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A Case Study Unveiling Challenges And Supports For Deafblind And Neurodivergent Researchers And Participants

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ABSTRACT

Significant gaps persist in the literature about the participatory experiences of Deafblind and neurodivergent researchers in the conducting of disability studies. Research is therefore needed to gain a better understanding about the academic and broader life experiences of these scholars. Aiming to contribute to this understanding, and how these lived experiences of disability might inform socially just and inclusive co-produced qualitative research, we have conducted a descriptive case study. Undertaking dual roles as researchers and study participants, the authors interviewed each other and applied thematic analysis to identify themes, and cross case analysis to reveal theme commonalities and differences across nine domains. These domains are: a) impairment history; b) important milestones in life with disability; c) research journeys; d) methodological challenges; e) involvement in research as participants; f) scholar activism; g) multiple roles and identities; h) experiences with ableism; and i) Covid experiences. Our co-produced qualitative research demonstrates how diverse disability and impairment types with different needs can be consistently 'matched' with accessibility provisions allowing inclusionary knowledge building dialogue and practice to take place.

1. INTRODUCTION

The term 'lived experience' draws upon the unique perspectives known to people who have first-hand experiences of disability-related challenges (Byrne,

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Happell, and Reid-Searl 2015). With inclusion fundamentally based in notions of equity and social justice (Koutsouris, Stentiford, and Norwich 2022), there are many benefits to accompany including researchers with lived experience of disability in the conducting of disability research. By involving people with lived experience of disability in disability research, such studies are likely to hold attributes of inclusion, relevance and trustworthiness (Li et al. 2022, Happell and Roper 2007, Szmukler, Staley, and Kabir 2011). Importantly, lived experience perspectives encapsulate the knowledge and expertise that follows shared experiences of discrimination, marginalisation and oppression (Byrne 2017, Duvnjak et al. 2022). Lived experience research recognises and values these experiences of disability (Boydell et al. 2021, Tooth et al. 2003). Further supporting the advancement of social justice, a qualitative study by Watharow and Wayland (2022) demonstrated that researchers with lived experience of disability can broadly foster inclusion by providing full accessibility to all who wish to participate. Moreover, lived experience research instils cultural and linguistic understanding to research methodologies including Deaf culture and sign languages (Byrne, Elder, and Schwartz 2021).

The terms co-production, co-design and co-creation are used interchangeably (Sarre et al. 2023, Pearce et al. 2020) and summarised as co-approaches (Grindell et al. 2022, Cowdell et al. 2022). Pearce et al. (2020) cautioned that the development of co-creation is undermined by a lack of clarity around its definition. An argument is also made against the need for a single definition of co-production as attempts to do so fail to recognise underlying complexities of intent and impact (Williams et al. 2020, Glynos and Speed 2012). Applied in a research context, co-production can occur throughout and might encompass the co-design and co-delivery of research activities (e.g., identifying research directions, communication of findings) (Sarre et al. 2023, UK Research and Innovation 2023). Co-produced research, however, is often described in the literature as studies that are conducted by academic researchers *with* non-academic research stakeholders including service users, carers and family members (Darby 2017, Beckett et al. 2018, UK Research and Innovation 2023). Colder Carras et al. (2022) too has cautioned that research methods, including qualitative methods, are frequently described in scholarly articles as participatory when the actual inclusion of people with lived experience is tokenistic. Far from commonplace, examples do however exist of research about disability that has been co-produced *by* people with disability who are also scholarly researchers. These co-produced studies have examined a range of topics including the lived experiences of Deaf professionals, a diversity of identities involving Deaf learners, and the advantages of neurodivergence in qualitative research (Listman and Kurz 2020, Grant and Kara 2021, McIlroy and Storbeck 2011). It is this inclusive approach to the co-production of research, specifically co-produced qualitative research by Deafblind and neurodivergent researchers that will be the focus of this exploratory case study.

