

BIROn - Birkbeck Institutional Research Online

Doyle, Nancy and McDowall, Almuth (2023) The neurodiversity movement. A tipping point. Community reflections on the lived experience of neurodivergent people through the lifespan. *AchieveAbility E-Journal* (4), ISSN 2634-0798.

Downloaded from: <https://eprints.bbk.ac.uk/id/eprint/53485/>

Usage Guidelines:

Please refer to usage guidelines at <https://eprints.bbk.ac.uk/policies.html> or alternatively contact lib-eprints@bbk.ac.uk.



The Neurodiversity Movement: A Tipping Point

Community reflections on the lived experience of
neurodivergent people through the lifespan

Authors: Doyle, N.; McDowall, A.

Art by Goodridge, G.

Editing: Cole, M.



Birkbeck
UNIVERSITY OF LONDON

What did we do?

Recent work conducted by our research centre surveyed 990 neurodivergent adults and found that, while tailored adjustments were important for staff retention, the most motivating factor for employees was career satisfaction (McDowall et al., 2023). We then conducted action research with 100 participants, which this paper outlines. Taken together, these two pieces of community engagement research signpost the need for more relational, positive, value-based research in which neurodivergent people are not just acknowledged and accommodated, but are actively empowered to fulfil their potential in education and work.

These were as follows:

(1) Professor Nancy Doyle, who is a white ADHDer and Psychologist researching Neurodiversity at Work and who has worked in employment support for over 20 years.



(2) Judy Singer, who is a semi-retired Autistic Sociologist and parent / daughter within a Jewish family who were refugees from Europe, who worked in community / family support for around 30 years.



(3) Whitney Iles, who is a Mixed Heritage Autist/Ticcer who works in trauma recovery, promoting peace in communities affected by systemic violence and supporting those in the criminal justice system.



Birkbeck
UNIVERSITY OF LONDON

*note: Profs. Doyle and McDowall from The Centre for Neurodiversity at Work would like to note that we have recently become aware that Judy Singer's views regarding the trans community diverge significantly from our own. We do not support her views. However, she played a part in this event. We debated her inclusion in this document and sought views from trans people in our academic community. We want to be transparent and accurate in the historical record and concluded that to obscure her part in this debate would be dishonest. We hope that going forward, open inclusive and respectful discussions can be restored. Neuroinclusion is for everyone, that is, for us, the whole point.

(4) Marcia Brissett-Bailey, is a Black Dyslexic who has worked in special needs education for over 30 years. and published a book called 'Black, Brilliant and Dyslexic'.



(5) Dr Joanne Cotton, who is a white neurodivergent psychologist and ADHD expert researching how to optimise wellbeing for neurodivergent individuals across the lifespan.



