

Beyond diagnosis: setting research priorities with the neurodivergent community

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Beyond Diagnosis: Setting Research Priorities with the Neurodivergent Community

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Abstract

Neurodiversity research remains heavily shaped by diagnostic categories, which increasingly appear inadequate for capturing the complex, lived realities of neurodivergent people. These categorical labels often obscure the social and structural barriers that shape daily experiences and limit the utility of research for designing inclusive services. Responding to this gap, our study sought to establish community-led research priorities that transcend diagnostic boundaries. Employing a rigorous, three-stage process – comprising participatory research, a large-scale survey, and a stakeholder workshop – we engaged neurodivergent individuals with diverse diagnostic and self-identified experiences throughout. The resulting top ten priorities expose embedded systemic barriers across mental health, education, social care, welfare, and neurodevelopmental services. Crucially, they also highlight forms of marginalisation that cut across diagnostic lines, including intersectional stigma, institutional discrimination, and exclusionary service models. Our study makes two key contributions: first, it foregrounds research priorities generated by neurodivergent communities themselves; second, it proposes an urgently needed shift in research practice – towards models that centre lived experience, challenge categorical norms, and attend to the structural dimensions of exclusion. By disrupting the diagnostic status quo, this project offers a more inclusive and socially grounded agenda for neurodiversity research.

Lay Abstract

Much research about neurodivergence focuses on formal diagnoses such as autism or dyslexia. But many neurodivergent people feel these labels don't reflect their real experiences or help improve services. This project asked neurodivergent people from different backgrounds what research should focus on instead. Through workshops, surveys, and discussions, they identified the top ten priorities for future research. These include addressing problems in mental health care, education, and social services, as well as tackling discrimination and stigma. The project shows how research can be more inclusive by listening directly to neurodivergent people, rather than relying on narrow diagnostic categories.

Keywords

neurodivergence, priority-setting, diagnostic categories, participatory methods, social inclusion, intersectionality

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Introduction

Neurodiversity, Diagnostic Categories, and Models of Disability

Neurodevelopmental diagnostic categories such as ADHD, autism, developmental language disorder (DLD), dyslexia, dyspraxia, foetal alcohol spectrum disorder (FASD) and Tourette's Syndrome are deeply embedded in how neurodivergence is conceptualised and studied (Astle et al., 2022). Diagnostic labels impose a structure on service provision and research and often dictate the availability of support

(Astle et al., 2022). Receiving a diagnosis can improve self-acceptance (Leedham et al., 2020), self-compassion (Lilley

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et al., 2022) or self-understanding (Cage et al., 2024). However, many neurodivergent individuals either receive multiple diagnoses or remain undiagnosed, highlighting the limitations of these categories in capturing the full diversity of experiences. A report by Embracing Complexity (2019a) found that 67% of respondents had multiple diagnoses or believed they met the criteria for more than one diagnostic category. Furthermore, evidence indicates that autism diagnosis rates in England are significantly higher among children (O’Nions et al., 2023), and subsequent exploratory projections suggest that between 59% and 72% of autistic individuals remain undiagnosed (O’Nions et al., 2023).

The concept of neurodiversity, developed within the online autistic community during the 1990s (Botha et al., 2024), describes how all humans vary in the ways they process information and experience the world (Fletcher-Watson, 2022). The term ‘neurodivergent’ was coined later by Asasumasu (2016) to describe a group of people whose ‘brains diverge’ from the dominant standards. With clear synergies with other theories of social justice, such as critical race theory (Delgado & Stefancic, 2000), the neurodiversity paradigm reframes neurodivergence as a result of societal power dynamics between neurotypical and neurodivergent individuals (Chapman, 2020), advocating for depathologisation and alignment with the social model of disability. In this way, it challenges deficit-based perspectives, emphasising the strengths and unique contributions of neurodivergent people while addressing systemic barriers to inclusion (Walker & Raymaker, 2021).

The field of neurodiversity remains relatively new and continues to evolve, with multiple interpretations and approaches emerging across research and practice (Dwyer, 2022). One area of ongoing debate concerns the definition and utility of the term *neurodivergent*. While the term lacks a universally agreed-upon definition and is subject to critique regarding its practical application (Dwyer, 2022; Ne’eman & Pellicano, 2022), it remains a useful collective descriptor for a broad group of individuals who are frequently the focus of neurodevelopmental research (Fletcher-Watson et al., 2021). Drawing from a socio-cultural perspective, some scholars argue that neurodivergence must be understood in relation to the cultural construction of cognitive normality (Legault et al., 2021).

Consistent with this paradigm, we use the term *neurodivergent people* throughout this article to refer to the group for whom this research priority-setting initiative was designed. This decision reflects the position of the Embracing Complexity coalition, which has sought to move away from clinical and diagnostic language, such as ‘neurodevelopmental conditions’ – towards a needs-led, barrier-focused framework (Ostaszewska & Sapiets, 2024). While originally using the term ‘people with neurodevelopmental conditions’ to describe the community it supports, the coalition recognised that this terminology is grounded in clinical discourse and inadvertently reinforces the boundaries of diagnostic

categories. As a result, the shift to using *neurodivergent people* represents a deliberate attempt to centre individual needs rather than diagnostic labels. For the purposes of this project and Embracing Complexity’s wider work, our working definition of ‘neurodivergent’ was to describe a group of people whose ways of processing information, behaving, and experiencing the environment differ from the neurotypical majority (Embracing Complexity, 2024).

However, like the broader disability population, the neurodivergent population is also diverse (Hillary, 2020). The coalition was composed predominantly of organisations working with individuals whose neurodivergence overlaps with neurodevelopmental diagnostic categories such as Autism, ADHD, DLD, Down’s syndrome, dyslexia, dyspraxia, dyscalculia, FASD, learning disabilities, and Tourette’s. Accordingly, while we acknowledge that *neurodivergent* can be used more broadly, our use of the term in this context refers specifically to those whose experiences align with neurodevelopmental disabilities. This framing aligns with the overarching goals of Embracing Complexity: to identify and remove systemic barriers and to advocate for inclusive practices that support the full participation of neurodivergent people in society. At the same time, we remain sensitive to the diversity of individual preferences regarding terminology and recognise that no single term will be universally accepted or applicable across all contexts.

The focus of the current research sits within the neurodiversity framework and explores systemic barriers and strategies to address them. While acknowledging that some challenges faced by neurodivergent individuals stem from individual factors, creating inclusive environments can substantially improve their lives (Mandy, 2023). Despite progress in societal attitudes and policies (Leadbitter et al., 2021), the deficit-based medical model of disability remains dominant within neurodivergence studies and services, and influences research priorities, societal narratives, and policy development, often to the detriment of neurodivergent individuals (Chapman, 2020).

