices, including positive behaviour support and minimise the use of restrictive interventions (e.g., chemical, mechanical and physical restraint)?'* – Developmental Disabilities (Tomlinson et al., 2014)
- *'Behavioural therapy'* – Tourette Syndrome (Tourettes Action, 2018)

Psychoeducation

There were 25 research priorities on psychoeducational and peer support for people with NDCs (*e.g., the provision of information, self-help, self-management, advocacy*). Overall, 13 of the 41 NDC research priority setting exercises included research on psychoeducation support (see **Appendix 4**).

For example (see further examples in **Appendix 6**):

- *'What are the positive and negative effects of psychoeducative treatment?'* – ADHD Treatments (SBU, 2014)
- *'Information access. Developing infrastructure to provide individuals with TBI, families, and professionals/service providers with access to the right information at the right time (e.g., wiki platforms, websites)'* – Traumatic Brain Injury (Nadler et al., 2018)
- *'Peer mentor education'* – Children and Youth with Special Health Care Needs (Coller et al., 2020)

Sensory and occupational therapy

There were 12 research priorities on sensory support or occupational therapy for people with NDCs. Overall, 6 of the 41 NDC research priority setting exercises included research on sensory support (see **Appendix 4**). For example (see further examples in **Appendix 6**):

- *'Are sensory processing/integration therapeutic programmes effective in improving behaviour and/or increasing play/participation for children and young people with neurodisability?'* – Childhood Disability (JLA, 2015)
- *'The SLT role in identifying and supporting sensory needs of a person with profound and multiple learning disabilities'* – Learning Disabilities – SLT (RCSLT, 2019)
- *'Occupational therapy'* – Autism - Interventions/Supports (Gotham et al., 2015)

Forensic

There were 10 research priorities on forensic support for people with NDCs, including criminal or youth justice support. Overall, 5 of the 41 NDC research priority setting exercises included research on forensic support (see **Appendix 4**). For example (see further examples in **Appendix 6**):

- *'Impact of using a consistent set of symbols across a forensic setting on adults with learning disabilities understanding of language'* – Learning Disabilities – SLT (RCSLT, 2019)
- *'Challenges experienced by individuals with DLD in the youth justice sector'* – Developmental Language Disorder – SLT (RCSLT, 2019)
- *'Criminal justice system'* – Autism (Gotham et al., 2015)

Service provision

There were 115 research priorities on service provision for people with NDCs not covered by other support sub-groups described above (e.g., general service delivery or provision, system navigation, comparing modes of service provision, service co-ordination and collaboration, service pathways, improving access to services). Overall, 24 of the 41 NDC research priority setting exercises included research on service provision (see **Appendix 4**). For example (see further examples in **Appendix 6**):

- *'How can access to coordinated care (including diagnosis and treatment)* ***for individuals with multiple neurodevelopmental disorders*** *be improved?'* – Neurodevelopmental Disorders (JLA, 2017)
- *'Transitions between services'* – Intellectual Disabilities - Palliative Care (Tuffrey-Wijne et al., 2016)
- *'Data sharing across platforms and agencies'* – Children and Youth with Special Health Care Needs (Coller et al., 2020)

Other or general support

The last sub-group within support for people with NDCs is other or general support, which includes any other support to those listed in the above sub-groups and support in general (e.g., research on 'support' 'interventions' 'treatments' for people with NDCs). Overall, 25 of the 41 NDC research priority setting exercises included research on general or other support (see **Appendix 4**).

For example (see further examples in **Appendix 6**):

- *'How do co-occurring disorders impact treatment decisions for individuals with a neurodevelopmental disorder?'* – Neurodevelopmental Disorders (JLA, 2017)
- *'To improve therapeutic outcomes'* – Epilepsy (Kwan et al., 2015)
- *'Evidence-based services and interventions'* – Autism (Pellicano et al., 2014)
- *'Financial issues' and 'Federal/state assistance'*– Autism (Gotham et al., 2015)

Understanding NDCs

The second most prominent area of research that emerged in the NDC research priorities was on research to develop understanding of NDCs, such as research on understanding the experiences of people with NDCs, their needs, daily life, and trajectories. Overall, 31 of the 41 NDC research priority setting exercises included research on understanding NDCs (see **Appendix 4**).

Example research priorities (see further examples in **Appendix 6**):

- 'How can we understand what it is like to live with learning difficulties from a child or young person's perspective?' – Learning Difficulties (JLA, 2018)
- 'Understanding co-occurring conditions' – Autism (Frazier et al., 2018)
- *'Understanding how experiences of community integration and support needs change across the life span (e.g., lifelong issues of individuals who sustain a TBI in childhood)'* – Traumatic Brain Injury (Nadler et al., 2018)
- *'Investigate the strengths and challenges faced by children with CCN in developing language and communication skills across ages, across disabilities, and across diverse cultural and linguistic backgrounds, including those children with the most complex needs'* – Complex Communication Needs (Light & McNaughton, 2012)

Families or carers of people with NDCs

Research related to family or carers of people with NDCs arose in 97 research priorities, including research on support for family members and carers, understanding their needs, and collaboration with families. Overall, 20 of the 41 NDC research priority setting exercises included research on families or carers of people with NDCs (see **Appendix 4**).

Example research priorities include (see further examples in **Appendix 6**):

- *'How can parents, carers, brothers and sisters and extended families of children and young people with learning difficulties, be best supported to achieve their best quality of life before, during and after the diagnosis or identification in home, school and community contexts?' – Learning Difficulties (JLA, 2018)*
- *'What are the most efficient ways of supporting and empowering parents/families of people with developmental disabilities (in specific social and cultural contexts)?'* – Developmental Disabilities (Tomlinson et al., 2014)
- *'Training diverse parent populations'* – Children and Youth with Special Health Care Needs (Coller et al., 2020)
- *'What support is there for parents/families?'* Tourette Syndrome (Tourettes Action, 2018)

Professionals working within NDCs

There were 60 research priorities regarding professionals working within NDCs, such as research on professionals' knowledge, skills and practice, training and supporting the development of professionals, and collaboration between professionals. This included some overlap with research on supporting people with NDCs (described above), due to the understandable connection between professionals and support provision. Overall, 19 of the 41 NDC research priority setting exercises included research on professionals working within NDCs (see **Appendix 4**).

Example research priorities include (see further examples in **Appendix 6**):

- *'What are the common experiences and attitudes of primary healthcare workers towards people with developmental disabilities?'* – Developmental Disabilities (Tomlinson et al., 2014)
- *'How best can non-specialists be trained and supervised to work with people with developmental disabilities?'* – Developmental Disabilities (Tomlinson et al., 2014)
- *'Network of centres of excellence (e. g. by strengthening existing centres such as who Collaborating centres for training and research in MNH)'* – Mental and Neurological Health (Khandelwal et al., 2009)
- *'Doctors and/or other health professional's knowledge'* – FASD (Finlay-Jones et al., 2020)

Recognition or identification of NDCs

There were 49 research priorities on research to improve the identification of NDCs, including recognition and identification of NDCs (e.g., early signs or features, screening, assessment or diagnosis) both broadly and within specific groups (e.g., children, adults, looked after children) or environments (e.g. health services, youth justice), identification methods (e.g., diagnostic criteria and instruments, measures), and service delivery or provision related to the recognition and identification of NDCs (e.g. multi-disciplinary assessment, co-ordinated services, collaborative work, access to services, delays in access, experiences of diagnostic process or care pathways). Overall, 17 of the 41 NDC research priority setting exercises included research on the recognition or identification of NDCs (see **Appendix 4**).

Example research priorities (see further examples in **Appendix 6**):

- *'What is the best way to assess learning difficulties in children and young people?'* – Learning Difficulties (JLA, 2018)
- *'Help clinicians better understand early signs'* – Autism - Early Research (Fletcher-Watson et al., 2017)
- *'Develop diagnostic criteria and instruments for diagnosis and assessment of the needs of older adults with ASDs'* – Autism - Older Adults (Piven et al., 2011)
- *'Who/where/how are FASD diagnoses made?'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020)

Causes or prevalence of NDCs

A less frequent area of research that emerged in the (36 research priorities) was research into the causes or prevalence of NDCs or co-occurring NDCs (i.e., aetiology and epidemiology research). Overall, 17 of the 41 NDC research priority setting exercises included research on the causes or prevalence of NDCs (see **Appendix 4**).

Example research priorities include (see further examples in **Appendix 5**):

- *'Identify as yet unrecognized causes of epilepsy (e.g., genetic, autoimmune, and infectious)'* – Epilepsy (Kelley et al., 2009)
- *'What are the causes of and casual pathways to CP?'* – Cerebral Palsy (McIntyre et al., 2009)
- *'How common is autism?'* – Autism (Pellicano et al., 2014)
- *'What is the prevalence of FASD?'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020)
- *'Genetics/hereditary'* – Tourette Syndrome (Tourettes Action, 2018)

Wider community

Another less common research area (28 research priorities) was research relating to the wider community, including public awareness and understanding of NDCs, societal and cultural attitudes and perceptions of NDCs, stigma, bullying, discrimination, inclusion, and participation. Overall, 18 of the 41 NDC research priority setting exercises included research on the wider community (see **Appendix 4**).

Example research priorities include (see further examples in **Appendix 5**):

- *'Are child-centred strategies to improve children's (i.e. peers) attitudes towards disability (e.g. buddy or Circle of Friends etc) effective to improve inclusion and participation within educational, social and community settings?'* – Childhood Disability (JLA, 2015)
- *'How do public attitudes to developmental disabilities and the care of people with developmental disabilities vary across cultural and language groups and across types of developmental disabilities?'* – Developmental Disabilities (Tomlinson et al., 2014)
- *'To reduce the stigma and discrimination against people with epilepsy'* – Epilepsy (Kwan et al., 2015)
- *'Awareness programmes'* – Mental and Neurological Health (Khandelwal et al., 2009)
- *'Accurate public awareness about autism'* – Autism (Pellicano et al., 2014)

Other research

In addition to the research areas described above, there were research priorities that covered research areas, which were less frequent and therefore grouped together for the purposes of reporting. This included a wide range of research areas, such as research infrastructure, research measurements, tools, models and methodological approaches, international or national policies and their influence on people with NDCs. Overall, 21 of the 41 NDC research priority setting exercises included other research than the areas describe above (see **Appendix 4**).

Example research priorities include (see further examples in **Appendix 5**):

- *'An international collaborative effort to agree a core set of demographic, health behavior and health outcome indicators most relevant to autistic people that can be compared with general population data'* – Autism - Older People (Warner et al., 2019)
- *'Facilitators and barriers to adults with learning disabilities being involved in research studies'* – Learning Disabilities – SLT (RCSLT, 2019)
- *'To improve the infrastructure and capacity in epilepsy research'* – Epilepsy (Kwan et al., 2015)
- *'Developing new measures/instruments'* – Intellectual Disabilities - Palliative Care (Tuffrey-Wijne et al., 2016)
- *'What is the impact of global initiatives in disability (e.g. UNCRPD) on policies, laws and services for people with developmental disabilities?'* – Developmental Disabilities (Tomlinson et al., 2014)

Barriers and Opportunities for Research Across Neurodevelopmental Conditions and Mental Health

We sought to identify barriers and opportunities for research across NDCs and mental health primarily through conducting interviews with researchers, supported by a general literature review. Purposive sampling was used; researchers with experience of conducting research on NDCs and/or mental health were invited to take part in a remote interview (e.g., video call, telephone call, email). Interviews generally lasted up to 30 minutes and calls were recorded and transcribed for the purposes of analysis. A full copy of the interview questions can be found in **Appendix 7**.

Overall, we conducted interviews with 19 researchers. The researchers we interviewed had a broad range of research experience on NDCs and/or mental health, ranging from 4 to 30 years. Specific NDCs researchers reported having research experience on included autism (n=14 researchers), ADHD (n=8), speech, language, and communication needs (n=8), learning/intellectual disabilities (n=7), Down syndrome (n=4), Tourette's syndrome (n=3), DLD (n=1), DCD/dyspraxia (n=1), epilepsy (n=1), tic disorders, and Williams syndrome (n=1). Others reported having research experience of NDCs generally (n=7) or other chromosomal or genetic conditions (n=2). In addition to their research experience, six researchers described clinical or practice experience with NDCs and two described their personal experience with NDCs.

Thirteen researchers reported having research experience on mental health conditions, mostly in relation to NDCs), including depression (n=4), anxiety (n=4), psychosis (n=2), attachment issues or disorders (n=1), bipolar (n=1), schizophrenia (n=1), eating disorders (e.g., anorexia nervosa, avoidant restrictive food intake disorder; n=1), and suicide (n=1). Ten researchers reported having research experience of mental health generally.

The researchers reported experience across a range of research topics, such as child development, assessment and diagnosis of NDCs, school transition (i.e., primary to secondary school) and school experiences, experiences of people with NDCs across the lifespan, family carers of people with NDCs, mental health conditions and NDCs (impact, causes, identification, supports), experiences of people with undiagnosed NDC, access to services, service improvement, friendships, executive functioning, sensory processing, joint hypermobility, pain, autonomic dysfunction, neurobiology, genetics, and so on.

Barriers to Research Across Neurodevelopmental Conditions

Several barriers (or challenges) emerged in conversations with researchers regarding conducting research spanning across multiple NDCs.

Research design and methodology

The most common barrier to conducting research spanning across NDCs were challenges related to research design and methodology (n=15 researchers). The very broad nature and heterogeneity of NDCs as a group frequently emerged in discussion with researchers, due to the magnitude of different conditions and presentations that fit under NDCs as a broad category.