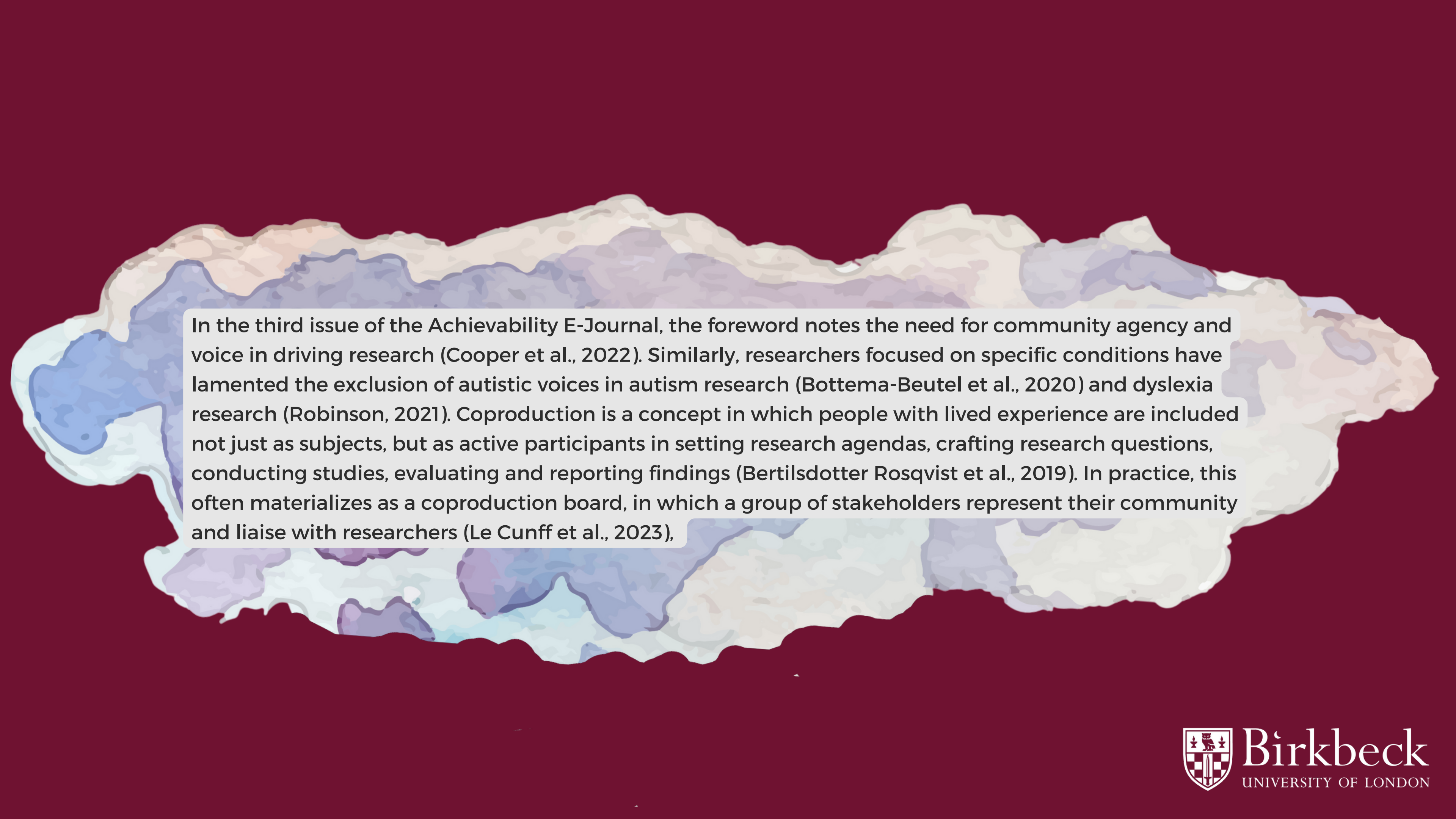
After the panel had a brief discussion, we invited contributions from the community (described below).

Why did we do this?

