

Embracing Complexity



Research Priority Setting

Top 10 Priorities for Research on Neurodivergence



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Introduction

About Embracing Complexity

Embracing Complexity is a coalition of over 60 organisations working together to facilitate the evidence-based inclusion of neurodivergent people.

Embracing Complexity works predominantly with people whose neurodivergence overlaps with neurodevelopmental diagnostic categories such as Autism, ADHD, Developmental Language Disorder (DLD), Down's Syndrome, Dyscalculia, Dyslexia, Dyspraxia, Foetal Alcohol Spectrum Disorders (FASD), Learning Disability, and Tourette's Syndrome.

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Embracing Complexity Members

Action Cerebral Palsy, ADHD Foundation, Autism Alliance, Afasic, Ambitious about Autism, #Attention UK, Autistica, Brain and Spine Foundation, The Brain Charity, British Dyslexia Association, Cerebra, Child Growth Foundation, CYPMHC, Communication Matters, Down's Syndrome Research Foundation, Dravet Syndrome UK, Dyspraxia Foundation, Employment Autism, Epilepsy Action, Epilepsy Research UK, Families In Focus CIC, FASD Awareness, FASD Hub Scotland, The Fragile X Society, Grow & Thrive, Kleefstrasynndrome.org, Max Appeal, The McPin Foundation, Mencap, MQ, NAPLIC, National Autistic Society, National Organisation for FASD, Nerve Tumours UK, Nessie, Neurodiversity Networks CIC, The Neurological Alliance, Nip in the Bud, Oshay's, PDA Society, Potential Kids, PWSA UK, RADiANT, Rett UK, RCOT, RCSLT, SEDSConnective, Seen & Heard, Sense, Sibs, The Sleep Charity, Special Networks, Speech and Language UK, Stamma, Stay Up Late, Sunshine Support, Technology for Good, Tizard Centre University of Kent, Tourettes Action, TSA, United Response, Unique, Williams Syndrome Foundation and Young Epilepsy.

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What do we mean by neurodivergence and the social exclusion of neurodivergent people?

The term “neurodivergent” describes a group of people whose ways of processing information, behaving, and experiencing the environment differ from the neurotypical majority. Embracing Complexity works predominantly with people whose neurodivergence overlaps with neurodevelopmental diagnostic categories such as Autism, ADHD, Developmental Language Disorder (DLD), Down’s Syndrome, Dyscalculia, Dyslexia, Dyspraxia, Foetal Alcohol Spectrum Disorders (FASD), Learning Disability, and Tourette’s Syndrome. A more in-depth explanation of the term “neurodivergent” and why we use it is in the appendix on page 32 of this report.

Public services, and society more broadly, are structured in a way that accommodates the needs of neurotypical people and discriminates against the needs of the neurodivergent minority.¹

Neurodivergent people encounter systemic barriers at schools,² in employment,³ when seeking healthcare,⁴ in interpersonal relationships,⁵ and in many other aspects of life.

The pervasiveness of the systemic barriers within society results in neurodivergent people facing health inequalities, social isolation, unequal access to education and employment, and an increased likelihood of developing mental health issues.

This multifaceted injustice is unacceptable and needs to be urgently addressed.

Why do we need research?

Research is the key to developing an understanding of the day-to-day experiences of neurodivergent people and improving their lives. The increased public awareness of neurodiversity and the growing inclusion of the community in research create a huge opportunity for making a meaningful change. However, the majority of funded and published research into neurodevelopmental differences does not reflect the priorities of the community, which limits its potential to drive meaningful changes.⁶

Another barrier to meaningful research and ultimately improving the lives of neurodivergent people is created by pre-defined neurodevelopmental diagnostic categories.⁷ Diagnostic categories have significant implications for research, the design of services, and, most importantly, the lives of neurodivergent people. However, as research shows, these categories do not reflect the day-to-day experiences of neurodivergent people and are not well suited to guide and inform support.⁸

What is the purpose of priority setting for research on neurodivergence?