Existing evidence base

Historically, research has typically focused on one NDC, directly excluding those with co-occurring conditions (i.e., recruiting *"pure samples"* or *"simple pure expressions of conditions"*). It was recognised that this does not necessarily translate into the real-world presentation of these conditions or related issues and limits the applicability of the research to a significant proportion of people with that condition, due to the high co-occurrence of NDCs and other conditions. For example: *"When you're a researcher designing a protocol, you want to streamline and simplify it as much as possible to be able to prove or disprove your hypothesis. Unfortunately, that means one of the first things you do is you exclude anyone that has comorbidities or other diagnoses. So, in effect you clean the population that you're going to study. But the problem is … that's unrealistic and doesn't represent the population of people with neurodevelopmental conditions, which is comorbidity".*

The robustness of the current research evidence base is further questionable due to gender biases in in research and NDCs, with assumptions often being made based on a male dominated population. Researchers raised the lack of consideration of females and additionally LGBT groups, particularly transgender people. It was also highlighted that NDC prevalence figures are likely to be underestimated, as existing data is mostly on one or two specific conditions and biased towards males.

In addition, varying levels of knowledge and evidence-bases for different conditions within NDCs was reported as a barrier, particularly for lesser-known conditions. This was reported as conceptual challenge, for example *"developing shared models and theories that might apply to all".*

A shift away from recruiting *"pure samples"* towards being more inclusive and not excluding those with co-occurring conditions emerged, which leads to specific challenges (described below). Despite this, indirect exclusion due to study design or methodology was highlighted, such as recruitment bias and using measures that are not accessible or exclude certain people with NDCs.

Recruitment and samples

The diversity of NDCs emerged as a practical challenge in relation to the recruitment of participants across NDCs. Researchers reported it was difficult to recruit participants with different NDCs and *"getting into successful recruitment channels"*. A lack of co-production in NDC research (specifically with people who have learning/intellectual disabilities) was identified as a potential barrier to recruitment, as co-production can ensure research materials are meaningful and relevant to potential participants. Furthermore, parameters of research studies may not be clear enough for participants (e.g., learning disability not learning difficulty, autism and learning disability rather than autism or learning disability). This can lead to interest from those that are not eligible based on inclusion criteria, with researchers having to turn people away who want to take part, generally in order to receive an intervention being trialled in research. A lack of patient registries for specific NDCs (e.g., no patient registry for Tourette's) or across NDCs was also raised as a potential barrier. In addition, it can be costly to recruit large sample sizes.

Clinical data is often small scale or single diagnosis due to exclusion criteria. While cohort data was recognised to be helpful in terms of looking across NDCs in large datasets, it can miss *"the most severe populations"* that are found in clinical datasets. Some research across NDCs has been criticised for having samples that are *"too heterogeneous to be meaningful"* especially for qualitative studies.

The rarity of some NDCs, such as rare genetic conditions, poses challenges to recruitment of adequate sample sizes, and has implications for statistical power in quantitative research. Similar challenges are present for lesser-known NDCs, that despite not being rare are less frequently recognised or diagnosed (e.g., developmental co-ordination disorder/dyspraxia), yet both report participants are often keen to get involved in research.

Recognition of NDCs. Furthermore, while participants may have one recognised or diagnosed NDC, they may have more unrecognised NDCs as *"people often just get diagnosed with one condition"*. For example, people may come into a study having diagnosis of ADHD but may also have undiagnosed autism, tics, dyslexia etc. *"That's a little bit of a problem. Some are diagnosed, someone aren't"*. Diagnostic practices impact research, such as changes to diagnostic criteria (e.g., previous diagnostic criteria prohibited dual diagnosis of autism and ADHD), under- or mis- diagnosis of NDCs, and clinicians giving diagnostic labels based on stigma of certain NDC labels rather than clinical presentation (e.g., Sapiets et al., 2020). Sampling those who have received diagnosis may therefore lead to ascertainment bias. Studies often do not explicitly assess for NDCs during a study (described further below), therefore co-occurrence of NDCs may not be known. Similarly, it was reported that big databases tend to only record primary diagnosis, making it difficult or impossible to determine other NDCs.

Assessing NDCs. In addition to assessing what is being explored in any given research study, it can be difficult and time-consuming to also do a comprehensive assessment of NDCs to determine which NDCs participants actually have, irrespective of obtained diagnosis or diagnoses. While there are some standardised tools for assessing NDCs or co-occurring NDCs (e.g., assessing ADHD in a person with Tourette's) there are not standardised tools for all NDCs or co-occurring NDCs for the research context. Therefore, it can be hard to know what NDC "criteria" participants meet.

Participation in research

The diversity of NDCs also impacted on participation in research. Different expressions of disability result in different access needs in terms of participation in research (e.g., ability or capacity to consent and engage in research, location of research, measures, and assessments). Existing research has largely focused on those with NDCs who have the capacity to consent and engage in research and therefore may only represent a small fraction of people with NDCs, for example: *"A lot of the research is focused on a subgroup of higher functioning, more able individuals at the expense of understanding people with more complexities"*. As it is difficult to develop inclusive methodologies, it is more complex to conduct research across NDCs.

Researchers reported challenges in measuring things across NDCs, especially as measures or tools are often not developed for (or validated across) NDCs. For example, measures may be validated for one NDC but not co-occurring NDCs (e.g., psychometric measures may be validated for Down syndrome but not for people with Down syndrome and co-occurring autism), therefore it is easier for researchers to exclude those with co-occurring NDCs. If different measurements are used, it can be difficult for researchers to determine if they are equally measuring the same thing. Further, tasks are often biased by diagnostic group (e.g., theory of mind tasks for autism, phonological processing for dyslexia, and so on). Adapting measures to be more inclusive of diverse NDCs is a challenge.

Research silos

The presence of research and clinical silos in NDCs was the second most frequent barrier that emerged in discussions with researchers (n=12 researchers). Researchers and clinicians generally each have their own area or field of expertise, which poses a challenge to investigating multiple NDCs, both in terms of condition (e.g., autism, ADHD, learning/intellectual disability) and discipline (e.g., psychology, psychiatry, health, social work). Researchers' and clinicians' NDC or discipline specific expertise can make it difficult for them to explore co-occurrence or *"complex cases"*. Practice silos and challenges also influence research, such as the disjointed services and the intersection of different professionals involved in NDCs. Further, research teams are generally set up with a singular focus.

It was reported that researchers tend to stick to their *"bubbles"* when conducting and disseminating research, generally not sharing information or engaging outside of these silos, resulting in a lack of joint work or thinking across NDCs and disciplines. For example, there are several condition or discipline specific conferences which don't cross-over, therefore limiting opportunities for researchers to share ideas or work together. Further, while there are many condition specific journals, there are not many journals that support the dissemination of research across NDCs, and it was reported as challenging to publish such research.

Research silos were reported to be related to research training often being focused on a specific condition and discipline, despite evidence of high co-occurrence, and a lack of training or support for early career researchers to conduct research spanning across NDCs, which is often more challenging and requires collaboration. For example: *"Traditionally people have been very siloed, so you study ADHD or you study autism. But very few people try to look across those diagnostic boundaries and that is challenging. It does require more teamwork and often people will be looking at those conditions from a particular perspective … trying to get a kind of common dialogue or common interest going can be a little bit challenging … you do need different perspectives"*.

Across research silos (conditions or disciplines), there is a broad range of language and terminology used, varying interpretation of language, and varying use of the same terms (i.e., the same term used to mean something different), which adds to this barrier. An example of differing terminology for similar concepts in UK practice and research can be found regarding statutory support plans for children and young people with special educational needs or additional learning/support needs; *"Education, Health and Care Plans"* are used in England, *"Individual Development Plans"* in Wales, *"Co-ordinated Support Plans"* in Scotland, and *"Statements of Special Educational Needs"* in Northern Ireland. While these terms are not fully interchangeable, there is considerable overlap in their use. Furthermore, different disciplines often have different priorities for research, stemming from different training, for example: *"a social worker might think that attachment is important, a psychiatrist might think that anxiety is important, a health professional might think that behaviour is important"*.

It was also reported that due to silos, there isn't currently a shared understanding of what NDCs are and a lack of understanding of the broad spectrum of NDCs, especially amongst students and early career researchers, perpetuated by a lack of focus of the education of researchers in this area. Because of silos, it was reported that researchers don't necessarily develop the knowledge to be able to identify the similarities and differences between NDCs. For example: *"There is not necessarily a shared understanding … people are trained in doing research in a neurodevelopmental condition, there isn't necessarily education around the spectrum of neurodevelopmental conditions. I have come across quite a lot of students or early career researchers who aren't particularly confident with what neurodevelopmental conditions are as a whole, what are their shared characteristics, and they're not particularly confident with the overlap in neurodevelopmental conditions."*

Research funding

Difficulties in obtaining research funding was the third most frequently reported barrier to conducting research across NDCs (n=11 researchers). This primarily related to how research funding is structured (research funders, funding calls, funding pots), often focused on a particular condition or discipline (similar to the silos described above). For example, there are several condition specific charities with separate pots of money, less likely to fund research jointly across NDCs. It was also reported that mental health funders often do not fund NDC research. Funding calls generally do not encourage multiple diagnosis research, and researchers tend to stick closely to the brief of funding calls in order to receive funding.

Researchers felt that funders do not consider the complexity of people with NDCs or how to capture people with multiple diagnoses. Poor awareness and/or understanding of NDCs and the co-occurrence of NDCs, in addition to under-estimated prevalence figures, were seen to contribute to this, making it difficult for researchers to *"make the case"* for funding to conduct research across NDCs. It was reported that it is difficult to obtain funding for research across NDCs, as these applications are often viewed as being less clear, despite the potentially significant value of such research. Several researchers reported having funding applications for research across NDCs rejected, despite the inclusion of researchers across disciplines.

Research spanning across NDCs sometimes requires more funding and is more expensive to conduct, for example *"Once you go beyond one diagnosis it becomes sort of doubly expensive because you're trying to recruit enough kids with two diagnoses, and that often doesn't necessarily fit within a sort of particular funding stream"*. It was also reported as being difficult to get funding for research that costs more, such as intervention or mechanistic research in comparison to observational studies.

Some researchers reported difficulty obtaining funding to research one NDC, let alone multiple NDCs.

Research attention for specific NDCs

Another barrier that emerged was the fact that some NDCs receive minimal research focus and attention compared to other NDCs (n=3 researchers). For example, DCD and Tourette's were reported as receiving minimal research attention in comparison to autism, regardless of similar prevalence rates. This is, in part, related to limited recognition of some NDCs in practice, for example a lack of clinical guidance, lack of understanding across professionals and across the public for certain NDCs.

Although NDC research activity has been reported to be associated with the "severity" and prevalence of particular conditions, exceptions are noted, for example increased research publications on autism and ADHD, related to the receipt research funding (Bishop, 2010). Considerably less research publications were found for other NDCs, such as dyslexia, dyscalculia, developmental coordination disorder, and speech sound disorder (Bishop, 2010).

Viewing NDCs as distinct

It emerged that the view (or convention) of NDCs as being distinct groups or categories without overlap is a barrier to conducting research spanning across NDCs (n=3 researchers). For example, historically, diagnostic criteria prohibited dual diagnosis of co-occurring autism and ADHD, due to the belief these were distinct. However, we know this is not the case, and co-occurrence is often the norm, therefore it raises concerns regarding how NDC distinctions have been drawn up, potentially reflecting history more than the true nature of neurodevelopment. Using such distinctions for NDCs and the application of diagnostic categories was reported as potentially limiting progress to understanding neurodevelopment, as diagnostic labels may not truly reflect needs. This relates to issues raised above regarding the recognition and assessment of NDCs (under research recruitment and samples), as shifting our conceptualisation of neurodevelopment away from diagnostic categories or labels may, in part, counteract these specific barriers.

While a transdiagnostic approach exploring underlying mechanisms in neurodevelopment was reported as potentially being of more value, this has been met with resistance. For example, one researcher reported difficulty obtaining funding and publishing neurodevelopmental research not using NDC distinctions, as reviewers and editors are used to thinking about NDCs as *"discrete disorder categories"*, and research using these is easier to integrate into existing literature and market to potential readers: *"Persuading them that these diagnostic entities may not be the best window through which to view neurodevelopment is challenging. This is especially so if your sample is intentionally mixed and heterogeneous. Some reviewers regard this as a mistake, when in fact it is usually the entire purpose of that recruitment strategy"*.

Other barriers

Other less frequently reported barriers reported by researchers included a poor understanding of NDCs in general, including the way NDCs overlap and the degree to which they are related, misunderstanding of NDCs and stigma around NDCs, and a lack of awareness of mental health conditions in people with NDCs (especially under-recognised NDCs).

Barriers to Mental Health Research Across Neurodevelopmental Conditions

Researchers were also asked about their perceptions of barriers or challenges to conducting mental health research spanning across multiple NDCs.