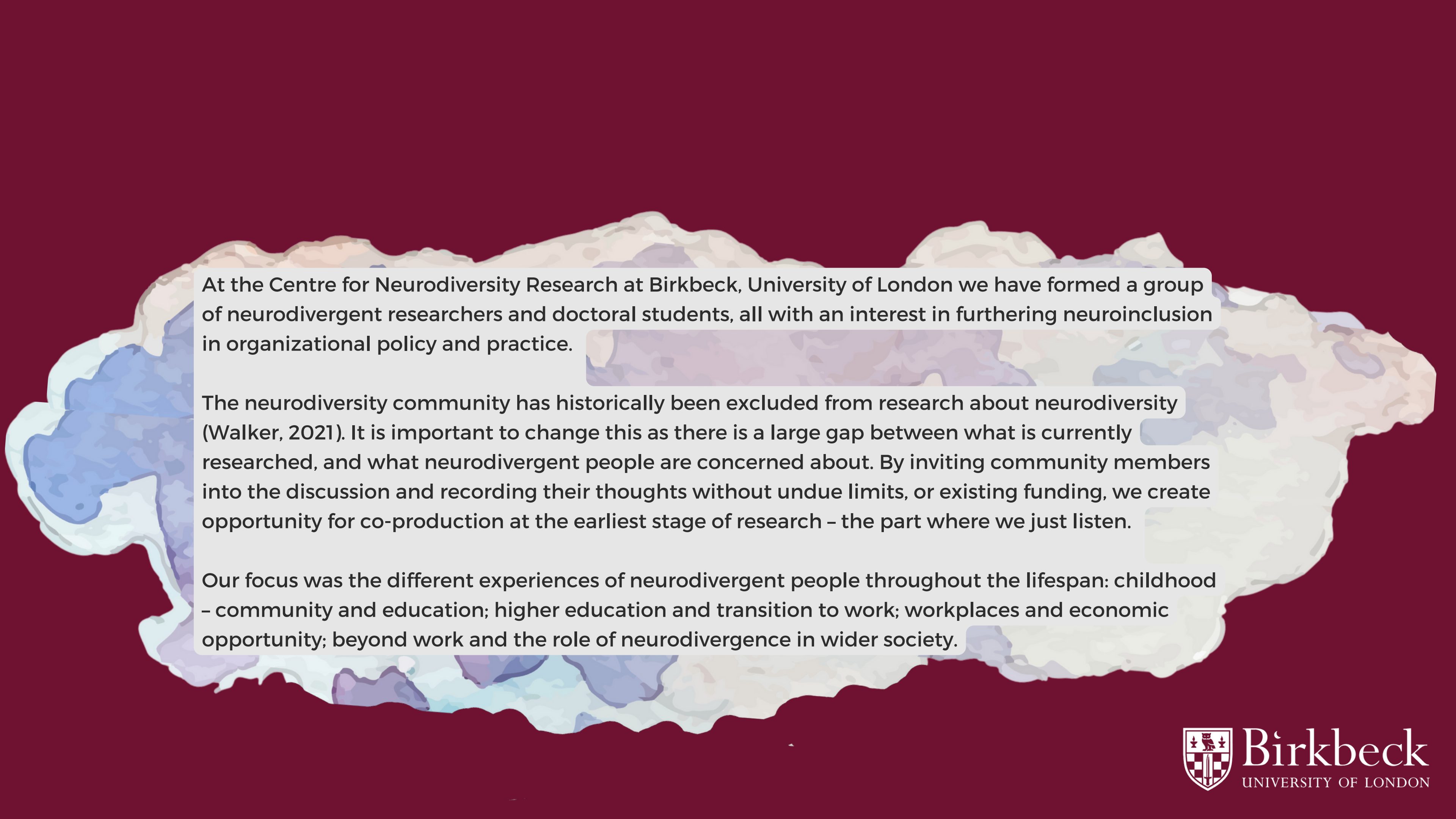
The neurodiversity community is typically excluded from research about neurodiversity. It is important to change this as there is a large gap between what is currently researched, and what neurodivergent people are concerned about.

By inviting community members into the discussion and recording their thoughts without undue limits, or existing funding, we create opportunity for co-production at the earliest stage of research.

Our focus was the different experiences of neurodivergent people throughout the lifespan: childhood – community and education; higher education and transition to work; workplaces and economic opportunity; beyond work and the role of neurodivergence in wider society.



In the third issue of the Achievability E-Journal, the foreword notes the need for community agency and voice in driving research (Cooper et al., 2022). Similarly, researchers focused on specific conditions have lamented the exclusion of autistic voices in autism research (Bottema-Beutel et al., 2020) and dyslexia research (Robinson, 2021). Coproduction is a concept in which people with lived experience are included not just as subjects, but as active participants in setting research agendas, crafting research questions, conducting studies, evaluating and reporting findings (Bertilsson Rosqvist et al., 2019). In practice, this often materializes as a coproduction board, in which a group of stakeholders represent their community and liaise with researchers (Le Cunff et al., 2023),



At the Centre for Neurodiversity Research at Birkbeck, University of London we have formed a group of neurodivergent researchers and doctoral students, all with an interest in furthering neuroinclusion in organizational policy and practice.

The neurodiversity community has historically been excluded from research about neurodiversity (Walker, 2021). It is important to change this as there is a large gap between what is currently researched, and what neurodivergent people are concerned about. By inviting community members into the discussion and recording their thoughts without undue limits, or existing funding, we create opportunity for co-production at the earliest stage of research – the part where we just listen.

Our focus was the different experiences of neurodivergent people throughout the lifespan: childhood – community and education; higher education and transition to work; workplaces and economic opportunity; beyond work and the role of neurodivergence in wider society.