To our knowledge, this is the first research priority-setting focused on neurodivergence, which moves beyond the boundaries of neurodevelopmental diagnostic categories and includes people with different diagnostic statuses. The purpose of the Embracing Complexity research is to identify barriers that lead to the social exclusion of neurodivergent people and effective ways of removing them. We hope that research that moves beyond the boundaries created by diagnostic categories and is informed by the priorities of the community will contribute to making society inclusive for neurodivergent people.

We carried out the Research Priority Setting to identify what areas of research are the most important to neurodivergent people, their families and carers, and all relevant professionals.

The final outcome of the Research Priority Setting is the list of the Top 10 Priorities for Research on Neurodivergence.

The priorities listed in this document cover different domains of public services and society, but some of them are related to similar themes.

Priorities ranked 1, 2, and 3 cover issues related to stigma, intersectionality, identity, and self-knowledge. Priorities 4, 5, and 6 relate to mental health, mental health services, and the correlation between neurodivergence and mental health. Priority 7 covers the need for research access to benefits and social care support. Priority 8 indicates the need for research into developing joined-up services for neurodevelopmental differences and mental health. Priorities 9 and 10 relate to issues that need to be addressed in the education system.

It is the ethical duty of researchers, policy-makers, and research funders to listen to neurodivergent people and carry out research informed by their priorities. We hope that the list of the Top 10 priorities will help to shape meaningful research and ultimately improve the lives of neurodivergent people.

Top 10 Priorities for Research on Neurodivergence

Priority 1 How can we effectively reduce the discrimination against neurodivergent people with additional marginalised identities within public services and society more broadly?

Priority 2 How can we overcome stigma toward neurodivergent people?

Priority 3 What are the most effective ways of supporting neurodivergent people in understanding and advocating for their own needs?

Priority 4 What is the relationship between unidentified or undiagnosed neurodivergence and mental health issues?

Priority 5 How can we develop joined-up services for neurodevelopmental differences and mental health?

Priority 6 What barriers do neurodivergent people face when accessing mental health services, and how can we effectively overcome these barriers?

Priority 7 How can we improve access to benefits and social care support services for neurodivergent people?

Priority 8 How can we develop and implement joined-up diagnostic pathways for all neurodevelopmental differences (e.g., ADHD, Autism, Developmental Language Disorder (DLD), Dyslexia, Dyspraxia, Foetal Alcohol Spectrum Disorder (FASD), and Tourette's Syndrome)?

Priority 9 How can we support schools and colleges in facilitating inclusive environments for neurodivergent students?

Priority 10 What are the most effective ways of assessing the needs of and providing adequate support to neurodivergent pupils in schools and colleges?





How can we effectively reduce the discrimination against neurodivergent people with additional marginalised identities within public services and society more broadly?

Why is this important?

Neurodivergent people often experience discrimination and prejudice from their peers, which leads to marginalisation and, ultimately, social exclusion. However, experiences of discrimination are different across the neurodivergent population. Different forms of oppression, such as classism, racism, patriarchy, heteronormativity, cisnormativity, ableism, and others shape discrimination. Neurodivergent people whose identities are stigmatised in multiple ways experience more severe forms of discrimination. To overcome multifaceted forms of discrimination, we need to build an understanding of how intersecting identities shape the experiences of marginalisation.

Research that addresses neurodivergent people often fails to attend to intersectionality and to consider the experiences of marginalised communities.⁹ The focus of this priority is to deconstruct how intersecting identities and different forms of oppression impact the discrimination of people who are marginalised in multiple ways. However, an intersectional approach needs to be applied in all the following priorities.

What are the information gaps, and how can they be addressed?

- ▶ How do multiple forms of oppression interact with each other and exacerbate the social marginalisation of neurodivergent people?
- ▶ How does a person's identity affect the formal process of identifying they are neurodivergent?



People subconsciously partake in these faulty systems and internalise them and the potential to discriminate. In my case, my race, gender, and recently identified neurodivergence were at stake. They were always considered a fault within an institution where the default of acceptance was never someone who looked like me.