Viewing neurodivergence through diagnostic categories presents two key limitations. First, much condition-specific research adopts a medical model, prioritising deficits and treatment over environmental adaptations (Pellicano & den Houting, 2022). This perspective risks reinforcing stigma and marginalisation while offering a limited account of how environmental disabling factors shape neurodivergent experiences (Mandy, 2023). Second, although neurodivergent perspectives are increasingly recognised as essential to research in this field, study design and eligibility criteria are often determined by diagnostic classifications (Cristescu et al., 2024; Kulkarni et al., 2022; Manning et al., 2025; Pellicano et al., 2014). Consequently, such research may exclude individuals whose experiences do not align with a specific diagnostic label, thereby limiting the scope and applicability of the findings. Additionally, research on neurodivergence is often not situated within the broader context of disability,

nor examined through the political and economic conditions that shape disablement (Jones & Orchard, 2024). This study aims to address these limitations.

Research Priorities of Neurodivergent People

In recent years, there has been an increasing recognition that for neurodivergence research to be impactful, it must meaningfully involve neurodivergent individuals and reflect their priorities (Embracing Complexity, 2019b; Fletcher-Watson et al., 2019). To identify these priorities, researchers conduct research priority setting exercises, which usually involve people with lived experience, families and carers and relevant professionals. However, these priority settings are usually shaped by neurodevelopmental diagnostic categories and focus on people who either have or self-identify with a specific diagnosis. For example, autism (Cusack & Sterry, 2017; Pellicano et al., 2014); DLD (Royal College of Speech and Language Therapists, 2019); dyslexia (Manning et al., 2025), and Tourette syndrome (Isaacs et al., 2024). These research priority-setting initiatives have an enormous value in identifying priorities of specific communities. However, by focusing on specific diagnoses they often tend to identify predominantly a need for research into ‘treatments’ for a specific group, for example, interventions to improve mental health for autistic people (Cusack & Sterry, 2017); evidence-based DLD interventions (Royal College of Speech and Language Therapists, 2019); or developing more effective treatments for tics (Isaacs et al., 2024). However, by centring on individual diagnostic categories, these approaches risk reinforcing issues posed by the medical model of disability, which locates the source of difficulty within the individual rather than within broader social and systemic contexts.

Two priority-setting studies have been carried out on wider groups of neurodivergent people and thus go beyond diagnostic labels: Lim et al. (2019), who included children with any condition which affected learning, and Morris et al. (2015), who focused on children with neurodisability. Lim et al.’s three top priorities were education-focused: upskilling education professionals, the education and community environment and multidisciplinary practice and working with parents. In contrast, Morris et al.’s priorities related more to treatments: to establishing the optimal frequency and intensity for mainstream therapies, the means for selecting and encouraging use of communication strategies and improving children’s attitudes towards disability. While both studies are somewhat relevant to the current research, both included people who would not identify as neurodivergent while also excluding some who would. Both also focused on children and young people, with parents and clinicians making up the majority of participants. Therefore, conducting a research priority study to focus on the needs and views of neurodivergent adults is a valuable addition to the literature.

Current Study

There is an urgent need for researchers and research funders to explore alternative approaches to neurodivergence research. This study aimed to adopt a broader approach than previous research by working with neurodivergent individuals across diagnostic categories and beyond their boundaries to better understand their perspectives and priorities for neurodivergence research. Given the limitations of diagnostic labels in capturing the diverse experiences of neurodivergent individuals, along with shared experiences of stigma and social exclusion, this broader approach is valuable as it has the potential to provide deeper insights into the experiences and needs of the neurodivergent community. To our knowledge, this is the first research priority-setting focused on neurodivergence as a whole, which moves away from pre-defined diagnostic categories in the context of increasing interest in the neurodiversity framework.

In practice, while this priority-setting exercise was designed to centre the views and experiences of neurodivergent people, it also drew from the insights of a broader community including relatives, carers, and a range of different groups of professionals supporting neurodivergent people. The methodology section below provides further detail on which of these stakeholder groups participated in which stages of the process.

The primary research question was: *What are the research priorities of neurodivergent people in the field of neurodiversity?* This work seeks to inform a more inclusive and impactful research agenda, addressing the limitations of deficit-focused, diagnosis-specific approaches and advancing the broader aims of the neurodiversity paradigm. Embracing Complexity was a coalition of organisations collaborating to facilitate the evidence-based inclusion of neurodivergent individuals. As part of its priority-setting process, the coalition aimed to identify barriers faced by neurodivergent people within both service provision and broader societal contexts. Prior to data collection, participants received explanatory materials outlining the concept of systemic barriers and were informed that their responses would inform the development of future research questions. This process aimed to identify the most pressing challenges faced by neurodivergent individuals – challenges that research must address in order to support meaningful change.

Methods, Data Collection and Analysis

This study employed a combination of qualitative and quantitative methods for a three-stage research-priority-setting process: (1) an initial qualitative priority-setting stage, (2) a quantitative prioritisation survey, and (3) a quantitative workshop prioritisation. Input and feedback were sought throughout the process from a Steering Group, comprising

Table 1. Summary of the Priority Setting Process with Numbers and Types of Participants at Each of the Three Stages.

Stage	Method	Total participants	Neurodivergent individuals	Parents/ carers	Professionals (incl. researchers)	Other notes
Stage 1	Advisory group	6	6	0	0	All members neurodivergent
Stage 2	Survey	231	106	78	293*	Participants could tick multiple identities
Stage 3a	Workshop Session 1	24	5	2	17	Some attendees held multiple roles
Stage 3b	Workshop Session 2	26	5	2	19	

Note. *Number of professionals is higher than total number of participants due to overlap between categories, for example, health professional, occupational therapist, diagnostician. See Appendix 4 for a more detailed breakdown.

academic researchers and member organisations of the Embracing Complexity coalition.

Table 1 provides an overview of the three stages and the number and type of participants involved in each stage.

Ethical Considerations

As this project was not originally designed as academic research, it did not undergo formal review by a university ethics committee. However, all work was carried out in line with the high ethical standards of Autistica and the Embracing Complexity coalition, including informed consent, accessibility, and participant wellbeing. We also confirmed with the journal prior to submission that this approach met their requirements for ethical conduct in research.

Stage 1 – Initial Priority Setting

Participants. At the outset, we formed the **Embracing Complexity Advisory Group**, consisting of six neurodivergent individuals (pseudonyms: Grace, Liz, Luke, Sophie, Alex and Damo) with diverse diagnostic profiles. The Advisory Group was established to foster meaningful partnerships with the neurodivergent community and ensure their involvement from the inception of the research. Participants were recruited through social media and via member organisations of the Embracing Complexity coalition. During the recruitment process, we asked applicants to select if they had, didn't have, or were on the waiting list for a formal neurodevelopmental assessment. Of the six members, three reported multiple diagnoses, two had one formal diagnosis but identified with multiple diagnostic categories, and one was on a waiting list for assessment. Participants had formal or self-identified diagnoses, or were awaiting assessment for autism, ADHD, DLD, dyscalculia, dyslexia, dyspraxia, and Tourette's. Among participants who received a formal diagnosis(es): two were diagnosed in early childhood (under five years), one between 14 and

18 years, one between 18 and 24 years, and one between 45 and 54 years.

We aimed to include participants with intersecting identities and a range of experiences across the United Kingdom. To ensure that this was the case, we asked applicants to answer six demographic questions to ensure diversity across several dimensions. These questions covered ethnicity, LGBTQA+ identity, area of residence in the United Kingdom, employment status, highest education level, and whether they had any physical or mental health conditions, including the extent to which these conditions affected their daily life (see Table 2). We were fortunate that our applicants did indeed represent varied and intersecting identities in line with our aims.