Author A and Author B as lived experience scholars and respective members of Deafblind and neurodivergent communities, are also advocates for co-produced disability research. Throughout this paper, we use the term Deafblind to mean hearing and vision loss co-occurring in such a way that neither sense can compensate for the other. In the case of Author A, the association and inheritance of vision loss (due to retinitis pigmentosa) with congenital deafness is well known from Charles Usher's landmark paper in 1914 which led to the eponymous Usher syndrome (Vernon 1969, Usher 1914). The impacts of deafblindness are significant and complex, and experienced across all aspects of life and in all social domains. These losses create complexities particularly with access to information, communication, mobility and orientation (World Federation of the Deafblind 2018). Deafblindness is rare in under sixty-five year olds at less than one percent of the population, but is increasingly common as we age being recorded at over 25 percent for people aged over 85 years (Schneider et al. 2012). Estimates from the Disability, Aging and Carers survey put the number of Australians living with full or partial hearing loss at 200,000 (Australian Bureau of Statistics 2019). This number is likely a significant underestimate as dual sensory impairment may not always be disclosed or diagnosed, especially in older people, First Nations people, the homeless, prisoners and those with other impairments (Watharow 2021). In contrast, 3.1 percent of Australians aged 16 to 85 years reported having Obsessive Compulsive Disorder (OCD) (Australian Bureau of Statistics 2022). In the case of Author B, medically diagnosed with OCD and identifying as neurodivergent. By neurodivergent, we mean people whose minds function in ways that vary significantly from societal depictions of the 'norm' (Walker 2023). The neurodiversity paradigm attempts to move beyond medical model endorsed language about mental 'disorders' with neurodivergence seen to be natural and normal (Walker 2023).

Recognising that deafblindness and neurodivergence studies remain in their early days, much of the available research on deafblind or neurodivergent people is seldom lived experience-led or co-produced (Watharow 2021, Simcock 2017, Williams and Lloyd 2014, Den Houting 2019). A failure to value and include lived experience of disability in the co-production of deafblind and neurodivergence research holds significant consequences. There is much exclusionary research that continues to be published in scholarly journals which has referred to deafblind and neurodivergent people in pathologizing ways or where vulnerability is emphasised (Walker and Raymaker 2021, Simcock 2017). To the authors' knowledge, no study to date has investigated disability research that has been co-produced by Deafblind and neurodivergent scholars. Hence, this descriptive case study will compare and contrast the academic and broader life experiences of a Deafblind researcher and a neurodivergent researcher with the aim of informing about inclusive qualitative research design practice.

2. RESEARCH METHOD

Case studies have been applied to successfully inform disability research in fields of Deafblindness (e.g., orientation/mobility) (Parker 2009) and neurodivergence (e.g., anti-bullying measures in the workplace) (Mellifont 2020). We have followed the Yin (2004) three-step approach to conducting case studies. These steps included: a) defining the case; b) stating the use of single or multiple cases; and c) deciding whether to start from a theoretical standpoint. The case for this study is defined as a narrative across nine domains which collectively depict academic and broader life experiences of a researcher with disability. Domains were designed between the researchers in a collaborative manner and consist of: a) impairment history; b) important milestones in life with disability; c) research journeys; d) methodological challenges; e) involvement in research as participants; f) scholar activism; g) multiple roles and identities; h) experiences with ableism; and i) Covid experiences. This diversity of domains reflects the complexities and contingencies of living with disability. Deciding not to commence with a theoretical position, themes were inductively derived from multiple (i.e., two) cases.

Data collection

The authors self-selected to be informants for this case study. For our co-produced research, we interviewed each other, hence the number of participants is two. Having dual roles as researcher and research-participant, the two lived experience researchers iteratively interviewed each other across the nine domains over a period of time from January 2023 to April 2023. The data collection method was discussed in conversations between the author-participants and agreement was reached that email interviewing provided a mutually accessible and inclusive approach. Email exchanges also served as a record of discussions, thoughts, and additional observations. This electronic communication allowed both researchers to work at their own pace with preferred accessibility software and human assistance (Author A) and without increasing anxiety (Author B). Email conversations were supported by Zoom exchanges with accessibility assistant support for author A.

Data analysis

Taking guidance from the Braun and Clarke (2006) espoused approach to conducting thematic analysis, an iterative process was applied whereby the two researchers independently: a) searched for themes; b) reviewed themes; c) named themes; and d) reported on themes. Author B imported interview responses for each narrative into NVivo where thematic coding took place. As NVivo was inaccessible to Author A, this researcher instead identified themes from the hand-coding of interview transcripts. Any differences in coding between the researchers were collaboratively discussed and resolved through a series of email and Zoom communication exchanges. Author B then applied cross case analysis to identify thematic commonalities (i.e., themes shared by both authors) and thematic differences (i.e., themes raised by only one author) across each of the nine domains. Findings from this cross-case analysis were discussed between the authors and agreements were again deliberatively reached.