- Advisory Group





How can we overcome stigma toward neurodivergent people?

Why is this important?

Stigma is a complex concept, which can be defined as a combination of the following interconnected processes: labelling, stereotyping, status loss, and discrimination.¹⁰ The term “stigma” encompasses three elements: problems of knowledge (ignorance), problems of attitudes (prejudice), and problems of behaviour (discrimination).¹¹

Stigma towards neurodivergent people is common and can be observed at a group and individual level.¹² This leads to very negative impacts on many aspects of life, for example, poor mental and physical health or social belonging. Overcoming stigma is essential to improving the lives of neurodivergent people, and research on how to reduce stigma is urgently needed.

What are the information gaps, and how can they be addressed?

- ▶ What are the causes of stigma toward neurodivergent people?
- ▶ How can we better understand how stigma toward neurodivergent people is perpetuated within society?
- ▶ How do cultural norms and beliefs shape stigma toward neurodivergent people?

“Attitudes from other people created barriers for me. Because they didn’t understand my neurodivergence. Their attitudes then caused my mental health to decline, and this has stopped me from socializing.”

- Advisory Group





What are the most effective ways of supporting neurodivergent people in understanding and advocating for their own needs?

Why is this important?

Culturally constructed norms and values often become internalised, and neurodivergent people often find it difficult to build an understanding of their own needs. Furthermore, these cultural norms are interwoven into all aspects of society and public services, e.g., schools, employment, healthcare, etc. Without an understanding of one's own needs and rights, it can be difficult for people to advocate for them. This can lead to disadvantages in education, employment, and healthcare, deterioration of mental health, and an increase in the likelihood of being abused.



When I was working at a help desk a while ago, I experienced a lot of anxiety and fear of getting something wrong. Having to talk to people was hard, and it was a fast-paced environment. I suspect that if I had more self-knowledge back at the time, it wouldn't be as difficult as I would be more aware of my needs.



- Advisory Group

What are the information gaps, and how can they be addressed?

- ▶ How can professionals, for example; teachers, employers, or healthcare professionals support neurodivergent people in building an understanding of their needs and advocating for them?
- ▶ How does the identification/diagnosis of neurodivergence help people to develop self-knowledge and identity?



What is the relationship between unidentified or undiagnosed neurodivergence and mental health issues?

Why is this important?

A lack of self-awareness about being neurodivergent can have negative effects on a person's mental health. It can create difficulties in self-understanding of a person's needs and experiences. This often leads to burnout, masking, and a lack of a sense of social belonging, which substantially increases the risk of mental health issues and suicide. Research shows that learning about being neurodivergent at a younger age can help people make sense of their experiences and improve their well-being.¹³ Therefore, the identification or diagnosis of neurodevelopmental differences is crucial for preventing mental health issues among neurodivergent people.

“**Undiagnosed/ unidentified neurodivergence can lead to worsening mental health. The mental health conditions are often seen before neurodivergence, and both need to be addressed together.**”

- Advisory Group



What are the information gaps, and how can they be addressed?

- ▶ What is the overlap between the presentation of neurodivergent traits and symptoms of mental health conditions?
- ▶ What are the consequences of misdiagnoses of neurodevelopmental differences and mental health conditions?
- ▶ Do mental health professionals have a good understanding of neurodivergence and its links to mental health?



How can we develop joined-up services for neurodevelopmental differences and mental health?

Why is this important?

Neurodevelopmental differences and mental health are closely interlinked. This interconnection often has a considerable impact on neurodivergent people's lives. Research shows that 8 in 10 autistic people meet the criteria for a mental health condition at some point in their lifetime.¹⁴ Therefore, all neurodevelopmental and mental health services should be prepared to provide support for neurodevelopmental differences and mental health at the same time.

What are the information gaps, and how can they be addressed?