Similar barriers to those described above

Most researchers (n=16) reported the challenges to conducting mental health research across NDCs were either the same or similar to the challenges to conducting research spanning across NDCs more generally, described above. Researchers also reported these barriers may be more pronounced in mental health research (e.g., the presence of research and clinical silos in NDCs and mental health) and that there may be additional barriers (e.g., the reliance on verbal communication skills to identify and treat mental health conditions). For example, one researcher said:

> *"I think you'll have the same sorts of challenges and you may have additional ones as well, because for mental health research, let's just take the common mental health problems, anxiety, depression, typically we rely on self-reports for these, but for people who are nonverbal or we know that some people who are affected with the neurodevelopmental problem find it quite difficult to reflect on their feelings. So, for example, we found even at age 25 that parents were still quite good informants, and I've sort of noticed that in clinic, so there's all sorts of issues about who reports, what sort of measures work best, and actually just getting, you know, people across the spectrum of neurodevelopmental conditions."*

In contrast, one researcher reported the challenges to conducting mental health research across NDCs are not the same or to the challenges conducting research spanning across NDCs *"simply because the idea that domains of mental health (e.g. anxiety and depression) are continuous and might be common symptoms of lots of underlying conditions is not so controversial."*

Lack of mental health research on NDCs

Several researchers (n=9) highlighted the lack of mental health research across NDCs as a barrier, noting gaps in current research and a lack of a strong evidence base. It was reported that mental health research does not typically consider NDCs, and if it does this is usually limited to one condition (e.g., if someone has a diagnosis of learning disability or autism), rather than looking across NDCs. It was also reported that there is a lack of knowledge and understanding of NDCs in researchers and clinicians that primarily focus on mental health.

Within this barrier, a lack of validated mental health measures (or markers) for people with an NDC or multiple NDCs also emerged. In addition, challenges with diagnostic overshadowing and being able to disentangle NDCs from mental health was reported, for example:

> *"Some of the behaviours and presentations that we may see in individuals with particular neurodevelopmental conditions can often be attributed to that condition rather than being understood and recognised as difficulties associated with distress and with a mental health condition … [we're at] really different stages in our understanding and ability to recognise mental health difficulties in different neurodevelopmental conditions.* ***There is a real danger and risk that some people's mental health conditions are not recognised as such and therefore they go unaddressed*** *and that further exacerbates that distress. It's particularly an issue if you think about behaviours that challenge, how they're understood from purely behaviours point of view versus recognising them as forms of communication and recognising them as something that could be addressed separate from the underlying neurodevelopmental condition. And that's a real issue. I think the tides turning a bit in autism, particularly with autistic people who don't have an intellectual disability and I think that's thanks to many autistic people actually challenging us and challenging the research environment to think about things differently. But I think for autistic people who also have intellectual disability and other neurodevelopmental conditions that are characterised by intellectual disability,* ***things have not really moved on as far as I would like them to in being able to disentangle the neurodevelopmental characteristics from mental health issues****."*

Inaccessible mental health supports

Another barrier that emerged (n=2 researchers) was the focus on verbally mediated treatments for common mental health conditions, such as cognitive behavioural therapy (CBT), guided self-help, counselling, and other talking therapies (NHS website, 2021), which are often specified as first-line treatments for mental health conditions in clinical guidelines (National Institute for Health and Care Excellence [NICE], 2013, 2016, 2019). However, these treatments often not accessible for people with NDCs. For example: *"One of the big challenges in neurodevelopmental disorders is that* ***many children won't be able to access those treatments because they won't have the language or cognitive capacity to make use of those treatments.*** *And I think if you are a researcher coming from a mental health perspective, you might not get that."*

This was acknowledged as being due to the drive for treatments to be able to scaled-up and rolled out universally, rather than focusing on the individual needs of people with NDCs: *"The idea that we could make something that would be useful for everyone is a barrier as well. We really think that for many children you need a more individualised approach, and I think that's harder to get funding for, because obviously ultimately that's more challenging and expensive way to roll out treatment … What policymakers tend to want is a kind of cheap, quick intervention that you can roll out to everybody in mainstream schools and from our perspective,* ***what most*** *__people with neurodevelopmental conditions might need is a more individualised approach__, and I think that those two things are difficult to reconcile … there is definitely a bit of a disconnect."*

Opportunities for Research Across Neurodevelopmental Conditions and Mental Health

Researchers also shared exciting ideas on how to move towards a transdiagnostic approach to conducting research across NDCs and mental health going forward. It was reported that there are significant opportunities to develop research across NDCs and mental health, for example:

"there's lots of research questions that need to be pursued and there's a willingness among people working in in developmental clinical services at one source or another, families and people with the conditions are often very keen to engage with research"

"there are opportunities for us all to develop in this area … there's a huge need to better serve people with complexity and multiple diagnosis ease"

"filling in the evidence gaps"

Bringing people together

The most frequently reported opportunity for future research spanning across NDCs and mental health was bringing people together (n=10 researchers), for example, bringing together researchers from different research fields and with different NDC expertise or specialism, in addition to bringing together researchers with other key stakeholders, such as individuals with NDCs, families and carers, clinicians, organisations supporting people, policymakers, and so on. This inevitably requires researchers to move away from silos and to be able to have a successful research career that doesn't just focus on one condition.

The importance of bringing people together was related to:

1. Increased awareness and sharing of information, for example: *"Having a network of researchers would be really useful to know what's going on in the in the wider community and the wider field would be very good. And to share results between, different people who are who are researching different neurodevelopmental conditions."*

2. Increased opportunities for research collaboration, having research team bringing together various specialisms, areas of expertise, and views. For example: *"a multidisciplinary team model in a research setting would be ideal"* and *"just bringing together that diverse group of people with a huge range of skills and experiences and getting them together to start really thinking about how they can bring their work together."*

A few suggestions on how to bring people together were suggested, such as setting up a research network or forum, or *"the creation of a comprehensive list of those organisations by specialism and area and how to contact them would instantly improve the ability of researchers to recruit, as a start."* A few researchers highlighted bringing people together would require co-ordination, for example by an organisation such as Embracing Complexity.

Researchers acknowledged that a key opportunity would be to bring together a broad overview of the research that is currently available across NDCs, acknowledging that this would require understanding of the different language and terminology that is used in different contexts (e.g., education, psychology, psychiatry). Therefore, **increasing recognition and clarity around the different language and terminology used across research fields and NDCs** was also seen as a key opportunity to facilitate future research across NDCs.

Changing how we look at neurodevelopment and neurodevelopmental conditions

Another potential opportunity reported by researchers was moving away from focusing on specific conditions or labels and instead looking at neurodevelopment more broadly (n=8 researchers). This would involve, for example, developing and testing broad frameworks of neurodevelopment that are not condition specific, such as ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations; Gillberg, 2010; Gillberg et al., 2013). This could enable exploration of the similarities and differences across NDCs, with crucial implications for supporting people. For example:

> *"There's potentially a real opportunity for us to be able to develop models of neurodevelopmental conditions that actually help us to work in a more holistic way clinically and educationally, by being able to identify what might be unique about a particular condition – and so someone who has that condition needs a particular type of support – but also what might be shared across people who have differing underlying conditions, and therefore, where we can create opportunities for people to work together or to access support or therapeutic interventions together without having to separately always try and find funding and have different neurodevelopmental pathways … I think the opportunities there for us to understand theoretically more about those conditions, but also just in terms of the pragmatics of running clinical services. If we can find where the commonalities are, that enables us to be more efficient with the very limited resource is that clinical services."*

> *"We can think what things are good for mental health generally, what things are good for language or academic success generally, how can we adapt what we know to meet the needs of individual children?"*

Identifying shared skills or developmental paths was reported as something that might help to develop better support strategies across people with NDCs. It was highlighted that this thinking would, in turn, need to influence practice to also move away from focusing on condition or labels (e.g., need for a certain diagnosis to access certain support) and would also require creating new language around how we talk about neurodevelopment and "neurodevelopmental atypicality."

Researchers highlighted that it is important to identify which research questions can be answered using pan-neurodevelopmental methods to move away from current research practice of replicating studies across conditions: *"for researchers to realise where the research questions can be addressed, or are better addressed, by adopting a pan neurodevelopmental condition perspective."* While it was reported that some research needs to be condition specific (for example, research on genetic underpinnings of conditions or behavioural phenotypes), it was raised that a significant proportion of research does not need to be condition specific. For example, it is likely feasible and beneficial to conduct research on supporting parents who have children with neurodevelopmental conditions as a group due to overlapping support needs, rather than focusing on supporting parents based on their child's specific diagnostic label or suspected condition (for example, see Coulman et al., 2020; Dykens, 2015).

Researchers also reported that it is important to be clear on the different types of pan-neurodevelopmental research, firstly research looking at NDCs as a whole, and secondly research exploring groups within NDCs.

Research funding

A key facilitator identified by researchers was related to research funding (n=7 researchers), such as getting research funders and commissioners of research to see the importance and value of research spanning across NDCs and lobbying for joint research funding rather than NDC specific funding pots, especially from larger research councils rather than NDC research charities. This also included calling for more funding and investment in research across NDCs and mental health research more generally, including ensuring there is enough investment to ensure researchers are working in this area. For example: *"I know Embracing Complexity did do some lobbying and they were successful in getting a funding call … I think that would be a really good direction for the group to go in, cause I know a lot of charities do lobbying with different funders and things like that to get their population served better"* and *"You have to get the research funders on board in understanding that it's really important to look across the neurodevelopmental conditions and that is just not happening at the moment. And not only that, we can't go back to historic samples because they were either only assessed on one neurodevelopmental condition or excluded those with other neurodevelopmental conditions, they're not really representative of what the clinic population is like."*

Data sharing

Another opportunity to facilitate future research across NDCs was to explore data sharing or establishing a registry for NDCs (n=6 researchers). This might include exploring possibilities for developing large datasets across NDCs or establishing a centralised database across NDCs, bringing together existing databases. For example: *"More open access datasets that span multiple NDDs"* and *"I think that what we need in the UK is some sort of platform or registry of people … where you get people across those boundaries coming in and signing up for research, filling in maybe some questionnaires and they can or cannot consent to, for example, linkage to NHS data. They could consent that they would be interested in hearing about intervention studies or genetic studies and, you know, I feel that we need a resource like this for a across the UK, cause I think for the next generation of researchers it's really hard to get funding for research and especially when we need large samples and to collect those samples is really difficult, so I feel like just like we've got the UK population cohorts, we need a cohort of people with neurodevelopmental problems that cross those sort of boundaries."*

While this would require significant funding to establish and maintain, it would enable researchers to recruit larger, more representative samples across NDCs, and enable co-ordination between researchers and people with NDCs for patient and public involvement, co-production and patient led research. Options for sharing data on a smaller scale also arose in bringing people together to collaborate on research.

Other opportunities or facilitators

Other less-discussed opportunities or facilitators of research across NDCs and mental health reported were:

- Developing educational or awareness raising resources for researchers and funders in NDCs (n=3 researchers), including specifically raising awareness of the co-occurrence of NDCs and supporting the development of early career researchers, for example *"I also wonder if we should be thinking about developing some sort of educational or* *awareness raising resources to get researchers and funders thinking about neurodevelopmental difficulties and how to promote inclusion practically as well. So, designing a study that is inclusive and avoiding unnecessary inclusion criteria, and that might come out as a guidance document or some sort of training module … we have a clinical practice module that's produced by NIHR and that it covers things like assessing capacity and we're not allowed to do research in the NHS without doing that module, so I thought something like that to encourage awareness in developmental difficulties … when I work with people in mental health or the non-learning disability world or the non-autism world, there's been like a huge lack of understanding about very basic accommodations, reasonable adjustments or they don't know about giving people enough time to consider the question and form an answer, and then through to those more methodological considerations. So, I feel like awareness, training for everyone in the research world couldn't hurt."*

- Conducting equitable and accessible research (n=1 researcher) *"understanding that the research needs to be conducted in an accessible form, otherwise we'll keep only reaching White middle class people who are educated, to complete a form that you have to put in handwriting, and you have to be able to read –when we're talking about neurodevelopmental conditions, where literacy might be an issue"*

- A few researchers (n=2 researchers) reported it would be helpful to have a series of papers highlighting the importance of mental health research across NDCs and taking a pan-neurodevelopmental approach to raise the profile of this *"A series of papers, research papers or reports, could be produced and this one sure would be meeting targets in terms of mental health research. You know, whether the government has different pots of money, etc. Written in the right way this would be also appealing to them, because we know that mental health costs economically a huge amount, and if we can find out what the precursors are, then hopefully that would also mean that we can put some kind of interventions and some kind of protective measures or support that would then reduce mental health difficulties in people with neurodevelopmental conditions."*

- Having forward thinking researchers to develop and test mental health measurements and tools for and across NDCs (n=1 researcher) *"we need researchers who are willing to guide and create these tools that the researchers can then implement and begin to look at supporting this community in diagnosis and treatment of mental illness"*

- Using the current context as a lever to call for change (n=1 researcher), for example the COVID-19 pandemic or press coverage about special educational needs: *"Obviously it's [COVID-19] horrible and I want it to end, but because everything is so different, maybe there is more scope to think differently and do things differently?"* and *"There has been a lot of press about children who have special educational needs and how those needs aren't being met at the moment, and I'm hoping that that will push this kind of research higher up the agenda."*

Key Findings and Next Steps for Research on Neurodevelopmental Conditions and Mental Health

Key Findings

A wide range of findings from this project are reported above, which are important to consider regarding future neurodevelopmental and mental health research. The key findings include:

The mismatch between research priorities and research being conducted

An overwhelmingly large proportion of research identified as a priority across NDCs was related to supporting people with NDCs (e.g., physical health, speech and language, mental health, social support, education, and so on). In some cases, research on supports was preferred versus other research, such as research on causes. For example, in a large European survey by Tourettes Action (2018), 70.9% (n=1608) of participants reported preference for research on treatment for Tourette's syndrome over research on the cause of Tourette's syndrome (29.1%, n=661).