Procedure. In the first stage of the priority-setting process, we employed participatory research methods (Nicolaidis et al., 2011) to co-design the project (Fletcher-Watson et al., 2024). Building trust was essential to creating meaningful collaboration and facilitating an inclusive research environment (Fletcher-Watson et al., 2021). To establish this, we provided participants with an introductory resource pack outlining the project's aims, collaboration purpose, and a glossary of potentially unfamiliar terms. Participants had the option to have an informal meeting with the lead researcher to ask questions and discuss expectations. We set expectations for our project and sent participants a 'research passport', which explained the process and included a set of questions to identify communication and participation preferences (see Appendix 1). Participants expressed that having these resources would help ensure that inclusive research methods were used, which we provided prior to data collection. To promote equality and transparency, the lead researcher also completed the resource and shared it with participants. The advisory group was offered the option of participating individually or as a group. However, all members expressed a preference to participate individually, so this was the method undertaken. While the initial draft of the key research question was

Table 2. Ethnicity, Employment, Education, Geography and Health Status of the Advisory Group Members.

Category	Description of members
Ethnicity	Five participants identified as White (Scottish, English, Northern Irish, or Welsh), and one identified as Black
Employment	Two participants were in part-time employment, one was self-employed, one was unemployed but not seeking work, one was unemployed and seeking work, and one was a student
Education	Four participants completed college or university, and two held postgraduate degrees
Geographic diversity	Two resided in East Anglia, two in Yorkshire and Humberside, one in the Southeast, and one in Greater London.
Health conditions	Two participants reported no health conditions, one reported a significant impact on daily life, one reported a minor impact, and one preferred not to disclose.

developed by the research team, it was shared with the Advisory Group for feedback and refinement prior to data collection. This collaborative shaping of the guiding question reflects our commitment to co-design and participatory research practices.

Data collection and analysis. Before data collection, we explained to the group that the project's focus was to identify systemic barriers faced by neurodivergent people and effective ways to remove these barriers. To identify these barriers, we asked participants to respond to the following question:

What systemic barriers or obstacles have you encountered in your life that prevented you from doing something or getting something you needed? (This is about barriers that you believe are rooted in the systemic exclusion of neurodivergent people).

Participants responded using various methods: in-person and online semi-structured interviews, via email and a voice recording. Verbal data was transcribed and combined with the written contributions. Summaries of all responses were anonymised and shared with participants for validation. After we received feedback, we conducted a thematic analysis (Braun & Clarke, 2006). The analysis was carried out by the first author and checked by the second author. The thematic analysis was iterative, and participants were asked for feedback throughout the process. Before beginning the coding process, we familiarised ourselves with all the data and identified keywords that reflected different barriers (e.g. the lack of support and systems, e.g. schools; see Appendix 2 for an overview of the codes, themes and sub-themes identified in the process). We used an inductive approach to theme development, which allowed us to identify codes directly from the data (Braun & Clarke, 2006). This process involved assigning barriers and systems highlighted in keywords into codes. To develop themes, we identified and grouped patterns across different barriers.

For example, a lack of understanding of adjustments provision among service delivery professionals and a lack of knowledge among general practitioners and mental health professionals were grouped into one barrier – 'lack of knowledge or understanding of neurodivergence'. Identifying the patterns between different barriers and systems allowed us to connect broader themes. As a result, we identified three top-level themes, which represented three main aspects of barriers: (1) Attitudes; (2) Systems and Structures; and (3) Diagnosis and Identification of Neurodivergence. In a second analytical phase of the qualitative data, a deductive approach was employed to further refine the themes and research questions in alignment with the central aim of the project: to identify key research priorities. Research questions were developed by the first and second authors and were derived from the Advisory Group contributions and informed by the codes and themes from the first stage of the analysis. The Advisory Group was asked for feedback throughout the process. In this phase, we adopted a deductive framework informed by Naeem et al. (2023), whereby the predefined objective – 'priorities for research on neurodivergence' – was used to structure and shape the research questions derived from Advisory Group contributions. To streamline the subsequent phase of the priority-setting process and to ensure clarity and manageability, we consolidated and refined the initial questions by merging similar items and broadening their scope.

The outcome of the qualitative stage of the priority-setting was a list of 36 research priorities (Appendix 3).

Regarding positionality, the first and second authors identify as neurodivergent. The third and fourth authors align with neurodiversity-affirmative approaches in research. Additionally, both first authors work for Autistica, a U.K.-based research charity focused on autism, which has led to a deeper knowledge of autism research compared to other fields, such as ADHD or dyslexia research. As a result, a higher number of autism-focused papers are referenced in this study. All authors align with

the neurodiversity paradigm rather than more medical approaches. The first and second authors brought lived experience to the interpretation of the data. Their positionality informed the framing of questions and the identification of themes, particularly around systemic exclusion and internalised stigma. While this enriched the analysis by grounding it in experiential understanding, steps were taken to ensure reflexivity and mitigate potential bias – including feedback loops with the advisory group, theme validation by a second coder, and discussion among the wider author team with varied professional and personal relationships to neurodivergence.

Stages 2 and 3: Prioritisation: Survey and Workshop

Participants. The prioritisation process consisted of two stages: a survey and a workshop. Participants for the survey were recruited by the member organisations of the Embracing Complexity coalition sharing the survey with their service users and professionals they work with. Respondents were asked to identify the stakeholder group(s) they represented, with the option to select multiple categories where applicable (stakeholder groups included neurodivergent people, families, carers and different groups of professionals supporting neurodivergent people; see Appendix 4 for a full list and count of these groups, as well as other demographic information). To ensure comprehensive engagement with all relevant stakeholders, demographic questions were included at the end of the survey. Aligned with our aim to move beyond predefined diagnostic labels and explore the boundaries of inclusion and exclusion within our work (Embracing Complexity, 2024), we asked only whether respondents were or were not neurodivergent, and did not collect more detailed information on their diagnoses. A total of 231 participants completed the survey.

The second stage of prioritisation involved two workshop sessions, with participants also recruited through our networks. Workshop attendees included representatives from various stakeholder groups, such as neurodivergent individuals, their families and carers, academic researchers, educators, mental health professionals, and speech and language therapists. Several participants identified with multiple stakeholder groups. The first workshop session, held on 19 January 2024, was attended by 24 participants, while the second session, held on 29 January 2024, included two more participants.

Data collection and analysis. Quantitative methods were employed in both stages of the prioritisation process. During the first stage, the survey presented participants with 36 research priorities developed through the initial priority-setting process. The purpose of the survey was to engage a broader group of stakeholders and refine the list of priorities. The survey consisted of three steps:

(1) selecting up to 15 research questions deemed most important, (2) ranking selected priorities from most to least important, and (3) providing demographic information. The survey was conducted using the SurveyMonkey platform, and both *standard* and *easy-read* versions were created with the assistance of a speech and language therapist.