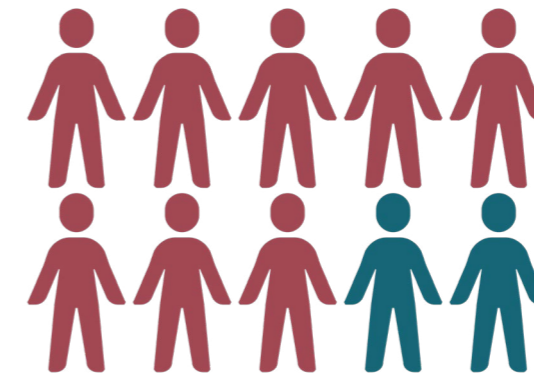
- ▶ Do we already have adequate resources and training for those working in the mental health sector to ensure that mental health support can be tailored to neurodivergent populations? How can they be disseminated/adopted more widely, and how can they be improved?
- ▶ How can mental health workers be better supported to recognise neurodivergence and adapt their work to neurodivergent populations?
- ▶ How can we design services that acknowledge the close link between mental health and neurodivergence and are prepared to address them together?



The mental health condition is often seen before the neurodevelopmental differences, and both need to be tackled together. Where is the joined-up thinking within these services in the NHS?



- Advisory Group



8 in 10 autistic people meet the criteria for a mental health condition at some point in their lifetime.



What barriers do neurodivergent people face when accessing mental health services, and how can we effectively overcome these barriers?

Why is this important?

Neurodivergent people are at an increased likelihood of developing mental health issues. However, they often encounter many barriers in accessing adequate mental health support. Existing research illustrates that the difficulties in accessing mental health support arise from being dismissed or disbelieved on the basis of being neurodivergent.¹⁵ Additionally, mental health support services are predominantly structured for neurotypical people and rarely accommodate the needs of neurodivergent people. This can result in neurodivergent people being unable to get appropriate mental health support, which can have very serious consequences on their lives.

“**[Local Mental Health services offered me] a 6-week group DBT even though I said I struggled with groups due to being autistic. They insisted. I went and I got badly triggered and distressed. They ignored me. When I wrote and said I could not do this, they said it was this or nothing else. There are no accommodations available for someone who is autistic.**”

- Advisory Group

What are the information gaps, and how can they be addressed?

- ▶ How can we effectively and efficiently implement mental health services that would accommodate the needs of neurodivergent people?
- ▶ How can we effectively implement person-centred mental health support for neurodivergent people?





How can we improve access to benefits and social care support services for neurodivergent people?

Why is this important?

Neurodivergent people are at an increased risk of experiencing mental health problems, especially anxiety, depression and physical health issues. These compounding issues, along with fatigue and burnout, may impact their capacity to obtain and sustain income.¹⁶ Lack of appropriate mental and physical health support and a largely unsuitable UK labour market result in many neurodivergent people being unable to work. Access to benefits and social care support is vital for those people. However, the process of applying for benefits and other social care support is difficult and inaccessible to many neurodivergent people, and the system pushes many people into destitution. We need to ensure that neurodivergent people who are unable to work can easily access benefits and other social care support.

“ It’s hard to make a claim for PIP because it’s done just via a written form, with too many questions. It’s hard for me to write about my disability, I find it easier to talk about it. ”

- Advisory Group

What are the information gaps, and how can they be addressed?

- ▶ What are the impacts of unsuccessful benefit claims on the lives of neurodivergent people?
- ▶ What social care support are neurodivergent people entitled to, and how can we make the process of applying for them easier?



How can we develop and implement joined diagnostic pathways for all neurodevelopmental differences (e.g., ADHD, Autism, Developmental Language Disorder (DL), Dyslexia, Dyspraxia, Foetal Alcohol Spectrum Disorder (FASD), and Tourette’s Syndrome)?

Why is this important?