What is this article about?

In this article, we give some details about our process and document the themes that were important to the neurodiversity community members present. Although we focused on different life stages, the themes were remarkably similar. We have summarised the themes that were discussed in the sections below.

We have also noticed an overarching theme, which is the sense of transition, that the neurodiversity concept is at a pivot point of acceptance and inclusion. Though there is still a long way to go for equality, the community has its own identity in a way that it didn't in the 20th century.

Method:



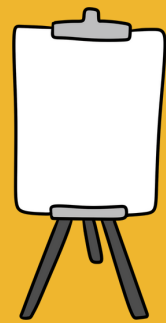
1) We had an audience of 100 community members, intersectionally represented in terms of race, ethnicity, sexuality, gender and transgender and an age range from young adult to older, including post-retirement.



2) We pinned flip charts around the room and asked the community members to write up comments on the broad themes of Neurodiversity in Education, Work and Social Justice, as well as Neurodiversity Identity from young adult to older, including post-retirement.

The data from the world café exercise were originally grouped into context: education, work, community, policy. The data were typed up into a word document verbatim. However, when first reviewed, it was clear that there were many consistent themes across the four contextual categories. The themes were drawn out and comment copied and pasted into the new themes, as below. The themes and comments were cross referenced by the two researchers, any disagreements were resolved by discussion leading to consensus.

3) Participants contributed to the flip charts or gave their views to an assistant who wrote for them.



The community members were not asked to identify themselves according to age, gender, race /ethnicity, socio-economic class or sexual orientation. However, the researchers evaluated the guest list to ensure representation from ages ranging from teenager to septuagenarian and to ensure representation from Black and Brown communities and from LGBTQ+ communities. Our guest list was 66% female and 68% white, which is an over representation of women and a high representation of Black and Brown people given the overall UK population, but low considering the London location.

Age and sexual / gender identity was not monitored to protect privacy, however specific invites to the older generation, generation Z and the LGBTQ+ community resulted in us being aware of five retirees, eight members of generation Z, one transgender person, two non-binary people, five lesbians, three gay men and two bisexual people.



4) These comments were grouped into the themes that follow as a representation of stakeholder voice during a period of community activism and developing agency.



5) The themes were grouped by Professor Nancy Doyle, with calibration and comment from Professor Almuth McDowall, through several iterations of writing them all individually and then grouping similar themes within the main sections. However, there were so many similarities between the sections of education, work and social justice that we decided it was best to group them together. We also wanted to draw them out where they had specific audiences, such as for politicians and policy makers who might work across multiple sectors.

Results

The final designs were created by a neurodivergent marketing professional with the themes grouped as follows:

a)

Being myself

b)

Representation
and
intersectionality

c)

Relationships
and trust

d)

Employers

e)

Public services
and politics

f)

Paradigm shift

*The initial comments and the first iteration of grouping comments under themes is available as supplemental data upon request, please contact the lead author n.doyle@bbk.ac.uk

Participants highlighted that they experience being taken advantage of, stigma, exclusion and more broadly denied the experience of being an asset.

Being myself

Participants drew psychological safety from their community at large and acknowledged the personal development journey that they were on. From the community, participants experienced acceptance, belonging, pride, confidence and a positive identity.

"Always felt different, didn't know why."

"I worry about ND people going into corporate workplaces."

"It feels 'brave' to 'come out' professionally and it shouldn't."

"How do I know that if I 'disclose', my application will be treated fairly?"



"It feels emotional to be here with other ND people."

"Learning to celebrate who you are requires deep understanding of pros and cons."

"Helps me to be kind to myself."

"Self-discovery was important, the need to celebrate who you are but also to learn about the way down as well as the way up."

To generate psychological safety in neurodiverse spaces, participants highlighted the importance of authentic allyship, being heard and considered for communication differences. It was welcomed when others took time to demystify social rules and etiquette and when they were approached with curiosity and compassion.

Representation & Intersectionality

The experience of representation of ND voices was mixed. While some participants felt they were “now where I should be”, others indicated that they needed to be heard.

“Stop telling me I am wrong.”