To determine the final ranked list of research priorities, only responses in which both the selection and ranking components were completed were included in the analysis ($n=231$). Data were collated and analysed using Microsoft Excel. For each response, the selected priorities were recorded with a rank value from 1 (*most important*) to 15 (*least important*). Rank frequencies were then calculated for each priority (e.g. Priority 1 was ranked first by 31 respondents, second by 21 respondents, and so on). To calculate an overall score for each priority, a reverse scoring system was applied: a rank of 1 corresponded to a score of 15, a rank of 2 to a score of 14, continuing in this pattern down to a score of 1 for a rank of 15. The total score for each priority was derived by summing these reverse scores. Finally, priorities were ranked in descending order of their total scores, with higher scores indicating greater perceived importance.

Following recommendations in the JLA Guidebook, additional analyses were conducted to ensure equitable representation of all stakeholder groups, regardless of the number of responses from each group. Respondents were permitted to select multiple stakeholder identities, meaning a single response could represent more than one group. To address this, data were categorised into two groups: (1) ‘neurodivergent individuals and their parents/carers’ and (2) ‘professionals’. We grouped these categories together to reflect overlapping lived experiences, particularly where neurodivergent individuals are also parents or carers, while recognising that overlap between all three groups was possible. Results for these two groups were compared to the overall ranking.

A total of 145 respondents identified with the ‘neurodivergent individuals and their parents/carers’ stakeholder group, and 184 identified as ‘professionals’. The results across categories and the overall rankings were broadly similar, and the overall top 20 ranked priorities were taken forward to the next stage as planned. However, one question from the longlist which did not reach the overall top 20 was highly ranked by the ‘neurodivergent individuals and their parents/carers’ group only, and another was highly ranked by the ‘professionals’ group only, so the decision was made to additionally include these in Stage 3. These were: (1) *What is the relationship between unidentified or undiagnosed neurodivergence and mental health issues?* – ranked highly within the professional stakeholder group only – and (2) *How can we improve access to benefits for neurodivergent people?* – which was highly ranked by neurodivergent individuals and their parents/carers only. The resulting 22 priorities are listed in Appendix 5.

The final phase of the overall priority-setting process was a two-day workshop. Before the workshop, participants were provided with the 22 research priorities identified during the survey phase and were asked to review these priorities, recording brief notes on their perspectives and identifying the priorities they considered most and least important. The first session of the workshop was attended by 24 participants, representing a range of stakeholder groups: neurodivergent individuals ($n=5$), parents and carers ($n=2$), researchers ($n=7$), mental health professionals ($n=4$), education professionals ($n=3$), funders ($n=1$), a speech and language therapist ($n=1$), and a diagnostician ($n=1$). The second session included 26 participants, with the addition of two researchers. These categories reflect the primary stakeholder group each participant represented; however, several participants with professional roles also had lived experience of neurodivergence. Attendees were divided into four groups comprising five to eight participants each. On the first day, group discussions focused on each priority, with participants sharing their views. The *Nominal Group Technique* (McMillan et al., 2016), a structured consensus-building method, was employed. At the outset of the workshop, participants were invited to suggest revisions to the phrasing of research priorities or propose merging overlapping priorities. Based on participant feedback, the priority *‘How can we improve access to benefits for neurodivergent people?’* was expanded to encompass a broader scope and reworded as *‘How can we improve access to benefits and social care support services for neurodivergent people?’*. Discussions across the groups revealed recurring themes, particularly surrounding the diagnosis and identification of neurodivergence. This theme emerged as a foundational element of the broader research focus on the social inclusion of neurodivergent individuals.

Data was collected on the second day of the workshop. Attendees ranked the priorities in the same four groups, and ranked priorities from each group were combined. At this stage, ranks 1–5 and 21–22 were consistent across all groups. However, there was a substantial disparity between ranks 6 and 20. Subsequently, data collection methods were adapted and ranks 6–20 were completed with a follow-up survey sent out to all attendees after the second day of the workshop. This was designed and analysed using the same methodology as the rankings performed during the workshop. The final outcome of the priority-setting was a list of the Top 10 Priorities for Research on Neurodivergence. Although the survey provided an initial ranking of 36 priorities, the final order of the top 10 was determined during the Stage 3 workshop and follow-up consensus survey. These sessions involved structured discussion and re-evaluation by a diverse group of stakeholders. As a result, the final ranking reflects collective deliberation rather than a continuation of the survey scores, and may differ significantly from the original survey order.

Results

The three-stage process resulted in the identification of the top 10 priorities for neurodivergence research. This section is structured by the results from the workshop and presents the top 10 identified research areas. To illustrate the full process of the priority-setting we present the results from the qualitative stage and ranks from the survey (the first step of prioritisation). Quotes provide contextual insights into the real-life experiences and subthemes underlying the identified priorities. Some quotes were edited to support clarity for the reader.

Priority 1 – Intersectionality of the Social Marginalisation of Neurodivergent People

(Overall survey rank: 13th, score: 8,683)

The highest-ranked priority underscores the critical importance of an intersectional approach to addressing social marginalisation of neurodivergent people who experience compounded stigma due to their race, gender, sexuality, class, and other intersecting forms of oppression. In the qualitative stage, participants highlighted how these overlapping systems of discrimination create significant barriers to acceptance.

The impact of intersecting oppressions. Participants shed light on the profound impact of intersecting oppressions – racism, sexism, and ableism – on their identity and lived experiences. One participant described how various forms of oppression – such as racism, sexism, and ableism – affect their identity and experiences within society:

I was made to be hyper-aware of my actions when I was younger, and it affected the way I navigated the world. I was constantly trying to move out of the margin, created by the white supremacist, patriarchal and capitalist centre, into that centre that belonged to them and not me. Just wanting to be seen as human, and not loud, aggressive, angry, or strong, just human and diluting bits of my identity just to be seen. And people, whether they are students or teachers, subconsciously partake in these faulty systems and internalise them, and have the potential to discriminate. And in my case, my race, gender and, more recently, neurodivergence were at stake. They were always considered a fault within institutions where the default of acceptance was never someone who looked like me. (Grace)

This contribution illustrates how dominant social norms compelled the participant to carefully monitor their behaviour. This hyper-vigilance illustrates the emotional labour required to navigate spaces that are biased against people from oppressed backgrounds. This contribution highlights how institutional structures perpetuate discrimination, and how intersecting aspects of identity amplify the challenges

they face, as institutions often perceive these characteristics as deficits rather than attributes worthy of respect and inclusion.

Stigma and access to diagnoses. Participants also highlighted how different forms of oppression shape unequal access to neurodevelopmental diagnoses. For example, one participant described how stigma towards Black neurodivergent people shapes the attitudes of minoritised communities towards neurodevelopmental ‘labels’:

For some parents who have the opportunity, it’s a privilege, but if you have the opportunity to get your child screened for certain neurodivergences, there’s an underlying fear of ‘If my child is labelled this, then they’re really going to suffer or they’re going to be treated a lot differently because of the fact that there has been a stigma attached to Black people having neurodivergence/being neurodivergent. (Grace)

Priority 2: Overcoming Stigma Towards Neurodivergent People

(Overall survey rank: 10th, score: 11,865)

The second-ranked priority emphasises the urgent need for effective strategies to overcome stigma against neurodivergent people. In the qualitative stage, participants shared their experiences of pervasive stigma across various public services, including education, employment, welfare systems, and healthcare. Additionally, they shared personal experiences of stigma from peers.