Getting a diagnosis can be a vital first step in developing self-knowledge, finding the right support, and overcoming difficulties in life. However, getting a diagnosis in the UK is a long and difficult process. People often have to wait years to get an assessment, and if they don’t meet the threshold for the diagnosis, they have to go on another waiting list for a different diagnosis and spend years before the next assessment. Additionally, research shows that neurodevelopmental diagnostic categories do not reflect the day-to-day experiences of neurodivergent people and are not well suited to guide and inform support.¹⁷ This results in many neurodivergent people not having access to a formal diagnosis. Neurodevelopmental diagnostic pathways for all neurodevelopmental differences could save people time and make the process of navigating the diagnostic system easier and more inclusive.

What are the information gaps, and how can they be addressed?

- ▶ What are the barriers to joining up services beyond a focus on a single diagnosis?
- ▶ Are joined-up services more cost-effective and preferable to stakeholders? Do they result in better outcomes for service users?



How can we support schools and colleges in facilitating inclusive environments for neurodivergent students?

Why is this important?

Every child has the right to an education, and schools need to be inclusive for all children. However, school and college environments often directly or indirectly discriminate against neurodivergent children. Research shows that neurodivergent children are at increased risk of school exclusion¹⁸ and face poor outcomes in academic achievements and emotional well-being compared to neurotypical peers.¹⁹

This creates a social injustice issue, in which some children get better access to education than others, and leads to many disadvantages beyond education, for example, unequal access to employment or social isolation.

“ There is a lack of understanding of neurodivergence among teachers and other staff. My children are not allowed to fidget in a classroom, and that could help them to relieve their anxiety. They are not even allowed to leave the classroom and get water during lessons. ”

- Advisory Group



What are the information gaps, and how can they be addressed?

- ▶ What elements/factors lead to discrimination of neurodivergent children in schools, and what are effective ways of removing them?
- ▶ Do educators have a good understanding of neurodivergence and how it manifests in the classroom? Is their understanding evidence-based and aligned with lived experience or based on myths/prejudice/outdated information?
- ▶ Do we have adequate resources and training to improve educators' understanding of neurodivergent populations? How can they be disseminated/adopted more widely, and how can they be improved?
- ▶ Which school policies can foster inclusive environments for neurodivergent children? Which school policies achieve the opposite and need to be reconsidered (e.g. exclusions, zero tolerance, etc.)?

10

What are the most effective ways of assessing the needs of and providing adequate support to neurodivergent pupils in schools and colleges?

Why is this important?

All children have different needs and require different support to succeed academically, feel safe, and create friendships in school. However, education systems in the UK and elsewhere are tailored to neurotypical children and often do not accommodate the needs of neurodivergent children. Research shows that many neurodivergent children experience distress and subsequently are denied access to education.²⁰ To ensure the emotional well-being of and chances to succeed academically for neurodivergent children, we need to urgently identify how to accommodate their needs and provide adequate support in education.

“**In education, specifically college, I was not given the correct support for my needs. I was told that I didn't need support because I wasn't physically disabled. When, in fact, I needed the support to help me to keep up in class, for example, I needed someone to take notes for me. I also needed the support to help me on an emotional level as well as an academic level. This prevented me from reaching my full potential because sometimes I wouldn't be able to complete work given because I had no help from a support worker.**”

- Advisory Group

What are the information gaps, and how can they be addressed?

- ▶ Are universal screening approaches needed/useful?
- ▶ Are profiling tools needed/useful?
- ▶ What are the training needs of educators to enable them to better identify and support neurodivergent pupils?



Process of Identifying Research Priorities

The list of the Top 10 Research Priorities was created over three stages: Participatory Research with the Advisory Group, Research Priority Setting Survey, and Research Priority Setting Workshop.

Participatory Research with the Advisory Group

We organised the Embracing Complexity Advisory Group to build a meaningful partnership with neurodivergent people and to co-design the research with them. The group consisted of 6 neurodivergent people with different diagnostic statuses. We consulted all members of the Advisory Group on inclusive research methods for them and conducted qualitative research in a variety of ways: 1-1 in-person interviews, email exchanges, and voice recording.

We carried out a thematic analysis of the contributions and identified three key themes: attitudes, social systems, structures and diagnosis, and identification of neurodivergence.