However, the way research funding is divided does not appear to reflect this as a research priority, with the majority of funded research focusing on topics other than supporting people with NDCs, such as research on causes, neuroscience, biology, genetics, and so on. For example, discussing reviews of autism research funding in different contexts, den Houting & Pellicano (2019, p.4400) report: *"autism research funding is* ***skewed towards biological and genetic research****, with biological research funding accounting for between 18 and 64% of reported autism funding, and research into genetic 'risk' factors accounting for, on average, 20% of funding. In comparison, research into services for autistic people and their families received, on average, only 6% of reported research funding, and lifespan issues received just 3% across analyses."* Additional information on autism research funding is reported in the literature (see den Houting & Pellicano, 2019; Pellicano et al., 2013; Daniels & Warner, 2018; Interagency Autism Coordinating Committee [IACC], 2021; Matson & LoVullo, 2009; Warner Cooper, & Cusack, n.d.). This mismatch is further highlighted in Shet and Oliver's (n.d.) unpublished review of the main focus of 24,908 papers published on autism between 2001 and 2011 – they found the most frequent research topics were 'causes' and 'neuroscience', combined these accounted for more than 50% of the papers published.

Clearly, research spanning across NDCs on supporting people with NDCs is much needed, especially around physical health, communication, mental health, social support, and education. It is not surprising that these were key research priority areas across NDCs, as they reflect overlapping needs across NDCs (Gillberg, 2010; Thapar et al., 2017), in addition to physical and mental health disparities that are experienced by this group (e.g., Allerton et al., 2011; Cooper et al., 2007; Karpur et al., 2019; Mason et al., 2019; Rydzewska et al., 2018, 2019). For example, mental health might be a key research priority due to the increased risk of mental health problems in people with NDCs (Alexander et al., 2021; Kumar et al., 2016; Lai et al., 2019; Larson et al., 2011; Maïano et al., 2018; Rydzewska et al., 2019). This may also reflect difficulties accessing appropriate support for mental health amongst people with NDCs (e.g., Ahmedani & Hock, 2012; Hall et al., 2013; Toms et al., 2015). For example, Toms et al. (2015) found low rates of access to specialised mental health services among children with intellectual disabilities in the UK, indicating high unmet needs amongst this group. Similar disparities in physical health conditions and access to healthcare support is reported in the literature (e.g., Mason et al., 2020; Karpur et al., 2019; Rydzewska et al., 2018, 2019).

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. Therefore, increased research in this area would better match these priorities. Less common research priority areas included research specifically on methodology (e.g., measurement, tools, models), the wider community, causes or prevalence of NDCs, and recognition and identification of NDCs. As described above, some of these topics are currently overrepresented in neurodevelopmental research funding and/or publications, as compared to established research priorities across NDCs described in this report.

Awareness and understanding about the overlap of NDCs

Another crucial finding that emerged was the perceived lack of understanding about the overlap between NDCs and neurodevelopment as a whole amongst researchers and research funders. This was partly related to the presence of research and clinical silos, with training for researchers and clinicians typically focusing on a specific condition or discipline, and silos related to research funding and publication. There was also a perceived lack of awareness of the importance of conducting research spanning across NDCs amongst other researchers. Furthermore, a lack of understanding of NDCs amongst mental health researchers and clinicians was reported, which may account for the limited inclusion of people with NDCs in mental health research, much less people with multiple NDCs. Related to this, a proposed link between neurodivergent people being misunderstood or misperceived by ‘the neurotypical majority’ and risk of poorer mental health and well-being has been reported (Mitchell et al., 2021).

A shift towards conceptualising neurodevelopment broadly, moving away form focusing on pre-defined diagnostic labels or categories, towards focusing on an individual’s presenting “neurodevelopmental needs”, may be beneficial. However, this would require buy-in from various researchers across NDC specialisms, disciplines, research funders, and research publishers. Brining together researchers from various silos to explore this in further detail and write a series of papers on the benefits of taking a pan-neurodevelopmental approach, may improve awareness and understanding of the overlap of NDCs, and facilitate future research using such an approach.

Due to the diverse nature of NDCs, **ensuring research is inclusive and accessible** to people with a range of needs is essential, otherwise research will continue to focus on easier-to-reach populations, therefore potentially missing the most vulnerable or stigmatised people. However, designing inclusive research requires effort to ensure accessibility, therefore funding for research needs to take accessibility into consideration.

Key Recommendations for Embracing Complexity in Research on Neurodevelopmental Conditions and Mental Health

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 co-ordination 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. This would need to bring together researchers across disciplines (e.g., health, education, psychology) as well as across neurodevelopmental specialisms. As a follow-up to this project, Embracing Complexity are setting up a Special Interest Research Group with Emerging Minds, as well as a network of researchers interested in NDCs (see below).

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 (e.g., Catalogue of Mental Health Measures[5]). Identifying a set of core measures to include in neurodevelopmental studies, as is already done in mental health (e.g., Wolpert, 2020), would enable researchers to more easily compare different groups.

3. **Exploring neurodevelopmental registries.** In many other areas of research, namely health research and most recently during the COVID-19 pandemic, voluntary patient registries have greatly accelerated the process of "matching" studies with would-be participants, For example, the Join Dementia Research registry, and the NHS COVID-19 Vaccine Research Registry. 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.** As described above, increasing awareness and understanding about the overlap between NDCs is a key area of action, especially amongst researchers and funders of research. Exploring feasible ways of conducting pan-neurodevelopmental research and sharing the benefits of it as an approach will also be beneficial.

6. **Ensuring research is inclusive and accessible.** Lastly, and perhaps most importantly, it is crucial that we ensure future research is inclusive and accessible to people with a range of neurodevelopmental needs. Continuing to focus on easier-to-reach populations risks (directly or indirectly) excluding 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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[5] The Catalogue of Mental Health Measures website: https://www.cataloguementalhealth.ac.uk/

Embracing Complexity Research Network

As part of this project, the **Embracing Complexity Research Network** has been set up – a group of research organisations and individual researchers with a shared interest in improving the lives of people with NDCs. The aim is to bring together researchers with various experience of NDCs across various disciplines and/or specialisms. All researchers and research organisations are invited to join the network – further information can be found on Embracing Complexity's website[6] or by emailing Georgia Harper (Embracing Complexity Lead): Georgia.Harper@autistica.org.uk.

Special Interest Research Group

With funding from Emerging Minds, Embracing Complexity has also set up a special interest research group **Embracing Complexity in Neurodevelopmental Conditions and Mental Health** (Emerging Minds, 2021). This brings together people with NDCs, carers, researchers and charities to address gaps in research and ensure research really benefits those who think differently.

Our first topic is indicators of mental health conditions in people with learning disabilities and complex communication needs. At present, there's very little evidence base for this, so treatment depends largely on how families and professionals understand individual people – as a result many are left without appropriate support, and at the same time many face harmful over-medication for distressed behaviour (NHS England, 2019).

Embracing Complexity in Neurodevelopmental Conditions and Mental Health SIRG

Thanks to the support of Emerging Minds

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[6] Further information on the Embracing Complexity Research Network or Special Interest Research Group is available on Embracing Complexity's website at: https://embracingcomplexity.org.uk/research

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Appendices

Appendix 1: Embracing Complexity Coalition Member List

Coalition Member	Focus	Website
Action Cerebral Palsy	Cerebral palsy	https://www.actioncp.org/
ADHD Foundation	ADHD, autism, dyslexia, dyspraxia, dyscalculia, Tourette's	https://www.adhdfoundation.org.uk/
Afasic	SCLN	https://www.afasic.org.uk/
Ambitious about Autism	Autism	https://www.ambitiousaboutautism.org.uk/
Attention UK	ADD, ADHD	https://attentionuk.org/
Autism Alliance	Autism	https://www.autism-alliance.org.uk/
Autistica	Autism	https://www.autistica.org.uk/
Bliss	Premature or sick babies	https://www.bliss.org.uk/
Brain & Spine Foundation	Neurological conditions	https://www.brainandspine.org.uk/
The Brain Charity	Neurological conditions	https://www.thebraincharity.org.uk/
British Dyslexia Association	Dyslexia	https://www.bdadyslexia.org.uk/
Cerebra	Brain conditions	https://cerebra.org.uk/
Child Growth Foundation	Growth conditions	https://childgrowthfoundation.org/
Children and Young People's Mental Health Coalition	Mental health	https://cypmhc.org.uk/
Communication Matters	SLCN	https://communicationmatters.org.uk/
Down Syndrome Research Foundation UK	Down syndrome	https://www.dsrf-uk.org/
Dravet Syndrome UK	Dravet syndrome	https://www.dravet.org.uk/
Dyspraxia Foundation	Dyspraxia	https://dyspraxiafoundation.org.uk/
Employment Autism	Autism	https://www.employmentautism.org.uk/
Epilepsy Action	Epilepsy	https://www.epilepsy.org.uk/
Epilepsy Research UK	Epilepsy	https://epilepsyresearch.org.uk/
Families in Focus CIC	Various (neurodevelopmental conditions and SEND)	https://www.familiesinfocus.co.uk/
FASD Awareness	FASD	https://www.fasdawareness.org.uk/
FASD Hub Scotland	FASD	https://www.adoptionuk.org/pages/site/scotland/category/fasd-hub-scotland
Fragile X Society	Fragile X	https://www.fragilex.org.uk/
Grow Communication	SCLN, autism, ADD, ADHD	http://www.growsalt.uk/
I CAN	SCLN	https://ican.org.uk/about-us/
Kleefstra syndrome	Kleefstra syndrome	https://www.kleefstrasyndrome.org/
Max Appeal!	DiGeorge syndrome, VCFS, 22q11.2 deletion	https://www.maxappeal.org.uk/

McPin Foundation	Mental health	https://mcpin.org/
Mencap	Learning disabilities	https://www.mencap.org.uk/
MQ	Mental health	https://www.mqmentalhealth.org/
NAPLIC	SCLN	https://www.naplic.org.uk/
National Autistic Society	Autism	https://www.autism.org.uk/
National Organisation for FASD UK	FASD	http://www.nofas-uk.org/
Nerve Tumours UK	Neurofibromatosis and nerve tumours	https://nervetumours.org.uk/
Neurodiversity Networks	Neurodiversity (ADHD, autism, dyslexia, dyspraxia)	https://www.facebook.com/neurodiversityNetworks/
Neurological Alliance	Neurological conditions	https://www.neural.org.uk/
Nip In The Bud	Mental health and related conditions – ADHD, anxiety, autism, conduct disorder, depression, OCD, PTSD	https://nipinthebud.org/
PDA Society	PDA	https://www.pdasociety.org.uk/
Potential Kids	Neurodiversity – autism, ADHD, dyslexia, dyspraxia, Tourette's	https://www.potentialkids.org/
PWSA UK	Prader Willi syndrome	https://www.pwsa.co.uk/
RADiANT	Learning disabilities, autism, ADHD, epilepsy, acquired brain injury	http://radiant.nhs.uk/
Rett UK	Rett syndrome	https://www.rettuk.org/
Royal College of Occupational Therapists	Occupational therapy	https://www.rcot.co.uk/
Royal College of Speech and Language Therapists	SCLN	https://www.rcslt.org/
Seen and Heard Therapy	Neurodiversity	https://seenandheardtherapy.co.uk/
Sense	Complex disabilities	https://www.sense.org.uk/
Sibs	Siblings of disabled people	https://www.sibs.org.uk/about-sibs/
The Sleep Charity	Sleep conditions	https://thesleepcharity.org.uk/
Special Networks	Neurodevelopmental conditions – ADHD, autism, DCD, DLD, dyscalculia, dyslexia	https://www.specialnetworks.co.uk/
STAMMA	Stammer	https://stamma.org/
Stay Up Late	Learning disabilities	https://stayuplate.org/
Sunshine Support	Special educational needs	https://www.sunshine-support.org/
Technology for Good	Neurological conditions	https://technologyforgood.co.uk/
Tizard Centre, University of Kent	Learning disabilities, autism, mental health, Tourette's, Fragile X	https://www.kent.ac.uk/social-policy-sociology-social-research/tizard
Tourettes Action	Tourette's	https://www.tourettes-action.org.uk/

Tuberous Sclerosis Association	Tuberous sclerosis	https://tuberous-sclerosis.org/
Unique	Rare chromosome and gene disorders	https://www.rarechromo.org/
Williams Syndrome Foundation	Williams syndrome	https://williams-syndrome.org.uk/
Young Epilepsy	Epilepsy	https://www.youngepilepsy.org.uk/

ADD = attention deficit disorder, ADHD = attention deficit hyperactivity disorder, DCD = developmental co-ordination disorder, DLD = developmental language disorder, FASD = foetal alcohol spectrum disorders, OCD = obsessive-compulsive disorder, PDA = pathological demand avoidance, PTSD = post-traumatic stress disorder, SCLN = speech language and communication needs.