Problems of knowledge (ignorance). A lack of awareness about neurodivergence often hinders educators from meeting students’ needs. One participant described how lack of knowledge about neurodivergence among teachers resulted in unmet needs and subsequently challenges with education:

I need a lot of adjustments, but when teachers don’t know neurodivergence and are stressed as a result of senior leadership putting so much pressure on them to get good grades, their first thought wouldn’t be that a student has a form of neurodivergence but [that the student isn’t] trying hard enough. (Grace)

Problems of attitudes (prejudice). Participants described experiences of prejudice and negative stereotypes, including those perpetuated by staff in educational settings. One participant recounted:

I also remember being told by my parents that when I was first diagnosed, the SENCo said to them [that] I’d never be able to get a job, read, or write. (Luke)

Problems of behaviour (discrimination). Discrimination stemming from negative attitudes was identified in participants’

contributions. One participant described how negative attitudes from their peers impacted their social belonging:

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 socialising. (Liz)

This priority highlights the multifaceted impacts of stigma and underscores the critical need for research exploring interventions to improve awareness, challenge prejudice, and eliminate discriminatory practices across society.

Priority 3: Supporting Neurodivergent People in Understanding and Advocating for Their Needs

(Overall survey rank: 9th, score: 12,513)

The third-ranked priority emphasises the importance of empowering neurodivergent people to develop self-awareness and advocate effectively for their needs. In the qualitative stage, Advisory Group members identified how dominant cultural norms often hinder the development of self-knowledge, self-compassion, and self-acceptance. These barriers can have profound negative effects on multiple aspects of their lives.

Challenges with self-knowledge. Participants shared that a lack of understanding of their neurodivergence can make it difficult to identify and address their needs in various situations. For example, one participant reflected:

Social gatherings can be difficult to cope with and draining. It’s good to know the limits you can deal with, but we have an internalised view that attending social meetings is important and good. (Sophie)

Internalised negative comments and mental health. Participants also highlighted the enduring impact of internalised negative comments on mental health, including anxiety, low self-esteem, and trauma. One participant explained: ‘*I internalised negative comments I received in childhood, which led to lifelong anxiety, lowered self-esteem, and trauma*’ (Sophie).

The effects of masking and external pressures. Another significant challenge identified was the effects of compounding a lack of understanding of one’s own needs and external pressure. One participant shared how this led to masking, which resulted in not getting the support they needed:

The school environment I was in was very much focused on academic education, and as a result, I felt like I needed to be clever or intelligent to be accepted. As a result, I masked or

mirrored what I thought I needed to be to be seen and accepted by tutors and peers. But it gets to the point whereby you mask so much that you're not given the sort of support that you need. I needed support in terms of reading and processing because I'm dyslexic. But I didn't know that at the age of 17. I was overworking to compensate for the lack of systems or solutions in place for me in order to do the work that I needed to do. (Grace)

These accounts underscore the need for research that aims to understand how we can support neurodivergent people in developing self-awareness, overcoming internalised stigma, and provide tools for self-advocacy. Effective support systems must address both individual and systemic factors, enabling neurodivergent people to identify their needs and access appropriate support without fear of judgment or misunderstanding.

Priority 4: The Relationship Between Unidentified Neurodivergence and Mental Health Challenges

(Overall survey rank: 23rd, score: 2,963)

The research area ranked as the fourth highlights the need for developing understanding of how unidentified neurodivergence impacts mental health of neurodivergent people. Participants highlighted a critical issue in the relationship between unidentified neurodivergence and mental health challenges: the focus on mental health symptoms and overlooking unmet neurodivergent needs.

One participant described their experience of seeking help for issues which were rooted in unmet needs, only to have their neurodivergence overlooked:

I went to my GP and they didn't pick up on this stuff (neurodivergence), they picked up on the symptom. They diagnose the symptom, so I was diagnosed with depression and maybe anxiety. But the root cause was the fact that the way I was learning or my way of gaining knowledge wasn't facilitated in the classroom. It just felt a bit disheartening. (Grace)

This quote highlights the problem of the healthcare system addressing mental health symptoms (e.g. depression or anxiety) without identifying the foundational difficulties stemming from their unique learning style and needs. This highlights the broader implications of failing to recognise neurodivergence. It points to the potential for a cycle of unmet needs, where neurodivergent people are left without the targeted support necessary for their well-being.

Contributions also highlighted that self-knowledge can serve as a foundation for identifying strategies to cope with stress, advocate for accommodations, and build resilience. By understanding their neurodivergent experiences – such as how they process information or respond to stimuli

– they can better address potential triggers or challenges that may impact their mental health.

One participant emphasised the importance of personal understanding and awareness in managing mental well-being:

Self-knowledge helps with mental health. (Sophie)

Without access to proper identification and understanding of their neurodivergence, the journey to self-knowledge can be delayed, potentially exacerbating mental health challenges. Thus, this priority highlights both the personal and systemic value of supporting identification of neurodivergence as part of mental health care.

Priority 5: Joined-up Services for Mental Health and Neurodevelopmental Differences

(Overall survey rank: 5th, score: 26,150)

This research priority closely relates to the priority ranked as fourth and highlights the issues with the fragmentation of services for mental health and neurodevelopmental differences. Participants' contributions highlighted a critical issue in the current healthcare and support system: the fragmentation of services for mental health and neurodevelopmental differences. A quote from one participant reinforces the urgent call for joined-up services that break down silos and provide comprehensive, coordinated care for 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. (Sophie)

This priority illustrates the urgent need for research into the design and implementation of integrated services that would consider both mental health and neurodevelopmental differences, together would better reflect the reality that these issues are deeply intertwined. Such an approach would not only improve diagnostic accuracy but also ensure that interventions are holistic and tailored to the individual's needs, ultimately leading to better outcomes.

Priority 6: Overcoming Barriers to Mental Health Services

(Overall survey rank: 4th, score: 33,746)

This research priority highlights the need to address barriers neurodivergent individuals face when accessing mental health services. Contributions from participants illustrate the significant barriers neurodivergent people face when trying to access mental health services. These barriers stem from a combination of limited understanding,

inflexible practices, and a lack of accommodations within the mental health care system. One participant emphasised a foundational issue regarding mental health frontline workers:

Mental health frontline workers have very little understanding about neurodivergence and they don't listen to you. (Sophie)

Another contribution provided a powerful example of how these systemic shortcomings manifest in practice. Despite seeking mental health support for over 20 years, the individual describes a pattern of quick fixes (e.g. medication) rather than meaningful, tailored support. Their experience highlights the rigidity of the system, which often prioritises standard treatments over personalised care, leading to worsening mental health:

I've been trying to access Mental Health Services for over 20 years. They are quick to medicate me (which doesn't work) but do not want to provide any ongoing support ... [Eventually, they gave me] a 4-weeks group [Dialectical Behavior Therapy] even though I said I struggled with groups due to being autistic. They insisted. I went, I got badly triggered and distressed. They ignored me. When I wrote and said I cannot do this, they said it was this or nothing else. (Alex)

This priority underscores the urgent need to overcome barriers to mental health care by increasing awareness of neurodivergence among providers, ensuring active listening and collaboration with patients, and offering flexible, individualised care plans. Without these changes, neurodivergent people will continue to encounter harmful and inaccessible systems instead of the support they need.