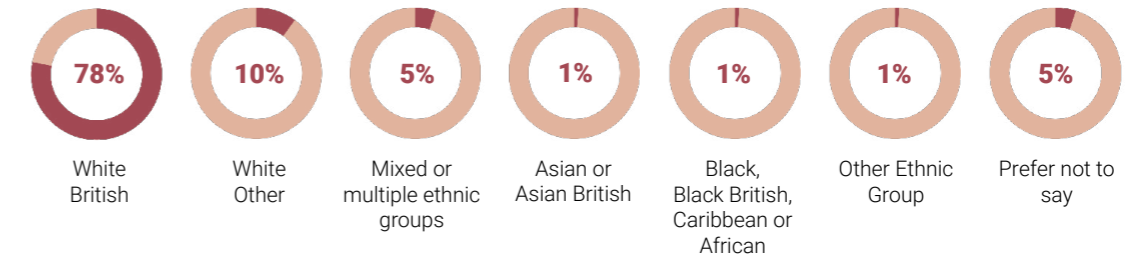
The iterative process of working with the advisory group resulted in a list of 36 research priorities.

Research Priority Setting Survey

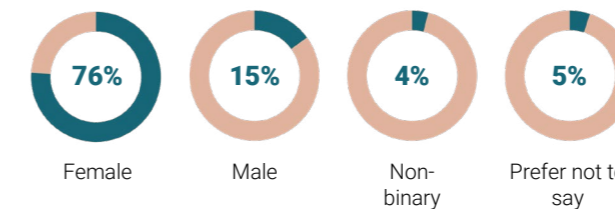
As the next step, we created a survey with the 36 priorities. The aim of the survey was to identify the top 20 research priorities. The survey was open from the 3rd of November until 17th of December 2023. We promoted the survey by contacting various people within our network. We created two versions of the survey: Standard and Easy Read. In total, 231 people responded to the survey.

Demographic representation of survey respondents

Ethnicity:



Gender:



Age: The respondents reflected different group ages.

Area of residency: The respondents reflected the UK population across different areas of residency apart from Northern Ireland.

Research Priority Setting Workshop

In January 2024, we held an online workshop to discuss the top 22 research priorities identified in the survey and identify the top 10.

27 people attended the workshop and represented the following stakeholder groups:

Neurodivergent People, Their Family and Carers, Academic Researchers, Educational Professionals, Mental Health Professionals, and Speech and Language Therapists.

Prior to the workshop, participants were sent the list of 22 research priorities and were asked to think about their top 5 priorities and bottom 3 priorities.

The workshop was split into two sessions. During the first session, attendees were split into four small groups (5-8 people) and discussed their perspectives on 22 priorities. During the second session, all groups did the ranking of all priorities.

During the workshop, we reached a consensus on the top 5 and bottom 2 priorities.

To finalize the ranking and establish ranks from 6 to 20, we created a survey and invited all participants to rank the remaining priorities.

The results from the workshop and the follow-up survey resulted in a ranked order of all priorities.



Strengths and Limitations of the Process

Research silos produced by pre-defined diagnostic categories are often a barrier to improving the lives of neurodivergent people. We aimed to overcome this barrier by including people with different diagnostic statuses and communication needs. This allowed us to build an understanding of the overlap between the day-to-day experiences of neurodivergent people with different diagnostic statuses and create a list of priorities that cross diagnostic boundaries.

A lack of representation of people with Foetal alcohol spectrum disorders (FASD), learning disability and Down's Syndrome in the advisory group resulted in not having the voices of these communities included in the design stage of the priority setting. Another limitation of the study can be observed in the underrepresentation of ethnic, sexual and gender minorities among survey respondents and workshop attendees.

Other Priorities

During the workshop, attendees reported that it's difficult to deprioritise some of the priorities because all of them are very important to them. However, the purpose of the workshop was to identify the top 10.

Below, there is a list of priorities that were ranked from 11 to 22.