Appendix 2: Terms and labels for neurodevelopmental conditions

Terms and labels for neurodevelopmental conditions
Neurodevelopmental conditions (NDC)
Neurodevelopmental disorders (NDD)
Neurodiversity
Neurodivergent/neurodivergence
Neuro-minority
Neurodevelopmental atypical(ity)
Neuro-disability
Neurological conditions
Neuromotor impairments
Brain conditions
Growth conditions
Rare chromosome and gene disorders
Special educational needs (SEN)
Special educational needs and disabilities (SEND)
Additional learning needs (ALN)
Additional support needs (ASN)
Autism
Autism spectrum condition (ASC)
Autism spectrum disorder (ASD)
Asperger’s/Aperger’s syndrome
Attention deficit hyperactivity disorder (ADHD)
Attention deficit disorder (ADD)
Attention differences
Speech language and communication needs (SCLN)
Language and communication disorders
Complex communication challenges
Developmental language disorder (DLD)
Specific language impairment (SLI)
Stammer
Developmental delay
Global developmental delay

Dyspraxia
Developmental co-ordination disorder (DCD)
Dyslexia
Dyscalculia
Tourette's/Tourette’s syndrome
Tic disorders
Tics
Developmental disabilities (DD)
Intellectual and developmental disabilities (IDD)
Intellectual disabilities (ID)
Learning disabilities (LD)
Learning difficulties
Learning disorders
Nonverbal learning disorder (NLD or NVLD)
Down’s/Down syndrome
Fragile X syndrome
Prader-Willi syndrome
Williams syndrome
Foetal alcohol syndrome (FAS)
Foetal alcohol spectrum disorders (FASD)
Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)
Pathological demand avoidance (PDA)
Acquired brain injury (ABI)
Rett syndrome
Cerebral palsy
DiGeorge syndrome
22q11.2 deletion
VCFS
Kleefstra syndrome
Growth hormone deficiency
Multiple pituitary hormone deficiency
IGF-1 deficiency
Premature sexual maturation (PSM)
Russell Silver Syndrome (RSS)
Intrauterine Restriction (IUGR)
Small for Gestational Age (SGA)
SHOX
Sotos Syndrome
Tatton Brown Rahman Syndrome
Weavers Syndrome
Neurofibromatosis
Nerve tumours
Tuberous sclerosis
Sleep disorders
Dravet syndrome
Epilepsy
Epileptic seizure

Notes. A range of broad and specific terms and labels are used under the wide-ranging umbrella term “neurodevelopmental conditions”.

Appendix 3: Related Research Priority Exercises (Non-NDC)

Topic for Research Priority Exercise	Group/Author	Year
Therapy or other professionals		
Occupational therapy	JLA	2020
Occupational therapy – international	Mackenzie et al.	2019
Occupational therapy – mental health	Bissett et al.	2002
Physiotherapy	JLA	2018
Therapy professionals in Norther Ireland –		
Physiotherapy	University of Ulster	2011
Occupational therapy	University of Ulster	2011
Nutrition and dietetics	University of Ulster	2011
Speech and language therapy	University of Ulster	2011
Podiatry	University of Ulster	2011
Orthoptics	University of Ulster	2011
Key stakeholders	University of Ulster	2011
Service users	University of Ulster	2011
Allied health clinicians	Davis et al.	2018
Adult social work	JLA	2018
Stroke nursing	Rowat et al.	2016
Nursing and midwifery service delivery	Ross et al.	2004
Related conditions		
Preterm birth	JLA	2014
Dysphagia	RCSLT	2018
Aphasia following stroke	Franklin et al.	2018
Life after stroke	JLA	2011
Spina bifida	Sinclair et al.	2019
Cleft lip with or without cleft palate	Sinclair et al.	2019
Congenital heart defects	Sinclair et al.	2019
Safe care for adults with complex health needs	JLA	2019
Mental health		
Mental health – learning disability trust	Owens et al.	2008
Mental health – children and young people	JLA	2018
Mental health – Europe	Wykes et al.	2015
Mental health – Australia	Banfield et al.	2018
Mental health – humanitarian settings	Tol et al.	2011
Public mental health – Europe	Forsman et al.	2015
Youth mental health	Mei et al.	2020
Specialised mental health services	NHS England	2018
Child and adolescent mental health services	NHS England	2018
Adult secure services	NHS England	2018
Perinatal mental health	NHS England	2018
Bipolar	JLA	2016

Depression	JLA	2016
Eating disorders – Netherlands	JLA	2016
Eating disorders – Canada	CIHR	2018
Schizophrenia	JLA	2011
Digital technology for mental health	JLA	2018
Mental health service users – UK	Rose et al.	2008

Appendix 4: Research Priority Coding Totals

Research Priority Exercise	Recognition and identification identification of NDCs	*Physical Health*	*Mental health*	*Speech and language*	*Social*	*Employment*	*Education*	*Psychoeducation*	*Developmental or functional*	*Sensory and occupational therapy*	*Forensic*	*Service provision*	*Sleep*	*Behavioural*	*Other or general*	Families or carers of people with NDCs	Professionals working within NDCs	Wider community	Causes or prevalence	Understanding NDCs	Other
Autism (JLA, 2016)	4	0	6	1	3	2	2	1	4	2	0	1	0	3	2	1	2	2	1	3	1
Learning difficulties (JLA, 2018)	5	2	3	1	6	1	6	0	2	0	0	3	0	0	6	8	3	3	0	4	1
Childhood Disability (JLA, 2015)	0	17	4	3	7	0	5	2	5	4	0	3	1	5	1	3	2	2	0	0	0
Neurodevelopmental Disorders (JLA, 2017)	1	4	3	0	1	0	3	0	3	0	0	5	0	2	4	4	2	0	0	0	0
Epilepsy (Wales Epilepsy Research Network, 2009)	0	8	1	0	0	0	1	2	0	0	0	0	0	0	0	0	0	1	0	0	0
Neuro-oncology (JLA, 2015)	1	16	6	0	0	0	0	0	1	0	0	0	0	0	3	1	0	0	0	1	0
ADHD Treatments (SBU, 2014)	0	5	1	1	1	0	1	2	1	0	0	0	0	1	0	1	0	0	0	0	0
Learning Disabilities – SLT (RCSLT, 2019)	2	11	5	68	13	1	5	1	1	3	4	2	0	4	3	15	7	2	1	5	4
Developmental Language Disorder – SLT (RCSLT, 2019)	10	1	7	34	3	0	14	4	4	0	3	8	0	2	1	8	14	1	0	6	1
Rehabilitation and Disability (NHS England, 2018)	0	1	0	0	0	0	0	0	0	0	0	1	0	0	1	0	0	0	1	0	1
Neurosciences (NHS England, 2018)	1	2	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0

Autism – Mental Health (Benevides et al., 2020)	0	2	3	0	0	0	0	1	0	0	0	0	0	1	0	0	0	0	0	3	0
Developmental Disabilities (Tomlinson et al., 2014)	2	9	2	2	1	1	3	1	2	0	0	2	0	1	0	5	5	2	2	1	5
Autism (Frazier et al., 2018)	1	5	1	0	0	0	0	0	1	0	0	1	0	1	1	0	0	0	1	9	1
Traumatic Brain Injury (Nadler et al., 2018)	0	2	1	0	3	0	1	2	2	0	1	3	0	0	2	3	2	1	1	3	3
Mental & Neurological Health (Khandelwal et al., 2009)	0	4	3	0	0	0	1	3	0	0	0	12	0	0	4	4	1	3	1	9	15
Epilepsy (Kwan et al., 2015)	0	2	1	0	0	0	0	0	0	0	0	3	0	0	1	0	0	1	4	1	1
Epilepsy (Kelley et al. 2009)	1	0	1	0	0	0	0	0	0	0	0	0	0	0	8	0	0	0	7	3	1
Epilesy (Gray Matters, 2008)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	5	0	0	0	1	1	0
Down Syndrome (Sinclair et al., 2019)	0	4	1	0	1	0	2	0	1	0	0	0	0	0	0	4	0	0	0	1	0
Augmentative and Alternative Communication (O'Keefe et al., 2009)	0	0	0	15	2	0	2	0	0	0	0	0	0	0	0	0	3	2	0	1	1
Complex Communication Needs (Light & McNaughton, 2012)	0	0	0	4	0	0	0	0	0	0	0	0	0	0	0	1	2	1	0	1	0
Brain & Spine Cavernous Malformations (JLA, 2016)	0	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	5	0
Intellectual Disabilities – Palliative Care (Tuffrey-Wijne et al., 2016)	0	13	0	1	0	0	0	0	0	0	0	8	0	0	4	0	2	1	0	2	11
Neurology and Psychiatry – Sleep (Bassetti et al., 2015)	0	2	8	0	0	0	0	0	2	0	0	0	23	2	0	0	0	0	0	0	6
Children and Youth with Special Health Care Needs (Coller et al., 2020)	0	18	2	0	9	0	1	4	2	0	0	39	0	2	0	24	3	0	0	1	1

Cerebral Palsy (McIntyre et al., 2009)	0	5	1	0	1	2	0	0	2	0	0	5	0	0	3	6	0	1	2	3	1
Autism – Sleep (Pavlopoulou & Dimitriou, 2019)	0	1	2	0	1	0	0	0	0	1	0	0	7	0	0	0	1	0	0	1	0
Autism (Pellicano et al., 2014)	1	1	0	0	0	0	1	0	2	0	0	2	0	0	1	0	0	0	3	7	0
Autism (Gotham et al., 2015)	1	3	1	0	2	1	2	0	1	0	1	1	0	0	8	0	0	1	3	6	0
Autism – Interventions/ Supports (Gotham et al., 2015)	0	3	1	1	1	1	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0
Autism – Older People (Warner et al., 2019)	0	9	2	0	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1	4
Autism – Older Adults (Piven et al., 2011)	1	3	2	0	1	0	1	0	1	0	0	1	0	1	1	0	1	0	0	3	0
Fetal Alcohol Spectrum Disorders (Schölin et al., 2020)	4	0	1	0	1	0	0	0	0	0	1	1	0	0	2	1	1	0	0	1	0
Autism – Early Research (Fletcher-Watson et al., 2017)	6	0	0	0	0	0	0	0	0	0	0	1	0	0	1	2	1	1	1	6	0
Autism – Transition and Employment (Nicholas et al., 2017)	0	0	1	0	0	12	0	0	1	0	0	0	0	0	0	3	0	0	0	0	5
Autism – Transition (Shattuck et al., 2018)	0	0	0	0	0	4	1	0	1	0	0	8	0	0	3	0	2	1	0	5	3
Autism – Anxiety (Vasa et al., 2018)	1	0	9	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	8	0
Neurodevelopmental Disorder – Psychiatry (Alexander et al., 2020)	0	4	7	0	2	0	1	1	0	1	0	2	1	3	2	1	0	0	0	0	1
Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020)	7	0	0	0	0	0	1	0	0	0	0	1	0	0	8	2	5	1	5	3	13
Tourette Syndrome (Tourettes Action, 2018)	0	6	0	0	1	1	1	0	0	0	0	0	1	2	2	0	0	0	1	2	0
TOTALS	**49**	**167**	**86**	**131**	**61**	**26**	**55**	**25**	**40**	**12**	**10**	**114**	**33**	**27**	**77**	**97**	**59**	**27**	**36**	**106**	**80**

Appendix 5: Example Research Priorities for Research Priority Areas

Research Priority Areas	Example Research Priorities
Supporting people with NDCs[1]	▪ *‘Which early interventions are effective for children and young people with learning difficulties, at what ages and stages are they best introduced and what are the long-term outcomes?’* – Learning Difficulties (JLA, 2018) ▪ *‘Effectiveness of a face-to-face versus indirect approach to intervention for individuals with DLD’* – Developmental Language Disorder (RCSLT, 2019) ▪ *‘How can system navigation be organized in a manner that enables coordinated services and supports across the lifespan for individuals with neurodevelopmental disorders and their families?’* – Neurodevelopmental Disorders (JLA, 2017) ▪ *‘To improve the access to epilepsy care and reduce the treatment gap.’* – Epilepsy (Kwan et al., 2015)
Understanding NDCs	▪ *‘How can sensory processing in autism be better understood?’* – Autism (JLA, 2016) ▪ *‘What is the impact of adolescence on autism? And what support is effective in helping autistic adolescents into adulthood?* – Autism (JLA, 2016) ▪ *‘What is the experience of living with autism? How can non-autistic people better understand what it's like to be autistic? How can autistic people better understand themselves?’* – Autism (JLA, 2016) ▪ *‘How can we understand what it is like to live with learning difficulties from a child or young person’s perspective?’* – Learning Difficulties (JLA, 2018) ▪ *‘What strengths do children and young people with learning difficulties have?’* – Learning Difficulties (JLA, 2018) ▪ *‘Do lifestyle factors (e.g. sleep, stress, diet) influence tumour growth in people with a brain or spinal cord tumour?’* – Neuro-oncology (JLA, 2015) ▪ *‘The perception of the term ‘social skills’ by people with learning disabilities compared to SLTs and implications for practice’* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *‘Perspectives from children with DLD on barriers and facilitators to having support needs met’* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *‘How can we develop better measurement tools for autistic quality of life, depression, anxiety, social well-being, and sleep as experienced by autistic adults?’* ▪ *‘Lifespan issues’* – Autism (Frazier et al., 2018) ▪ *‘Understanding co-occurring conditions’* – Autism (Frazier et al., 2018) ▪ *‘Understanding how experiences of community integration and support needs change across the life span (e.g., lifelong issues of individuals who sustain a TBI in childhood)’* – Traumatic Brain Injury (Nadler et al., 2018) ▪ *‘Identify and characterize the full range and age specificity of comorbidities in people with epilepsy’ and ‘Identify predictors and underlying mechanisms that contribute to comorbidities’* – Epilepsy (Kelley et al., 2009) ▪ *‘Better understanding of childhood epilepsies and brain development’* – Epilepsy (Gray matters, 2008) ▪ *‘identify the variables that impact on the lifestyles of persons who are non-speaking’* – Augmentative and Alternative Communication (O'Keefe et al.,2009) ▪ *‘Investigate the strengths and challenges faced by children with CCN in developing language and communication skills across ages, across disabilities, and across diverse cultural and linguistic backgrounds, including those children with the most complex needs’* – Complex Communication Needs (Light & McNaughton, 2012)