Priority 7: Access to Social Security and Social Care

(Overall survey rank: 28th, score: 1,334)

Research area identified as seventh in importance focuses on the need for research addressing access to social security and social care. Contributions highlighted issues of accessibility, inflexibility, and a lack of understanding within these systems. One participant addressed the difficulty of applying for benefits like Personal Independence Payment (PIP), a process that heavily relies on complex written forms:

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. (Damo)

Another participant described the emotional toll of engaging with social support systems. This reflects a broader issue of inadequate training and awareness among social care professionals, whose approach can unintentionally alienate or distress neurodivergent people:

I was always crippled with anxiety when I went to the jobcentre as the guy I would see to help me was actually really abrupt. (Luke)

Participants also highlighted a systemic contradiction: working individuals are often excluded from accessing social care support, even if they are struggling to cope. This creates a vicious cycle where the lack of support makes it harder to maintain employment, increasing stress and pressure on already vulnerable individuals. One participant shared:

If you are working, you are not able to access social care support even if you are struggling to manage to cope. This adds extra pressure making working even harder. (Alex)

Together, these experiences point to a pressing need for research and reform in social security and care systems. Research needs to explore more accessible application processes, training for professionals to foster understanding and sensitivity, and flexible eligibility criteria to ensure support is based on need rather than rigid categorisations. Addressing these barriers is essential to create a more inclusive and supportive system for neurodivergent people.

Priority 8: Need for Joined-up Neurodevelopmental Pathways

(Overall survey rank: 11th, score: 9,839)

The priority points to the pressing need for comprehensive neurodevelopmental pathways capable of addressing the wide range of neurodevelopmental differences, including ADHD, autism, DLD, dyslexia, dyspraxia, FASD, and Tourette's syndrome. The contributions from Advisory Group members highlighted a systemic issue in the current approach to neurodevelopmental identification and diagnoses: they are fragmented, siloed, and often fail to address the lived experiences and holistic needs of neurodivergent individuals. These gaps result in significant challenges both in obtaining a diagnosis and in accessing meaningful post-diagnostic support. An Advisory Group member articulated a core issue underpinning these gaps:

Diagnoses are siloed and don't look at the whole person, but put neurodivergent people into separate categories, which isn't helpful as it means you get support in siloes too. Mental health and neurodivergence are not connected in services either, so again, two different places to get support ... Policy changes needed. (Sophie)

Participants also commented on the reliance on diagnostic labels, arguing that they can oversimplify neurodivergent experiences by focusing on criteria that often fail to capture the full spectrum of an individual's needs. This focus on categorisation can lead to gaps in support, as

services may only address needs that fit narrowly defined criteria. The result is a system that prioritises classification over individuality, leaving many neurodivergent people without access to the support they require. One participant shared:

Diagnostic labels aren't very useful and they reject individuality. Diagnostic criteria mean that not all support needs are addressed. (Sophie)

Participants' contributions also highlighted the lack of meaningful support following a diagnosis. For many, receiving a diagnosis is a pivotal moment. However, rather than providing practical guidance or resources to help people understand and manage their experiences, the diagnosis often serves as a 'label' without actionable insights. One contribution revealed frustration with the lack of meaningful guidance and resources following a diagnosis:

I didn't get my autism diagnosis until I was 47 ... The diagnosis just gave me a label, it didn't help me to understand how the autism was impacting me. Five years later, I'm still trying to work out what is happening. (Alex)

The lack of post-diagnostic support underscores the need for frameworks that go beyond simply assigning a label. Instead, these frameworks should offer practical tools, educational resources, and personalised strategies to help neurodivergent individuals navigate their lives effectively.

Priority 9: Inclusive School Environments

(Overall survey rank: 1st, score: 83,857)

Research priority ranked as ninth illustrates the importance of research into methods of making school environments inclusive for all children and young people.

Participants highlighted different examples of exclusionary practices in educational settings, ranging from barriers in the sensory environment through to behaviour policies which unfairly disadvantage neurodivergent students. One of the significant issues in the inclusivity of school environments for neurodivergent students was a lack of understanding and flexibility among teachers and staff. One participant shared their concern about their children being denied small accommodations that could play a crucial role in them manage their anxiety and stay engaged in the learning process:

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. (Sophie)

This rigid approach can inadvertently exclude neurodivergent students by failing to accommodate their needs

and preferences, which are essential for their well-being and ability to learn effectively.

This contribution points to the broader issue of insufficient training and awareness among educators about neurodivergence. Without a foundational understanding of how neurodivergent students process information, regulate emotions, or manage sensory inputs, school policies and practices may unintentionally marginalise these students.

Priority 10: Providing Adequate Support to Neurodivergent Students in Schools and Colleges

(Overall survey rank: 10th, score: 46,997)

In addition to flexibility in the broader school environment as described above, many neurodivergent students need more proactive, tailored support to reach the best of their abilities in education. The research area ranked as tenth addresses the need for research into effective methods of assessing the needs of, and providing adequate support to, neurodivergent students in schools and colleges. In the qualitative stage, participants shared that they often didn't receive adequate support, which negatively impacted their opportunities for successful learning. One participant described the negative consequences of the lack of proper recognition and support for their needs:

In education, especially 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...This prevented me from reaching my full potential because sometimes I wouldn't be able to complete given work because I had no help. (Liz)

Without appropriate support, neurodivergent students are hindered in their academic performance and personal development. These systems should include thorough assessments of individual needs and the implementation of tailored support measures, instead of uniformity.

This priority emphasises the critical need for research into exploration of how educational systems can expand their understanding of neurodiversity and develop inclusive frameworks that provide equitable support to neurodivergent students.

Discussion

This study aimed to identify research priorities for the social inclusion of neurodivergent individuals using an approach that transcends the boundaries of neurodevelopmental diagnostic categories. The research question facilitated an examination of the social exclusion experienced by neurodivergent individuals, while the methodology enabled an exploration of exclusion within research itself. The findings highlight the need for a critical evaluation of inclusion and exclusion criteria shaped by diagnostic classifications, revealing how

research exclusions often reflect broader patterns of social exclusion. Both the research process and findings underscore the importance of applying neurodiversity and intersectional frameworks to enhance inclusivity in neurodivergence research and strengthen its potential to achieve its overarching goal – overcoming societal barriers.

Intersectional Exclusions

The highest-priority research area underscored the need for an intersectional approach to understanding the marginalisation of neurodivergent people. Intersectionality provides a framework for examining how overlapping systems of oppression – including classism, racism, patriarchy, heteronormativity, cisnormativity, and ableism – shape experiences of social exclusion (Crenshaw, 2018). Scholars have argued that different forms of oppression cannot be considered independently (Bauer et al., 2021) and that applying an intersectional lens to neurodivergence research yields valuable insights into social inequalities (Mallipeddi & VanDaalen, 2022) and the deconstruction of neurodivergence stereotypes (Cascio et al., 2020). Existing evidence highlights the consequences of intersectional oppression; for example, autistic youth experience higher rates of discrimination based on race, gender identity, and disability status compared to neurotypical peers (Menezes et al., 2025). Despite this, research continues to underrepresent neurodivergent from marginalised communities (Botha & Gillespie-Lynch, 2022; Giwa Onaiwu, 2020; Kourti, 2022; Maye et al., 2022; Nair et al., 2024). To prevent neurodivergence research from perpetuating these exclusions, it is essential to integrate intersectionality into all stages of studies (Botha & Gillespie-Lynch, 2022).