“Support everyone to find their thing – not just computer scientists.”

“Listening to children (voice matters).”

“I want to be given the chance to climb the ladder.”

There was a sense that we neurodivergent people are starting to re-tell the narrative through our own perspective.

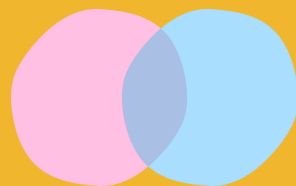
As part of the new narrative, participants sought more emphasis on thriving, progression, retention (not just recruitment and onboarding).



Reporting to individual needs.



Allowing for slower learners.



Better understanding of overlaps needed!



Exploring differences outside of the stereotypical representation of neurodivergence.



Recognising different presentations of stress and anxiety.

Negotiating identity – this is tricky when you don't have the words for navigating neurodiversity.

There were significant comments about the key role of intersectionality in moving the neurodiversity debate forward. The participants reported that there were still high levels of stereotyping and injustice, that without intersectional identities we have to caveat that we are only considering a small portion of who the person is.



Particular issues included:

Different demands and styles between cultures in the battle for success and the levels of internalised ableism.

The need for diversity and representation in the system itself.

The need for systemic change in activities such as Stop & Search, where there is significant racial and gender bias.

Poverty matters, where poor ND kids are in prison and middle class ND kids are in arts- and science-based Uni courses.

Foreign accents matter, particularly in diagnostic tools which are set up for UK norms.

It is not always clear how neurodiversity fits into the wider disability community. Maybe due to ableism?

Being a Neuroqueen? How does language consolidate and validate/dismiss who I am?

Relationships and trust were highlighted as a potential place for improving awareness. Some participants felt that, as their understanding of ND improved, their behaviour around their own ND changed.

Participants noted that everyone deserves the chance to “succeed” in a way that fulfills them and supports them to get there. This is dependent on understanding behaviours and breaking down perceptions, but also being believed, listened to and supported in the way we might support and encourage a friend.



“Our relationship self with self needs to be kinder.”

“Self-limited thoughts and beliefs make a difference in outcomes.”

“It's not fixed (as in static).”



Birkbeck
UNIVERSITY OF LONDON



“There needs to be forgiveness and a way back if we ‘fail’.”

“We are not problems to be fixed.”





Businesses in general were considered not yet ND friendly, that profit over people is not ND compliant and that there needs to be a system change in order to accommodate the flexibility required for good inclusion. Participants thought that leadership needed to be reminded that there is a competitive advantage to neuroinclusion, and that the world is richer with NDers in it.

“Often the problem isn’t the person but the environment.”





Public Services and Politics

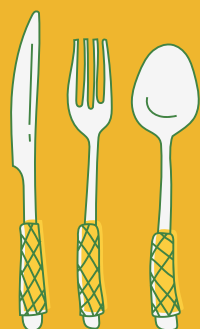
The group were, on balance, remaining pessimistic about the more recent efforts towards neuroinclusion evidenced in publications from the Criminal Justice Joint Inspectorate (CJJI, 2021) Department for Education (DfE, 2023) and the Chartered Institute of Personnel Development (CIPD, 2018). Contrasting with the narratives in the business press about 'neurodivergent superpowers' (Archer, 2014), the community members were not experiencing any marked uptick in opportunities or inclusion, though there was appreciation for increased awareness and improved language around neurodiversity.

A recurring and very strong theme was the need to join up services and ensure that ND needs are considered in mental health provisions.

In particular, ND needs to be a consideration in:



Alcohol (sensory processing) and drug use treatment



Eating disorder services



Anger management (is it anger or regulation needs?)

In identifying and addressing barriers to social change, there was alarm about the state of diagnostic services; that they take too long and that the diagnostic criteria needs updating. This is then followed by a lack of support, an absent network of support.



“Kids need earlier support! Diagnosis? ND Awareness for faculties!”

“Identify early to break the chain.”



It was noted that support is totally missing for Freelancers who are not in employment, education, training or health services and that families need their own holistic support and education.

Within the theme of education, participants requested a focus on strengths, such as abilities, interests, visual learning. This could then lead to more ND appropriate work experience and apprenticeships, though it was noted that GCSEs are currently needed for apprenticeships, which is particularly exclusionary for ND kids.