	▪ *'What is the relationship between CP and poverty?'* – Cerebral Palsy (McIntyre et al., 2009) ▪ *'What does the future hold for autistic adults?'* – Autism (Pellicano et al., 2014; Gotham et al., 2015) ▪ *'What is the place of autistic people in society today?'* – Autism (Pellicano et al., 2014; Gotham et al., 2015) ▪ *'How are autistic people's brains different from the brains of non-autistic people?'* – Autism (Pellicano et al., 2014; Gotham et al., 2015) ▪ *'Are there different types of autism?'* – Autism (Pellicano et al., 2014; Gotham et al., 2015) ▪ *'Place of autistic people in society'* – Autism (Pellicano et al., 2014; Gotham et al., 2015) ▪ *'Co-occurring conditions'* – Autism (Pellicano et al., 2014) ▪ *'When does "autism" start?'* – Autism - Early Research (Fletcher-Watson et al., 2017) ▪ *'Understand the unique development of autistic children'* – Autism - Early Research (Fletcher-Watson et al., 2017) ▪ *'How QoL and functional outcomes change'* – Autism – Transition (Shattuck et al., 2018) ▪ *'Understanding determinants of PAE'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020) ▪ *'Brain (structure/circuits/brain scanning)'* – Tourette Syndrome (Tourettes Action, 2018)
Families or carers of people with NDCs	▪ *'How can parents and family members be supported/educated to care for and better understand an autistic relative?'* – Autism (JLA, 2016) ▪ *'How can parents, carers, brothers and sisters and extended families of children and young people with learning difficulties, be best supported to achieve their best quality of life before, during and after the diagnosis or identification in home, school and community contexts?'* – Learning Difficulties (JLA, 2018) ▪ *'Which parenting approaches and strategies are most helpful for young parents or carers who themselves have learning difficulties?'* – Learning Difficulties (JLA, 2018) ▪ *'Which resources are needed to more effectively address the health, social and emotional needs of families or caregivers of individuals with neurodevelopmental disorders?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'How can families and caregivers be more involved and supported to make informed decisions that address their needs, preferences and priorities?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'What is the effect of interventions to help carers cope with changes that occur in people with a brain or spinal cord tumour, compared with standard care?'* – Neuro-oncology (JLA, 2015) ▪ *'What are the positive and negative effects of parental support programmes?'* – ADHD Treatments (SBU, 2014) ▪ *'Impact on attainment of personalised goals for people with profound and multiple learning disabilities when involving parents/carers and staff in addition to the individual with profound and multiple learning disabilities'* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *'Most meaningful targets for individuals with DLD from the parent perspective'* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *'What are the most efficient ways of supporting and empowering parents/families of people with developmental disabilities (in specific social and cultural contexts)?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'What is the psychosocial impact of my child's condition on my child and our family?'* – Down Syndrome (Sinclair et al., 2019) ▪ *'Training diverse parent populations'* and *'Technology to train parents'* – Children and Youth with Special Health Care Needs (Coller et al., 2020) ▪ *'Parent advisory group best practices'* – Children and Youth with Special Health Care Needs (Coller et al., 2020) ▪ *'Family as professional team members'* – Children and Youth with Special Health Care Needs (Coller et al., 2020) ▪ *'What policies are needed to improve quality of life for families caring for Australians with severe disabilities?'* – Cerebral Palsy (McIntyre et al., 2009) ▪ *'increase support for families of adults with ASD'* – Autism - Transition and Employment (Nicholas et al., 2017) ▪ *'Brief, group based, ADHD focused, parent-training intervention in children and young people aged 5-18 years'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020) ▪ *'What support is there for parents/families?'* – Tourette Syndrome (Tourettes Action, 2018)

Professionals working within NDCs	▪ *‘How can training for health and social care professionals be improved so that they are more able to recognise symptoms of autism/treat autistic people appropriately?’* – Autism (JLA, 2016) ▪ *‘How do learning difficulties affect the everyday life of children and young people living with a learning difficulty and those involved in their care?’* – Learning Difficulties (JLA, 2018) ▪ *‘Which school characteristics (e.g. policies, attitudes of staff etc.) are most effective to promote inclusion of children and young people with neurodisability in education and after-school clubs?’* – Childhood Disability (JLA, 2015) ▪ *‘Facilitating confidence and competency of teaching assistants to follow SLT programmes set by a therapist for children with DLD’* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *‘Impact of teacher training (on specific strategies/ language support) on academic attainment in adolescents with DLD in secondary schools’* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *‘What are the common experiences and attitudes of primary healthcare workers towards people with developmental disabilities?’* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *‘How best can non-specialists be trained and supervised to work with people with developmental disabilities?’* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *‘How can medical training best prepare doctors to work with people with developmental disabilities?’* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *‘Network of centres of excellence (e. g. by strengthening existing centres such as who Collaborating centres for training and research in MNH)’* – Mental and Neurological Health (Khandelwal et al., 2009) ▪ *‘Adult CYSHCN provider workforce size and competence’* – Children and Youth with Special Health Care Needs (Coller et al., 2020) ▪ *‘Practitioner training’* – Autism (Pellicano et al., 2014) ▪ *‘Develop mechanisms to support training in research on aging in ASDs’* – Autism - Older Adults (Piven et al., 2011) ▪ *‘Doctors and/or other health professional's knowledge’* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020)
Causes or prevalence	▪ *‘What are the causes of autism?’* – Autism (JLA, 2016) ▪ *‘What is the prevalence of developmental disabilities? How does this vary with child and environmental characteristics?’* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *‘What are the most common preventable causes of developmental disabilities (e.g., neurotoxins, undernutrition, infections, poverty, poor education)? How do these vary across regions and countries (and within countries)?’* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *‘Environmental risk and protective factors’* – Autism (Frazier et al., 2018) ▪ *‘Epidemiological research to establish prevalence, the scale, and costs of TBI to society’* – Traumatic Brain Injury (Nadler et al., 2018) ▪ *‘To understand the etiologic or modifying factors for the development of epilepsy’* – Epilepsy (Kwan et al., 2015) ▪ *‘To identify the pathologic basis of epilepsy’* – Epilepsy (Kwan et al., 2015) ▪ *‘To understand the lifestyle risk factors of epilepsy’* – Epilepsy (Kwan et al., 2015) ▪ *‘To understand the genetic basis of epilepsy’* – Epilepsy (Kwan et al., 2015) ▪ *‘Identify as yet unrecognized causes of epilepsy (e.g., genetic, autoimmune, and infectious)’* – Epilepsy (Kelley et al., 2009) ▪ *‘Identify underlying mechanisms of epileptogenesis’* – Epilepsy (Kelley et al., 2009) ▪ *‘How do brain or spine cavernomas start and develop?’* – Brain and Spine Cavernous Malformations (JLA, 2016) ▪ *‘What are the causes of and casual pathways to CP?’* – Cerebral Palsy (McIntyre et al., 2009) ▪ *‘To what extent is autism caused by genetic factors?’* – Autism (Pellicano et al., 2014) ▪ *‘How common is autism?’* – Autism (Pellicano et al., 2014) ▪ *‘What aspects of the environment contribute to autism?’* – Autism - Early Research (Fletcher-Watson et al., 2017)

	▪ *'Are there certain periods within pregnancy that drinking alcohol causes higher risk of FASD?'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020) ▪ *'What is the prevalence of FASD?'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020) ▪ *'Genetics/hereditary'* – Tourette Syndrome (Tourettes Action, 2018)
Recognition and identification of NDCs	▪ *'How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?'* – Autism (JLA, 2016) ▪ *'How can we diagnose autism earlier? And does diagnosis/earlier diagnosis improve outcomes/wellbeing?'* – Autism (JLA, 2016) ▪ *'What training do school and nursery teachers need to achieve the best possible experiences/ outcomes/employment prospects for children with autism and/or identify the early signs of autism?'* – Autism (JLA, 2016) ▪ *'What knowledge, skills and training do educational professionals need to identify the early signs of learning difficulties and provide optimal support for children and young people affected to help them achieve the best possible outcomes?'* – Learning Difficulties (JLA, 2018) ▪ *'How can multiple types of professionals work together with parents and carers to improve identification, diagnosis, interventions and treatments and achieve the best outcomes for children and young people with learning difficulties?'* – Learning Difficulties (JLA, 2018) ▪ *'What is the best way to assess learning difficulties in children and young people?'* – Learning Difficulties (JLA, 2018) ▪ *'Language screening for children with behaviour that challenges'* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *'Effective ways to assess the language skills of individuals within the youth justice sector and impact on identification of DLD'* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *'How can health systems improve in early detection (during infancy and early childhood) of developmental disabilities in low and middle income countries?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'How can we best operationally define and identify (screen for) people with developmental disabilities?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'Screening and identification'* – Autism (Frazier et al., 2018) ▪ *'Develop effective methods for diagnosis, treatment and prevention of nonepileptic seizures (NES)'* – Epilepsy (Kelley et al., 2009) ▪ *'How can we better recognise the signs and symptoms of autism?'* – Autism (Pellicano et al., 2014) ▪ *'Develop diagnostic criteria and instruments for diagnosis and assessment of the needs of older adults with ASDs'* – Autism - Older Adults (Piven et al., 2011) ▪ *'Service design and professional education to ensure coordinated diagnosis and support can be provided to affected individuals and families'* – Fetal alcohol spectrum disorders (Schölin et al., 2020) ▪ *'What are the signs of autism in babies?' 'To identify autism earlier in life' 'Help clinicians better understand early signs' 'Help parents get a quick diagnosis'* – Autism - Early Research (Fletcher-Watson et al., 2017) ▪ *'Who/where/how are FASD diagnoses made?'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020) ▪ *'What are the outcomes/benefits to diagnosis?'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020)
Wider community	▪ *'How can public understanding and tolerance of autism be improved? And what is the impact of any improvement in awareness on the wellbeing of autistic people?'* – Autism (JLA, 2016) ▪ *'Which strategies are effective in preventing stigma and bullying towards children and young people with learning difficulties?'* – Learning Difficulties (JLA, 2018) ▪ *'How can we improve public awareness about learning difficulties and what is the impact of any improvement in awareness on the wellbeing of people with learning difficulties?'* – Learning Difficulties (JLA, 2018) ▪ *'What effect does having a formal label or a diagnosis have on children and young people living with a learning difficulty and those involved in their care and the public?'* – Learning Difficulties (JLA, 2018)

	▪ *‘Are child-centred strategies to improve children’s (i.e. peers) attitudes towards disability (e.g. buddy or Circle of Friends etc) effective to improve inclusion and participation within educational, social and community settings?’* – Childhood Disability (JLA, 2015) ▪ *‘Does promoting public positive attitudes towards disability improve participation in recreation and leisure activities for children and young people with neurodisability?’* – Childhood Disability (JLA, 2015) ▪ *‘Public awareness (eg, ‘What advice should be given to all schools about epilepsy, and how would this improve epilepsy control for schoolchildren? Can better education about epilepsy improve quality of life for people with epilepsy by reducing stigma?’)’* – Epilepsy (Wales Epilepsy Research Network, 2009) ▪ *‘SLT role in advocating for people with learning disabilities in the wider community’* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *‘Impact of public awareness raising activities around learning disabilities and communication skills on the social participation outcomes of people with learning disabilities’* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *‘Raising awareness. Using components of successful awareness-raising campaigns for health disorders (e.g. autism) to inform a developmental language disorder strategy’* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *‘How do public attitudes to developmental disabilities and the care of people with developmental disabilities vary across cultural and language groups and across types of developmental disabilities?’* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *‘What are the nature and forms of stigmatization in different cultures and contexts (low, middle, high income countries; rural/urban)?’* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *‘Awareness programmes’* – Mental and Neurological Health (Khandelwal et al., 2009) ▪ *‘To reduce the stigma and discrimination against people with epilepsy’* – Epilepsy (Kwan et al., 2015) ▪ *‘design programs for increasing public awareness’* – Augmentative and Alternative Communication (O'Keefe et al.,2009) ▪ *‘determine ways to increase public awareness and improve attitudes regarding AAC’* – Augmentative and Alternative Communication (O'Keefe et al.,2009) ▪ *‘Investigate the most effective techniques to disseminate information, increase public awareness, improve preservice/inservice training of professionals, and enhance collaboration with families and professionals to ensure that AAC is incorporated effectively into the everyday lives of children with CCN’* – Complex Communication Needs (Light & McNaughton, 2012) ▪ *‘Societal attitudes towards dying and people with ID’* – Intellectual Disabilities - Palliative Care (Tuffrey-Wijne et al., 2016) ▪ *‘Accurate public awareness about autism’* – Autism (Pellicano et al., 2014) ▪ *‘Understanding/ Acceptance of Adults with ASD’* – Autism (Gotham et al., 2015) ▪ *‘More awareness raising needed’* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020)
Other	▪ *‘Facilitators and barriers to adults with learning disabilities being involved in research studies’* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *‘CYSHCN research methods innovations’* – Children and Youth with Special Health Care Needs (Coller et al., 2020) ▪ *‘Animal models’* – Autism (Frazier et al., 2018) ▪ *‘Research capacity - Tools, instruments and mechanisms’* – Mental and Neurological Health (Khandelwal et al., 2009) ▪ *‘To improve the infrastructure and capacity in epilepsy research’* – Epilepsy (Kwan et al., 2015) ▪ *‘Adapting existing measures (incl contrast with general population)’* – Intellectual Disabilities - Palliative Care (Tuffrey-Wijne et al., 2016) ▪ *‘Developing new measures/instruments’* – Intellectual Disabilities - Palliative Care (Tuffrey-Wijne et al., 2016) ▪ *‘Developing economic models’* – Intellectual Disabilities - Palliative Care (Tuffrey-Wijne et al., 2016) ▪ *‘Research logistics’* – Autism (Pellicano et al., 2014) ▪ *‘An international collaborative effort to agree a core set of demographic, health behavior and health outcome indicators most relevant to autistic people that can be compared with general population data’* – Autism - Older People (Warner et al., 2019)

	▪ *'The current landscape of SLT services for adolescents and adults with DLD, in the context of the SEND code of practice (2014)'* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *'What is the impact of global initiatives in disability (e.g. UNCRPD) on policies, laws and services for people with developmental disabilities?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'Relevant national and international laws'*– Intellectual Disabilities - Palliative Care (Tuffrey-Wijne et al., 2016)

Notes: [1]There were several sub-groups within 'Supporting people with NDCs', see appendix 5 for example research priorities each of the sub-groups.