Exclusionary Social Practices

Exclusionary social practices – such as stigma, discrimination, and marginalisation – emerged across multiple research priorities. In autism research, studies on stigma have been reviewed by Turnock et al. (2022), and overcoming stigma against autistic people has been identified as a key research priority (Botha et al., 2024). This priority-setting underscores the importance of research on overcoming stigma as a critical area of investigation for the broader neurodivergent community. A significant contributor to stigma is the deficit-based criteria embedded in neurodevelopmental diagnostic criteria, which pathologise neurodivergence (Bottema-Beutel et al., 2021; Chapman & Carel, 2022; Pellicano & den Houting, 2022). Given that overcoming the negative narrative and the dehumanisation of neurodivergent people is a core tenet of the neurodiversity movement (Graby, 2015; Leadbitter et al., 2021), it is essential to critically assess the appropriateness of diagnosis-specific approaches in research addressing stigmatising social practices. Furthermore, broadening the scope of inquiry to

include different experiences of neurodivergence-based exclusion – beyond those confined to specific diagnoses, can provide a more comprehensive understanding of stigma and marginalisation.

Barriers to Public Services

The most prominent barriers were identified in mental health support (Priorities 5 and 6), the welfare system and social care (Priority 7), neurodevelopmental services (Priorities 5 and 8), and education (Priorities 9 and 10). Some of these services have been identified in previous priority-setting studies, for example, mental health support. The research priority-setting exercise for autistic people in Scotland found that mental health and well-being were top priorities (Botha et al., 2024), mirroring findings from Autistica's 2017 study emphasising the need for tailored mental health interventions (Cusack & Sterry, 2017). Our study broadens this focus, demonstrating that mental health support is a critical concern across different forms of neurodivergence.

While welfare and social care have been extensively examined in broader disability studies (see Clifford, 2020; Duffy, 2013; Graby, 2016), the specific challenges faced by neurodivergent people remain underexplored. While not all neurodivergent people identify as disabled, legal recognition of disability provides a crucial framework for defining rights and addressing discrimination, as established by the Equality Act 2010. This is particularly significant, as disabled people with more 'hidden' or fluctuating impairments have been disproportionately affected by austerity measures and cuts to welfare and social care (Graby, 2016). The social model of disability has played a crucial role in driving systemic change for disabled individuals (Clifford, 2020). Expanding this model to encompass neurodivergence within social care and welfare could help challenge its predominant classification as a disorder, thereby enhancing access to support and services for neurodivergent individuals (Woods, 2017). Current discussions and research on neurodivergence are often not situated within the broader context of disability, which results in neglecting the political and economic dimensions of neurodivergent people's experiences and obscuring the stakes for those most affected by structural oppression (Jones & Orchard, 2024). In light of the contributions of disability activism and scholarship in demonstrating how disabling barriers constitute social injustice (Oliver & Barnes, 2012), it is essential that the experiences of neurodivergent people are examined through the framework of disability.

The need for joined-up neurodevelopmental diagnostic pathways illustrates the practical implications of this project's overarching aim – namely, bridging the boundaries between different diagnostic categories and applying the neurodiversity framework. Neurodevelopmental diagnostic pathways have been proposed as an alternative to the single-

diagnosis approach (Cage et al., 2024). Current diagnostic processes are characterised by long wait times, age restrictions, and fragmented referral pathways (Embracing Complexity, 2019a). Mirroring issues within neurodivergence research, current access to diagnosis is shaped by intersectional exclusions. For example, children from working-class backgrounds are less likely to receive a formal dyslexia diagnosis (Macdonald & Deacon, 2019), while racial and ethnic minorities face disparities in autism and ADHD diagnoses (Coker et al., 2016; Mandell et al., 2009). Similarly to research, bridging diagnostic boundaries within diagnosis pathways has the potential to enhance inclusivity. Furthermore, incorporating the neurodiversity paradigm into the assessments could provide an opportunity to overcome the negative framing of neurodivergent traits and create neutral criteria (Rutherford & Johnston, 2023).

Education emerged as a critical area requiring further research to develop inclusive environments for neurodivergent students. Despite being a fundamental right, many neurodivergent children face substantial barriers to school participation, including disproportionately high rates of exclusion (Brede et al., 2017) and significant school-related distress (Connolly et al., 2023). Empirical evidence underscores the importance of timely and appropriate support in facilitating positive educational outcomes, with delays in such provision being associated with adverse consequences (Vo & Webb, 2024). Recent research on neurodivergence in educational settings has increasingly moved beyond diagnostic categories, adopting a more holistic approach to inclusion. For example, Zdorovtsova et al. (2023) have developed a resource for school professionals that offers strategies for planning, implementing, evaluating, assessing, and preparing inclusive school policies. Similarly, the Learning About Neurodiversity at School project seeks to enhance the inclusion of neurodivergent children by educating all students about neurodiversity and neurodivergence, thereby addressing stigma and exclusion at a systemic level (Alcorn et al., 2024).

Research Inclusion

A secondary aim of this study was to examine how neurodevelopmental diagnostic frameworks influence inclusion and exclusion criteria in neurodivergence research. Evidence suggests that many neurodivergent individuals either have or believe themselves to meet the criteria for multiple diagnoses (Embracing Complexity, 2019a), yet diagnosis-specific studies often fail to capture this complexity (Embracing Complexity, 2021). Most research focuses on a specific issue within a particular diagnostic group – for example, stigma and ADHD, quality of life and DLD (Eadie et al., 2018), or developmental coordination disorder (Dyspraxia) and higher education. However, some researchers have begun broadening their scope by examining two diagnostic groups, such as social cognition in

autism and ADHD (Bölte, 2025), the diagnosis and treatment of children and adolescents with autism and ADHD (Hatch et al., 2023), and risks associated with undiagnosed ADHD and/or autism (French et al., 2023) although there is still relatively little research that takes this approach.

The present study expanded the inclusion criteria by incorporating neurodivergent participants with different neurodevelopmental diagnostic statuses, including those with multiple diagnoses. Rather than selecting participants based on a specific diagnosis, this study included individuals who had experienced social exclusion and marginalisation based on neurodivergence. This approach aligns with Astle et al. (2022) who argue that easing recruitment criteria or adopting alternative sampling methods for individuals with neurodevelopmental differences enhances the diversity and representativeness of research populations.