“Lots of different kids – lots of different ways – why only 1 education system?”

“LEANS (Learning about Neurodiversity at school)”
Edinburgh research project

“All need funding and specialist staff who are supported and integrated into the education system.”

Participants noted that there was a lack of investment in schools, that teachers felt unsupported and there are fewer and fewer options for 121 support. Access to EHCPs is down and schools are behind on understanding accommodations, the need for safe spaces and the harm that standardised testing and exclusion/detention does for ND children. Accessibility devices are still not available. All this adds up to the experience of “being refused a proper education.”



Unified
diagnostic
language.



Change the
definition of
antisocial
behaviour.



Updating
legislation.



**In general, participants
would welcome political
action on:**

Equity (not
just equal
opportunities)
and removal of
stigma.

Reducing the
blaming of
parents children's
neurodivergence.



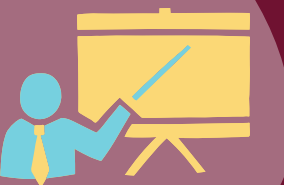
Social
exclusion to
be seen as a
type of
bullying.



Universal
basic
income.



Lack of training for
teachers= exclusions!
Teachers, Police, and
Judges.



Society & Paradigm Shift

Participants reflected on the current state of the world:



"The world is beautiful – please notice!"

"STRIKE! We can't go on this way."



"Community over consumerism."



"Planet over profit."



"Social mobility as a priority."

Overall, participants felt that the neurodiversity narrative was changing societal norms. It was considered relevant to the whole world, and the point was made that understanding neurodiversity is crucial to understanding people and behaviours, allowing for a deeper understanding of how the brain works.

The clash between the social and medical models was highlighted as a current theme, with a need to “let kids be” and “stop measuring”. Participants acknowledged that some aspects were “hot” or “cold” right now, and that neurodiversity has not been universally accepted yet.

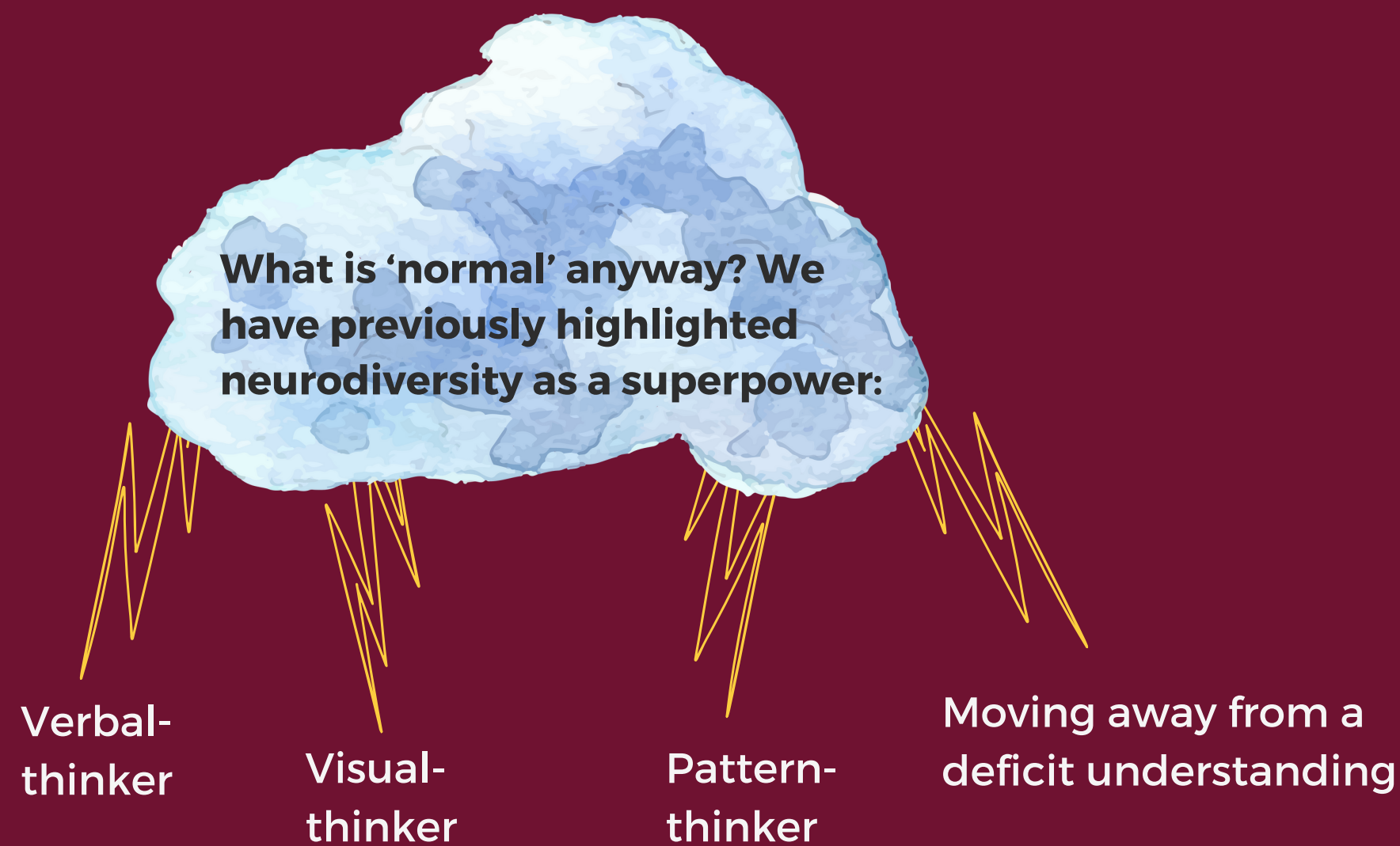
How to connect neurodivergent themes and insights to the world and society at large was considered:

“How do we advocate for the social market of disability? Is this a concept that really works? The unsuitable Human Rights model.”



“Conventional thinking is becoming less valuable. Creativity/different thoughts more valuable.”

Changing narratives within society are leading to changing understandings of self.



But there is still much to do. We are in a state of transition to being more accepted and belonging, to finding our community and feeling empowered and, to being more preventative than reactive.

However, there are still too many people not knowing what 'neurodiversity' is and the experience of ND is different to the description of ND. There was a sense of NT apathy towards ND challenges. Language preferences are still in flux. Participants asked:

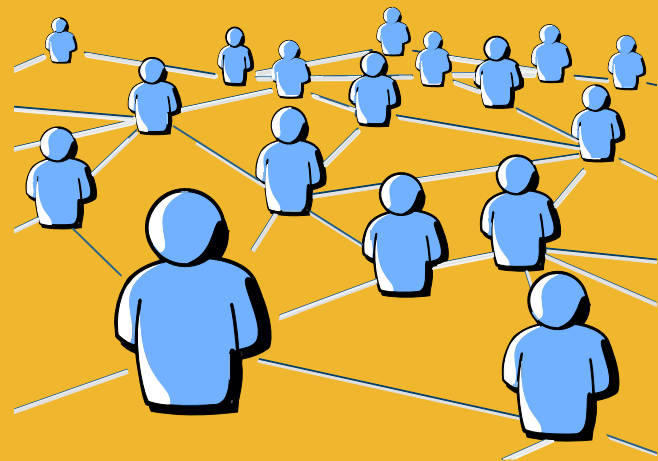


And a fundamental question: "Who has the right to decide what people can/can't identify as?"

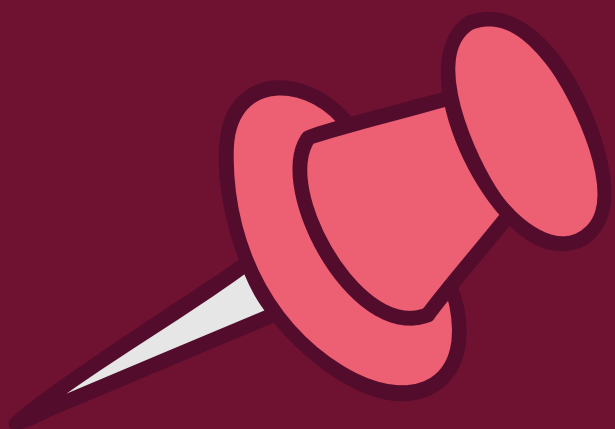
Discussion:



- At the Centre for Neurodiversity at Work we aim to be inclusive of all neurodivergent people and to lead our research designs with co-production.
- From the themes observed in this data collection, we note a need to expand our understanding of psychological safety for neurodivergent people at work.
- Psychological safety refers to the sense that you are:
 - (a) allowed to be candid.
 - (b) allowed to make mistakes.
 - (c) people will respond with a positive approach - "what can we learn from this?"



- This theme is noted in the sections on "being myself" and "relationships and trust".
- There is a sense of developing community between ND people, where we feel safe, juxtaposed against the themes of bullying and exclusion in mainstream settings, as seen in the sections on "employers" and "public services and politics".
- We need to understand how to navigate between feeling comfortable to be our authentic selves and resolving misunderstandings or conflict.
- These themes are already written about in research on intersectionality, from which we can learn a lot, and where representation in research is already more advanced.



- This will be a core mission for our next round of research design at the Centre.
- We think developing our understanding of psychological safety in neurodiversity inclusion will help neurodivergent individuals communicate with more confidence, and employers to feel less anxious about important conversations.
- This in turn will help improve policies and education / workplace practices.

References

Archer, D. (2014, May 14). ADHD: The Entrepreneur's Superpower. Forbes.

<https://www.forbes.com/sites/dalearcher/2014/05/14/adhd-the-entrepreneurs-superpower/?sh=4f30d67d59e9>

Bertilsson Rosqvist, H., Kourti, M., Jackson-Perry, D., Brownlow, C., Fletcher, K., Bendelman, D., & O'Dell, L. (2019). Doing it differently: Emancipatory autism studies within a neurodiverse academic space. *Disability & Society*, 34(7-8), 1082-1101.

<https://doi.org/10.1080/09687599.2019.1603102>

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., Hand, B. N., & Otr, L. (2020). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood*, 00(00), 1-12.

<https://doi.org/10.1089/aut.2020.0014>

CIPD. (2018). Neurodiversity at work (pp. 1-48). Chartered Institute of Personnel Development

CJJI. (2021). Neurodiversity in the Criminal Justice System: A review of evidence (pp. 1-77). Criminal Justice Joint Inspection.

Cooper, D. R., Hewlett, D. K., Hermanstein, D., Maskell, K., Morris, B., Pitts, R., & Thorley, D. M. (2022). Calling for change from intersectional perspectives. *AchieveAbility E-Journal*, 1(3), 1-79.

[extension://elhekieabhbkmcefcobjddigjcaadp/https://www.achieveability.org.uk/files/1675863828/achieveability-3rd-edition-neurodivergent-voices-calling-for-change-from-intersectional-perspectives-2022.pdf](https://elhekieabhbkmcefcobjddigjcaadp/https://www.achieveability.org.uk/files/1675863828/achieveability-3rd-edition-neurodivergent-voices-calling-for-change-from-intersectional-perspectives-2022.pdf)

DfE. (2023). Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan: Right Support, Right Place, Right Time. HM Government.

Le Cunff, A.-L., Ellis Logan, P., Ford, R., Martis, B.-L., Mousset, I., Sekibo, J., Dommett, E., & Giampietro, V. (2023). Co-Design for Participatory Neurodiversity Research: Collaborating With a Community Advisory Board to Design a Research Study. *Journal of Participatory Research Methods*, 4(1). <https://doi.org/10.35844/001c.66184>

McDowall, A., Doyle, N., & Kisleva, M. (2023). Neurodiversity at Work 2023: Demand, Supply and Gap Analysis (p. 60). *Neurodiversity in Business*.

Robinson, S. (2021). A Black, Dyslexic, Gifted and Male Entrepreneur: The Unheard Voice. *Journal of African America Males in Education*, 12(2).

Walker, N. (2021). *Neuroqueer Heresies: Notes on the Neurodiversity Paradigm, Autistic Empowerment, and Postnormal Possibilities*. Autonomous Press.