Appendix 6: Example Research Priorities for 'Supporting People with NDCs' Sub-Group Research Priority Areas

Support Sub-Group Areas	Example Research Priorities
Physical health	▪ *'Physical health in people with ASD' 'Health care access'* and *'Health conditions'* – Autism (Gotham et al., 2015) ▪ *'Medication choice in people with coexisting conditions'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'Alternative treatments e.g. acupuncture, diet'* – Tourette Syndrome (Tourettes Action, 2018) ▪ *'Conduct studies of psychosocial, behavioral, educational, and pharmacological interventions in older individuals with an ASD'* – Autism – Older Adults (Piven et al., 2011) ▪ *'Investigation of health care self-advocacy strategies and potential barriers to effective health care self-advocacy for autistic people'* – Autism – Older People (Warner et al., 2019) ▪ *'What are the most effective methods of pain management so the secondary complications can be reduced?'* – Cerebral Palsy (McIntyre et al., 2009) ▪ *'Telemedicine implementation'* – Children and Youth with Special Health Care Needs (Coller et al., 2020) ▪ *'What is the current state of affairs with regards to PC [palliative care] for people with ID [intellectual disabilities], and how does this compare to the general population?'* –Intellectual Disabilities – Palliative Care (Tuffrey-Wijne et al., 2016) ▪ *'Does exercise enhance the immune system of children with Down syndrome?'* – Down Syndrome ▪ *'What are the most efficient ways of training health care workers to reduce the discrimination faced by people with developmental disabilities in health care systems?'* – Developmental Disabilities ▪ *'Deep brain stimulation for epilepsy'* and *'Deep brain stimulation for Tourette's'* – Neurosciences (NHS England Clinical Reference Groups, 2018) ▪ *'Effectiveness of SLT intervention on the health and wellbeing outcomes for a) children and b) adults with learning disabilities and sensory feeding difficulties'* – Learning Disabilities (RCSLT, 2019) ▪ *'Which of the two pharmaceuticals, atomoxetine or methyldiphenidate, is most effective, with the least side effects?'* – ADHD Treatments (SBU, 2014) ▪ *'What are the long-term physical and cognitive effects of surgery and/or radiotherapy when treating people with a brain or spinal cord tumour?'* – Neuro-oncology (JLA, 2015) ▪ *'Prescribing in pregnancy'* – Epilepsy (Wales Epilepsy Research Network, 2009)
Mental health	▪ *'Which interventions reduce anxiety in autistic people?'* – Autism (JLA, 2016)

	▪ *'Why are children and young people with learning difficulties more likely to experience mental health problems?'* – Learning Difficulties (JLA, 2018) ▪ *'Are counselling/psychological strategies (e.g. talking therapies) effective to promote the mental health of children and young people with neurodisability?'* – Childhood Disability (JLA, 2015) ▪ *'Which supports are most effective to protect individuals with neurodevelopmental disorders from abuse (e.g. physical, sexual, bullying) and other threats to their wellbeing?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'Treatment of depression as a comorbidity'* – Epilepsy (Wales Epilepsy Research Network, 2009) ▪ *'When, for who, and under what conditions do self-managed interventions and preferred activities used to address well-being and mental health result in improved quality of life and reduced mental health symptoms? What is the effect of employing community available approaches and techniques such as exercise/physical activity, yoga, mindfulness and meditation, tai-chi, animal-assisted therapy, art and music-based approaches to well-being?'* – Autism – Mental Health (Benevides et al., 2020) ▪ *'What is the impact of trauma on mental health outcomes in autistic individuals, and what approaches can be used to effectively address trauma among autistic adults (e.g. trauma-informed care)? What are the best indicators or measures of PTSD, trauma, and adverse childhood experiences in autistic individuals?'* – Autism – Mental Health (Benevides et al., 2020) ▪ *'Rates of co-occurring DLD and low-mood or anxiety'* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *'How can employment opportunities for individuals with developmental disabilities and/or autism be increased? What is the impact of employment on the psychological well-being* of the adult working *(and their families)?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'Mental health and development disorders in children and adolescents'* – Mental and Neurological Health (Khandelwal et al., 2009) ▪ *'Mental and emotional health in people with ASD'* – Autism (Gotham et al., 2015) ▪ *'Individual psychotherapy'* – Autism – Interventions/Supports (Gotham et al., 2015) ▪ *'Child and family mental health screening'* – Children and Youth with Special Health Care Needs (Coller et al., 2020) ▪ *'Development of a tool to improve understanding of how factors influence personal well-being for autistic people'* – Autism – Older People (Warner et al., 2019) ▪ *'The mental health impact of individuals with FASD when seen together with comorbid traumatic experiences and prison populations'* – Fetal alcohol spectrum disorders (Schölin et al., 2020) ▪ *'Themes relating to family engagement suggested the need to enhance support to parents and families in general, in order to nurture optimal independence and quality of life via community-level support (e.g., job coaching, mental health services)'* – Autism – Transition and Employment (Nicholas et al., 2017) ▪ *'To develop objective measures of anxiety (e.g., behavioral paradigms, physiological tools)' 'To examine the role of emotional dysregulation in the development and maintenance of anxiety' 'To understand whether psychological mechanisms that underpin anxiety (e.g., cognitive rigidity, intolerance of uncertainty, emotion dysregulation) respond to treatment'* Autism – Anxiety (Vasa et al., 2018) ▪ *'Pharmacological and psychological interventions for anxiety disorders in adults with mild-to-moderate intellectual disability who have autism'* – Neuordevelopmental Disorder – Psychiatry (Alexander et al., 2020)
Speech and language	▪ *'Which interventions are effective in the development of communication/language skills in autism?'* – Autism (JLA, 2016) ▪ *'Which information and communication technologies (ICT) (e.g.augmentative and alternative communication (AAC) devices, ICT-based communication aids, assistive technology, iPads/writing aids/tablet/phone) are effective and how can they best be accessed by children and young people with learning difficulties?'* – Learning Difficulties (JLA, 2018) ▪ *'To improve communication for children and young people with neurodisability: (a) what is the best way to select the most appropriate communication strategies? And (b) how to encourage staff/carers to use these strategies to enable communication?'* – Childhood Disability (JLA, 2015)

	▪ *'Provision of speech interventions for people with learning disabilities across UK-wide SLT services'* and *'Measuring suitability for speech intervention for people with learning disabilities'* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *'Effectiveness of speech and language therapy intervention for children with DLD when delivered using technology: current practice and parent perspectives'* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *'What is the utility and effectiveness of easy read and pictorial information provided to people with moderate and severe ID?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'determine new and better ways of teaching individuals who use AAC to read'* – Augmentative and Alternative Communication (O'Keefe et al.,2009) ▪ *'Design a new generation of innovative AAC systems that are truly responsive to the needs and skills (motor, sensory perceptual, cognitive, linguistic) of children with CCN; that are easy to use; that are appealing; and that offer powerful communication options across environments.'* – Complex Communication Needs (Light & McNaughton, 2012) ▪ *'Patient participation in decision making, incl communication issues'* – Intellectual Disabilities - Palliative Care (Tuffrey-Wijne et al., 2016) ▪ *'Speech/language therapy'* – Autism - Interventions/Supports (Gotham et al., 2015)
Social	▪ *'What are the most effective ways to support/provide social care for autistic adults?' and '16. Which interventions improve social skills in autistic people?'* – Autism (JLA, 2016) ▪ *'Which interventions are most effective to help individuals with neurodevelopmental disorders improve their social skills and develop and maintain social relationships?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'Are child-focused strategies (e.g. one-to-one or group social and skills training) effective to improve confidence, self-esteem and promote participation in recreation and leisure activities for children and young people with neurodisability?'* – Childhood Disability (JLA, 2015) ▪ *'What are the positive and negative effects of supported conversation?'* – ADHD Treatments (SBU, 2014) ▪ *'Measuring impact of social skills intervention for people with learning disabilities'* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *'Understanding and modifying environmental factors that influence community integration (e.g., housing support, caregiver supports)'* – Traumatic Brain Injury (Nadler et al., 2018) ▪ *'Can people with CP equitably access the community?'* – Cerebral Palsy (McIntyre et al., 2009) ▪ *'Friendship'* and *'Romantic relationships'* – Autism (Gotham et al., 2015) ▪ *'Social skills training'* – Autism - Interventions/Supports (Gotham et al., 2015) ▪ *'Factors associated with sustained, high-quality, residential care'* and *'Psychosocial interventions for people with severe and profound intellectual disability'* – Neuordevelopmental Disorder – Psychiatry (Alexander et al., 2020)
Employment	▪ *'How can we encourage employers to apply person-centred interventions & support to help autistic people maximise their potential and performance in the workplace?'* – Autism (JLA, 2016) ▪ *'What percentage of children and young people with learning difficulties receive the appropriate care and support that meets their needs at home, in clinic, in education and at work?'* – Learning Difficulties (JLA, 2018) ▪ *'Impact of training on SLCN for employers when considering the experiences of a person with learning disabilities who is seeking employment/ currently employed'* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *'How can employment opportunities for individuals with developmental disabilities and/or autism be increased? What is the impact of employment on the psychological well-being of the adult working (and their families)?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'What are the barriers to employment that exist for people with CP?' and 'How can people with CP be better trained with the necessary skills to enter the workforce?'* – Cerebral Palsy (McIntyre et al., 2009) ▪ *'Employment'* – Autism (Pellicano et al., 2014) and – Autism (Gotham et al., 2015) ▪ *'Vocational skills training'* – Autism - Interventions/Supports (Gotham et al., 2015)

	▪ *'In the area of employer capacity, subthemes consisted of the need to proactively engage employers and multisectoral industries and in turn, better link potential employers with people with ASD who are able and willing to work. The need to create long-term supports for individuals with ASD for sustained employment was highlighted'* – Autism - Transition and Employment (Nicholas et al., 2017) ▪ *'The longitudinal patterns of service use and related outcomes. (For example, how do people cycle in and out of eligibility for SSI and vocational rehabilitation?)'* – Autism – Transition (Shattuck et al., 2018) ▪ *'Daily living issues (dealing with Tourette Syndrome at home, work and school)'* – Tourette Syndrome (Tourettes Action, 2018)
Education	▪ *'Daily living issues (dealing with Tourette Syndrome at home, work and school)'* – Tourette Syndrome (Tourettes Action, 2018) ▪ *'What training do school and nursery teachers need to achieve the best possible experiences/ outcomes/employment prospects for children with autism and/or identify the early signs of autism?'* – Autism (JLA, 2016) ▪ *'What knowledge, skills and training do educational professionals need to identify the early signs of learning difficulties and provide optimal support for children and young people affected to help them achieve the best possible outcomes?'* – Learning Difficulties (JLA, 2018) ▪ *'Which school characteristics (e.g. policies, attitudes of staff etc.) are most effective to promote inclusion of children and young people with neurodisability in education and after-school clubs?'* – Childhood Disability (JLA, 2015) ▪ *'How can educators and multi-disciplinary teams be better trained to provide individualized education for and accommodate children with neurodevelopmental disorders to ensure optimal outcomes?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'What are the positive and negative effects of teacher support?'* – ADHD Treatments (SBU, 2014) ▪ *'Impact of communication difficulties experienced by children with foetal alcohol syndrome and learning disabilities on a) quality of life and b) educational attainment, compared to children with typically developing language profiles'* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *'Assessing education outcomes, social inclusion and mental health in relation to DLD presentation'* and *'Impact of SLT or specialist teachers input on literacy outcomes for children with DLD'* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *'What are the most effective ways of promoting the rights to health and education of children with developmental disabilities in low and low-middle income countries?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'Setting based, particularly school based, interventions'* – Mental and Neurological Health (Khandelwal et al., 2009) ▪ *'How can I maximize my child's educational attainment?'* – Down Syndrome (Sinclair et al., 2019) ▪ *'determine the best teaching methods for developing reading and writing skills in people who use AAC'* and *'determine new and better ways of teaching individuals who use AAC to read'* – Augmentative and Alternative Communication (O'Keefe et al.,2009) ▪ *'School integration'* – Children and Youth with Special Health Care Needs (Coller et al., 2020) ▪ *'How do autistic people think and learn?'* – Autism (Pellicano et al., 2014) and – Autism (Gotham et al., 2015) ▪ *'Education'* – Autism (Gotham et al., 2015) ▪ *'Conduct studies of psychosocial, behavioral, educational, and pharmacological interventions in older individuals with an ASD'* – Autism - Older Adults (Piven et al., 2011) ▪ *'Teacher-, parent- and peer-meditated psychosocial interventions in pre-school children with autism'*– Neuordevelopmental Disorder – Psychiatry (Alexander et al., 2020) ▪ *'How can schools support students with FASD?'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020)
Psychoeducation	▪ *'Information and self-management'* – Epilepsy (Wales Epilepsy Research Network, 2009) ▪ *'What are the positive and negative effects of psychoeducative treatment?'* – ADHD Treatments (SBU, 2014) ▪ *'Impact of post-diagnostic education from SLTs given to individuals with autism and learning disabilities, and their carers, compared to no direct education, in terms of a) awareness of the individual's diagnoses and b) the individual's quality of life'* – Learning Disabilities – SLT (RCSLT, 2019)