Historically, participation in neurodivergence research, particularly in autism studies, has been contingent upon a formal diagnosis. However, self-identification as neurodivergent is increasingly recognised as a valid criterion in both personal and research contexts. For instance, autism research has increasingly included participants who self-identify as autistic (Botha & Gillespie-Lynch, 2022; Davies et al., 2024; Maitland et al., 2021). This shift challenges traditional diagnostic boundaries and expands opportunities for inclusion. Nonetheless, diagnostic categories continue to play a central role in research participation, as self-identification remains a prerequisite. People who do not fit within existing diagnostic frameworks may struggle with self-recognition as neurodivergent, further complicating inclusion efforts. While many neurodivergent people rely on diagnostic frameworks for self-understanding, moving beyond traditional labels presents both practical and personal challenges. These findings highlight the need for intersectional approaches in neurodivergence research – specifically, approaches that critically examine which groups are excluded from particular diagnoses and how these exclusions shape broader understandings of neurodivergence and access to research participation.

Despite widening the inclusion criteria, certain limitations occurred in this project. Asasumasu (2016), who coined the term neurodivergent, defined it as encompassing all individuals who are ‘neurologically divergent from typical’ and emphasised its role as ‘specifically a tool of inclusion’. Given that our study aimed to identify research priorities for this population, it is essential to acknowledge the limitations arising from the exclusion of certain groups. While the study successfully included neurodivergent individuals from various diagnostic categories, we were unable to recruit individuals with Down’s syndrome, learning disabilities, or FASD for the advisory group. Consequently, perspectives from these groups were not incorporated into the research priority-setting process. Moreover, the complexity of neurodivergence and the diversity within the neurodivergent community present challenges in achieving broad representation.

Recruitment for the advisory group was open to all individuals who self-identify as neurodivergent, including those with a single formal diagnosis, multiple diagnoses, individuals on diagnostic waiting lists, and those who had chosen not to pursue a formal diagnosis. However, no applications were received from the latter group, and only one participant was awaiting a formal diagnosis. This raises important questions regarding who perceives themselves as eligible to participate in research when inclusion and exclusion criteria are not strictly defined by diagnostic categories. Moreover, in order to meaningfully engage with Advisory Group members and elicit their detailed views in an accessible way within Embracing Complexity's limited resources, the Advisory Group was limited to six participants, limiting the range of views used to develop the original longlist in Stage 1. However, although the initial advisory group was small, the results were expanded and triangulated through a survey of over 200 participants and a multi-stakeholder workshop strengthening robustness.

Additionally, the study primarily focused on neurodivergent individuals who identify with neurodevelopmental diagnostic categories, thereby excluding individuals with other forms of neurodivergence, such as those with mental illnesses, Multiple Sclerosis, Parkinson's disease, or Apraxia (Asasumasu, 2016).

Future Research and Policy Implications

A critical consideration in neurodivergence research is that the growing adoption of the neurodiversity framework necessitates a more comprehensive examination of the broader social context, which has often been overlooked in autism research (Bottema-Beutel, 2024). Simply endorsing this framework without critically analysing the wider socio-political forces (Bottema-Beutel, 2024) or the discriminatory economic structures that perpetuate exclusion (Chapman, 2024) risks failing to generate meaningful change. Therefore, future research must adopt an interdisciplinary approach that accounts for the complex interactions between scientific, social, political, and economic factors shaping the lives of neurodivergent people (Bottema-Beutel, 2024).

This study highlights the significant influence of diagnostic categories across various domains. To develop effective strategies for reducing the social exclusion of neurodivergent people, it is essential to critically assess how these classifications contribute to limiting progress in scientific, social, political, and economic contexts. As discussed, multi-diagnostic approaches may help address the constraints of existing classification systems. However, given the substantial role diagnostic categories currently play in the lives of neurodivergent people, any transition away from these frameworks must be implemented cautiously and gradually to minimise potential harm.

Furthermore, this study emphasises the critical role of intersectionality in neurodivergence research and service

design. Integrating intersectionality theory with the neurodiversity paradigm at a theoretical level holds significant potential for fostering innovative interventions, reciprocal developments, and meaningful change (Strand, 2017). Future research employing the neurodiversity paradigm should therefore incorporate an intersectional framework to ensure greater inclusivity and maximise its impact.

This project foregrounds the collective experiences of neurodivergent people as a marginalised group, not defined by medical labels, emphasising the social and structural factors that produce their exclusion, rather than attributing it to individual diagnoses, for example, autism or ADHD. Conceptualising neurodivergent people as an oppressed group means that the identified barriers need to be explored in the social, political and economic contexts, while most of neurodivergence research is currently explored within individual frameworks. Disability scholarship has produced an extensive body of work on the political and economic dimensions of disabled people's oppression (Charlton, 1998; Russell, 2019). Accordingly, the barriers identified in this project, should be analysed through the lens of disability justice, situating neurodivergent experiences within broader frameworks of social and structural injustice (Mladenov, 2016). Our study highlights that barriers to inclusion exist across multiple societal settings, and overcoming these barriers will require policy changes. Future research should map out all relevant local and national policies to identify how they can better reflect the structural and environmental factors that shape neurodivergent experiences. Some policies, both implicitly and explicitly, reinforce exclusion. Therefore, future research must identify which policies facilitate inclusion and which ones reinforce exclusion. To address these systemic challenges, policy development must be guided by inclusive approaches, which could be further strengthened by the social model of disability (Woods, 2017).

Conclusion

Our study set out to identify and prioritise the most pressing research questions related to systemic barriers faced by neurodivergent people. By combining participatory methods with structured prioritisation processes, we generated a Top 10 list of research priorities grounded in lived experience, shaped through dialogue across diverse stakeholder groups, and structured to inform future policy, funding, and practice.

The process itself was as important as the outcome. Early-stage involvement of neurodivergent individuals ensured that the framing of barriers – and what was counted as a research priority – emerged from experiential knowledge, rather than being pre-defined by academic or clinical agendas. Subsequent survey and workshop stages broadened the conversation, enabling triangulation across perspectives, and the final priorities reflect both convergence across groups. Key areas of focus were identified, including

improving access to support services, challenging exclusionary systems, and rethinking diagnostic pathways. These signal gaps in the evidence base, but also structural failures in policy and provision.

Our work makes three central contributions. First, it demonstrates that research priority-setting can centre neurodivergent voices in a meaningful and methodologically robust way. Second, it reveals a striking consensus around the systemic nature of exclusion, particularly in education, health, and welfare, and a shared demand that research focuses on structural change. Third, it provides a usable, community-informed research agenda for funders, researchers, and policymakers seeking to respond to the needs and rights of neurodivergent people. The process also raises important questions about inclusion: who participates, whose knowledge is privileged, and how power is negotiated in collaborative research. As interest in participatory and neurodiversity-affirmative approaches grows, these questions must remain central, not merely as ethical considerations, but as epistemological imperatives.

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Ethical Approval and Informed Consent Statements

As this research was not conducted at a university, formal ethical approval was not initially obtained from participants. However, when the authors decided to write this paper, we obtained written informed consent from all participants in the study. Details of steps we took to ensure anonymity, and safety of participants is detailed in the article.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Availability Statement

Due to the sensitive and potentially disclosive nature of the participatory group interviews, the raw data from this study will not be shared. This decision was made to protect the privacy and confidentiality of participants, in line with ethical guidelines.

Supplemental Material

Supplemental material for this article is available online.

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