Rank 11

What are the reasons for diagnostic overshadowing faced by neurodivergent people, and what are the most effective methods of overcoming it?

Rank 12

How can we improve understanding of neurodivergence among mental health professionals to make sure that the needs of neurodivergent people are listened to and met?

Rank 13

What skills and knowledge do mental health professionals need to identify neurodevelopmental differences (e.g., Autism, ADHD, and others) when neurodivergent people access mental health services?

Rank 14

How effectively do neurodevelopmental diagnostic categories (e.g. Autism, ADHD, Developmental Language Disorder (DLD), Dyslexia, Dyspraxia, Foetal Alcohol Spectrum Disorder (FASD), and Tourette's Syndrome) map out the support needs of neurodivergent people?

Rank 15

What are the most effective methods of creating inclusive work environments?

Rank 16

How can we improve the way the key stakeholders (e.g. parents, teachers, teaching assistants, senior management of schools, SENCOS, councils) work together to ensure the emotional well-being of neurodivergent children in schools?

Rank 17

How can we effectively improve the experiences of neurodivergent people in contacting healthcare services?

Rank 18

What are the impacts of receiving a neurodevelopmental diagnosis on the outcomes of neurodivergent people?

Rank 19

What are the most effective methods of supporting neurodivergent people in Higher Education?

Rank 20

How does knowledge of neurodiversity amongst schoolchildren and school staff impact attitudes to neurodivergence, and how can we improve it?

Rank 21

How can we overcome indirect and direct discrimination against neurodivergent people in job recruitment processes?

Rank 22

How can we evaluate the effectiveness of training for school and college staff on the inclusion of neurodivergent students?

Call to action

We need support from coalition member charities, researchers, funders, services and other partners to make progress on these research priorities.

- ▶ Members of the coalition should promote these priorities and the approach that moves beyond diagnostic categories among researchers, research funders, and commissioners.
- ▶ Members and funders should commission or support research informed by the priorities of the community.

Coalition commitment

- ▶ The coalition will feed into an impact report focused on these priorities, outlining progress made and areas for development.
- ▶ The coalition will engage funders and other partners with these priorities and will share progress and updates and host webinars to explore the priorities.

Appendix

Terminology

Our research approach attempts to “move away from pre-defined diagnostic labels”.²¹ Therefore, it involves engaging with the boundaries of what our work and purpose includes and excludes, and we decided that the term “neurodivergent” best serves the purpose of our work.

Neurodiversity is a term that emerged in the Autistic online community in the 1990s and was brought into the academic discourse by Judy Singer in 1998.²²

Marginalisation refers to the treatment of a person or group as inferior and leads to exclusion from society.

Participatory Research is a form of research that is planned and conducted with the people whose lived experience is under study. The premise of participatory research is that it is done with the community, not on the community. The term describes the fact that all people vary in the ways they process information, behave, or experience their environment and that there is no right or wrong way of being.

The term **neurodivergent** was coined by Kassiane Asasumasu, who declared that “neurodivergent refers to neurologically divergent from typical” and that “it is specifically a tool of inclusion”.²³

Neurodiversity describes the fact that all people vary in the ways they process information, behave, or experience their environment and that there is no right or wrong way of being.

Following the terminology of neurodiversity, some people are considered to be **neurotypical** and others to be **neurodivergent**.

Diagnostic overshadowing refers to a judgment bias where healthcare professionals mistakenly attribute clinical symptoms of physical illness (e.g. pain, hypertension) to manifestations associated with neurodivergence.

Intersectionality refers to the social, economic, and political ways in which systems of oppression and privilege (such as gender, gender expression, race, and others) connect, overlap, and influence one another.

Masking refers to a conscious and unconscious process of hiding neurodivergent traits. Masking is a strategy to avoid stigma.²⁴

Marginalisation refers to the treatment of a person or group as inferior and leads to exclusion from society.

Participatory Research is a form of research that is planned and conducted with the people whose lived experience is under study. The premise of participatory research is that it is done with the community, not on the community.

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