	▪ *'Impact of programmes aimed at developing self-awareness and self-esteem of adolescents with DLD (e.g. DLD and me)'* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *'What are the most efficient health promotion models for people with developmental disabilities?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'Information access. Developing infrastructure to provide individuals with TBI, families, and professionals/service providers with access to the right information at the right time (e.g., wiki platforms, websites)'* – Traumatic Brain Injury (Nadler et al., 2018) ▪ *'Advocacy'* – Mental and Neurological Health (Khandelwal et al., 2009) ▪ *'Peer support credentials and professional standards' 'Peer mentor education' and 'Peer-peer coaching for self management'* – Children and Youth with Special Health Care Needs (Coller et al., 2020) ▪ *'Investigation of health care self-advocacy strategies and potential barriers to effective health care self-advocacy for autistic people'* 70 – Autism - Older People (Warner et al., 2019) ▪ *'Teacher-, parent- and peer-meditated psychosocial interventions in pre-school children with autism'* 81 – Neuordevelopmental Disorder – Psychiatry (Alexander et al., 2020)
Developmental or functional	▪ *'Which early interventions are most effective in autism? And do they lead to better outcomes?'* – Autism (JLA, 2016) ▪ *'Which early interventions are effective for children and young people with learning difficulties, at what ages and stages are they best introduced and what are the long-term outcomes?'* – Learning Difficulties (JLA, 2018) ▪ *'Which strategies are effective in helping children and young people with learning difficulties live independent lives, including during times of transitions?'* – Learning Difficulties (JLA, 2018) ▪ *'Which intervention(s) are the most effective for improving executive functioning (e.g. rigid thinking, planning, organizing, sustaining attention, working memory, etc.) in individuals with neurodevelopmental disorders?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'In brain tumour patients, what is the effect of cognitive interventions (including memory training) on improving memory after radiotherapy, compared with standard care?'* – Neuro-oncology (JLA, 2015) ▪ *'What are the positive and negative effects of computeraided working memory training?'* – ADHD Treatments (SBU, 2014) ▪ *'Effectiveness of a targeted approach compared to a developmental norms approach on functional skills of children with learning disabilities'* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *'What is the availability, cost and efficacy of early intervention and rehabilitation programs for children with developmental disabilities in low and low-middle income countries?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'Developmental and behavioral interventions'* – Autism (Frazier et al., 2018) ▪ *'Developing and evaluating individualized interventions to optimize function and participation and prevent relapse (e.g., self-management intervention; customized care plans, cognitive rehabilitation)'* – Traumatic Brain Injury (Nadler et al., 2018) ▪ *'Would early intervention, eg, tummy time, creeping, and crawling, enhance my child's development?'* – Down Syndrome (Sinclair et al., 2019) ▪ *'What early intervention (dependent on CP type) will prevent and minimize structural impairments?'* – Cerebral Palsy (McIntyre et al., 2009) ▪ *'What are the best ways to improve the life skills of autistic people?'* – Autism (Pellicano et al., 2014) ▪ *'How to improve the life skills of people with ASD'* – Autism (Gotham et al., 2015) ▪ *'How does variation in institutional settings, policies, and practices people are exposed to at an earlier stage during the life course impact the transition to adulthood?'* – Autism – Transition (Shattuck et al., 2018)
Sensory and occupational therapy	▪ *'Which interventions improve sensory processing in autistic people?'* – Autism (JLA, 2016) ▪ *'Are sensory processing/integration therapeutic programmes effective in improving behaviour and/or increasing play/participation for children and young people with neurodisability?'* – Childhood Disability (JLA, 2015)

	▪ *'The SLT role in identifying and supporting sensory needs of a person with profound and multiple learning disabilities'* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *'Occupational therapy'* – Autism - Interventions/Supports (Gotham et al., 2015)
Forensic	▪ *'Impact of using a consistent set of symbols across a forensic setting on adults with learning disabilities understanding of language'* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *'Challenges experienced by individuals with DLD in the youth justice sector'* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *'Criminal justice system'* – Autism (Gotham et al., 2015) ▪ *'The mental health impact of individuals with FASD when seen together with comorbid traumatic experiences and prison populations'* – Fetal alcohol spectrum disorders (Schölin et al., 2020)
Sleep	▪ *'What is the long term safety, effectiveness and sustainability of behavioural strategies and/or drugs (e.g. melatonin) to manage sleep disturbance in children and young people with neurodisability (outcomes include time to onset, duration, and reducing impact on family)?'* – Childhood Disability (JLA, 2015) ▪ *'Interventions to obtain adequate sleep are expected to promote neuroplasticity and cognitive processes during rehabilitation after brain damage and during cognitive behavioural therapies'* – Neurology and Psychiatry – Sleep (Bassetti et al., 2015) ▪ *'develop sleep interventions' 'multidisciplinary partnerships with sleep professionals'* and *'gather data on sleep medication and use of different sleep related strategies'* – Autism – Sleep (Pavlopoulou & Dimitriou, 2019) ▪ *'Managing sleep problems in children and young people with autism'* – Neuordevelopmental Disorder – Psychiatry (Alexander et al., 2020) ▪ *'Problems other than tics related to Tourette Syndrome (other symptoms/co occurring conditions) for example: sleeping, anger, panic etc.'* – Tourette Syndrome (Tourettes Action, 2018)
Behavioural	▪ *'Which interventions are effective in the treatment/management of challenging behaviour in autism?'* – Autism (JLA, 2016) ▪ *'Are behavioural and sensory interventions (e.g. early intensive behavioural intervention, EarlyBird, encouraging socialisation with peers etc.) effective in managing symptoms of Autistic Spectrum Disorder?'* – Childhood Disability (JLA, 2015) ▪ *'Which interventions best help individuals with neurodevelopmental disorders develop emotional and behavioural regulation (including increasing impulse control and reducing compulsive behaviour)?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'The impact of intensive interaction carried out by parents/carers or staff on reducing communication-related behaviours that challenge of people with learning disabilities, compared to no behaviour-focused intervention'* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *'What are the potential long- and short-term negative side effects or adverse outcomes of currently recommended therapies and interventions (including behavioral and pharmacological), as measured in autistic individuals across the life span?'* – Autism - Mental Health (Benevides et al., 2020) ▪ *'How best can we scale up access to behaviour support practices, including positive behaviour support and minimise the use of restrictive interventions (e.g., chemical, mechanical and physical restraint)?'* – Developmental Disabilities (Tomlinson et al., 2014) ▪ *'Developmental and behavioral interventions'* – Autism (Frazier et al., 2018) ▪ *'Conduct studies of psychosocial, behavioral, educational, and pharmacological interventions in older individuals with an ASD'* – Autism - Older Adults (Piven et al., 2011) ▪ *'Managing challenging behaviour in children and young people with autism'* – Neuordevelopmental Disorder – Psychiatry (Alexander et al., 2020) ▪ *'Behavioural therapy'* – Tourette Syndrome (Tourettes Action, 2018)
Service provision	▪ *'How should service delivery for autistic people be improved and adapted in order to meet their needs?'* – Autism (JLA, 2016) ▪ *'How can multiple types of professionals work together with parents and carers to improve identification, diagnosis, interventions and treatments and achieve the best outcomes for children and young people with learning difficulties?'* – Learning Difficulties (JLA, 2018)

	▪ *'Are interventions to improve consistency of approach between health and education agencies (e.g. keyworkers) effective to improve behavioural problems in children with Autistic Spectrum Disorder (ASD)?'* – Childhood Disability (JLA, 2015) ▪ *'What are the most effective treatment options/plans (e.g., timing, frequency, duration, type, intensity or dosage) for individuals with neurodevelopmental disorders for both short and long-term benefits?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'How can system navigation be organized in a manner that enables coordinated services and supports across the lifespan for individuals with neurodevelopmental disorders and their families?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'How can barriers be reduced to ensure timely access of services, treatments and supports for neurodevelopmental disorders?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'How can access to coordinated care (including diagnosis and treatment)* ***for individuals with multiple neurodevelopmental disorders*** *be improved?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'Clinical reasons informing on an individual with learning disabilities' entry in to and exit of different UK learning disabilities services, from SLTs perspectives'* – Learning Disabilities – SLT (RCSLT, 2019) ▪ *'Effectiveness of a face-to-face versus indirect approach to intervention for individuals with DLD'* – Developmental Language Disorder – SLT (RCSLT, 2019) ▪ *'Service delivery evaluation of care pathway for functional neurological disorder (FND) to establish evidence for a service delivery model for the diagnosis and management of FND in order to inform future service delivery and commissioning of care'* – Neurosciences (NHS England Clinical Reference Groups, 2018) ▪ *'Identification of obstacles to service delivery'* – Mental and Neurological Health (Khandelwal et al., 2009) ▪ *'To improve treatment delivery to people with epilepsy'* – Epilepsy (Kwan et al., 2015) ▪ *'Transitions between services'* – Intellectual Disabilities - Palliative Care (Tuffrey-Wijne et al., 2016) ▪ *'Data sharing across platforms and agencies'* – Children and Youth with Special Health Care Needs (Coller et al., 2020) ▪ *'What can be done to address the mismatch between what service parents and people with CP need and what they actually receive?'* – Cerebral Palsy (McIntyre et al., 2009) ▪ *'How can public services best meet the needs of autistic people?'* – Autism (Pellicano et al., 2014) ▪ *'Service design and professional education to ensure coordinated diagnosis and support can be provided to affected individuals and families'* – Fetal alcohol spectrum disorders (Schölin et al., 2020) ▪ *'Help provide services for children at higher likelihood of autism'* – Autism - Early Research (Fletcher-Watson et al., 2017) ▪ *'Local accessible care'* – Neuordevelopmental Disorder – Psychiatry (Alexander et al., 2020) ▪ *'Need more clinics/services/supports'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020) ▪ *'Widening access to care - Developing, evaluating, and implementing interventions targeting system-level and policy challenges (e.g., models of integrated care, or interventions targeting health system transitions)'* – Traumatic Brain Injury (Nadler et al., 2018) ▪ *'Integration across service sectors. Interventions targeting the service delivery system to optimize receipt of the right care at the right time (e.g., partnering across sectors of care, education to enhance the ability of other sectors for instance mental health or criminal justice systems to manage TBI)'* – Traumatic Brain Injury (Nadler et al., 2018)
Other or general	▪ *'How do co-occurring disorders impact treatment decisions for individuals with a neurodevelopmental disorder?'* – Neurodevelopmental Disorders (JLA, 2017) ▪ *'What is the effect of additional strategies for managing fatigue, compared with standard care, in people with a brain or spinal cord tumour?'* – Neuro-oncology (JLA, 2015) ▪ *'Devices and other technology'* – Autism (Frazier et al., 2018)

- *'National clinical survey and development of guidelines for management of agitation after traumatic brain injury in England to establish current practice and best clinical evidence for the management of acute agitation after traumatic brain injury in order to decrease unnecessary, inconsistent and variable treatment across England'* – Rehabilitation and Disability (NHS England Clinical Reference Groups, 2018)
- *'Disaster interventions'* – Mental and Neurological Health (Khandelwal et al., 2009)
- *'To improve therapeutic outcomes'* – Epilepsy (Kwan et al., 2015)
- *'Optimize existing therapies and develop new therapies and technologies for curing epilepsy'* – Epilepsy (Kelley et al., 2009)
- *'Improving treatment of epilepsy'* – Epilepsy (Gray matters, 2008)
- *'Influencing factors on decision making'* – Intellectual Disabilities - Palliative Care (Tuffrey-Wijne et al., 2016)
- *'What are the optimal treatments for CP?'* – Cerebral Palsy (McIntyre et al., 2009)
- *'Evidence-based services and interventions'* – Autism (Pellicano et al., 2014)
- *'Financial issues'* and *'Federal/state assistance'*– Autism (Gotham et al., 2015)
- *'Help children develop skills so they don't later get a diagnosis'* – Autism - Early Research (Fletcher-Watson et al., 2017)
- '*What is the best/most effective support for those with FASD?'* – Fetal Alcohol Spectrum Disorder (Finlay-Jones et al., 2020)

Appendix 7: Interview Questions

Embracing Complexity in Neurodevelopmental Research – Interview Questions

1. Briefly, what is your experience with research on neurodevelopmental conditions (e.g., autism, learning disability, ADHD, speech, language and communication needs, Tourette’s, dyslexia, dyspraxia, Down syndrome) and/or mental health?

2. What do you think are the barriers or challenges to conducting research spanning across multiple neurodevelopmental conditions?

3. Are these challenges the same for conducting mental health research spanning across multiple neurodevelopmental conditions?

4. What opportunities do you think there are for conducting research spanning across multiple neurodevelopmental conditions (or what would facilitate this sort of research?)

5. What actions do researchers and funders need to take to ensure we are taking a more pan-neurodevelopmental approach?

6. What do you think are the key priority research areas for research spanning across neurodevelopmental conditions?

7. Are you interested in conducting future research spanning across neurodevelopmental conditions? If so, what are research topics are you interested in?