Inclusive and accessible qualitative research co-design

Two lived experience researchers, one Deafblind (Author A) and one neurodivergent (Author B) co-designed this qualitative study from initial email discussions about individual requirements. Author A preferred in-person communications with accessibility assistants but was able to use email and Zoom technology with accessibility features, again with support from their assistants. Author B preferred no in-person meetings due to a requirement for travel between states, while email and Zoom communications were suitable. Individualised accessibility needs were consistently met throughout all stages of our research. For example, in the data collection stage, Author B provided their interview responses in written form and emailed these to Author A, rather than recording ‘live interviews’ as an accommodation for their neurodivergence. The email content was made in a large font size with white text and dark background as an accommodation for Author A. Author A then used Zoom text software to enable a very large print version to be read. Furthermore, an accessibility assistant was on hand for Author A during all phases: responding to questions; reading responses; undertaking analysis; and writing the manuscript. Writing the manuscript entailed further thoughts around accessibility as MS Word track changes was not accessible for Author A, nor was formatting documents. The researchers negotiated that Author A would use in text capitalisations to mark additions, changes and comments to Author B. Author B would then format the article in line with editorial requirements.

3. RESULTS AND DISCUSSION

Results are summarised as follows with illustrative excerpts provided for each domain. Supporting research rigor and reliability, interview quotes are provided which are reflective of each respective theme. To increase readability and accessibility, we have purposefully provided our results in an accessible format (i.e., no use of tables or boxes) which can present issues for screen readers with table content failing to display properly after zooming in on the text to enlarge it (University of Virginia 2023). Author A confirmed this particular accessibility challenge through their previous experiences.

Commencing with domain 1 (i.e., disability history), both researchers reported about useful disability supports (Author A: “the single most valuable communication support I have is human accessibility assistance”), disability as a prolonged and permanent state (Author B: “I’ve always been a worrier….”), educational mistreatment (Author A: “I failed a subject at Uni because the lecturer insisted on giving them in the dark”), delayed diagnoses (Author B: “despite my long history with anxiety, I wasn’t formally diagnosed with obsessive compulsive disorder (OCD) until I reached my thirties”), and unhelpful treatments (Author A: “I sought advice from three ophthalmologists in one year who all said I must eat more carrots and see a physiotherapist for my clumsiness”).

For domain 2 (i.e., important milestones in life with disability) researchers described delays in receiving diagnosis as mentioned above, anxiety about parenthood (Author B: “attending the birth of my son in 2006 and not fainting at any point”), the gaining of professional employment (Author A: “I go into GP therapy, which I actually love … I know that I need to move into something else, so I do a PhD”), public disclosure of disability (Author B: “openly disclosing my neurodivergence on my LinkedIn profile and elsewhere”), commencing and completing PhD studies (Author A: “the PhD arose as a late onset thing in response to health care discrimination and trauma experiences by my patients and myself”), And the launching of professional research careers in the academy (Author B: "becoming employed as a lived experience research fellow in the Centre for Disability Research and Policy").

Domain 3 (i.e., research journeys) involved similar recounts of unconventional pathways (Author A: "very untraditional!"), late starts to the PhD path (Author B: "I had to develop confidence in my abilities following my experiences in an unaccommodating high school environment"), embracing life-long learning (Author A: "MBBS, Master of psychological medicine, diploma of event management, PhD and Master of arts (creative writing)"; landmark experiences (Author B: "I completed over 30 publications on topics supporting the social and economic inclusion of people with disability"), strong personal beliefs (Author A: "I also believe it is not enough to generate scripts and send patients on their not so merry ways"), and the dominance in disability research of non-disabled researchers (Author B: "are they trying to protect their privilege and the many economic benefits that follow?"). Author A's reported differences for this third domain included experiences of inaccessibility in the academy ("Author A: "I am finding it tricky as all the funding processes are inherently inaccessible"), protracted time to conduct research (Author A: "generally, I took two to seven times as long to achieve tasks"), not enough assistance/fatigue (Author A: "I have to be careful what I say yes to for reasons of assistance, fatigue etc"), assumptions of others (Author A: "I was stuck by how others thought I had some sort of 'advantage' with the technology"), and others claiming research work as their own (Author A: "my boss took all the credit and presented my paper in an ICU conference"). Author B reported of challenges in commencing an academic career (Author B: "an appalling lack of career pathways for academics with disability").

In terms of domain 4 (i.e., methodological related issues) both researchers described a need for methodological modifications (Author A: "the majority of application forms are inaccessible"), the modifications themselves being individualised rather than a system wide culture of inclusive methodologies (Author B: "I receive questions to interviews in advance"), as well as benefits following receipt of these modifications that include giving voice to other researchers with disability (Author A: "the research methodologies gives voice to those otherwise excluded") and lowering stress (Author B: "the University of Sydney has been great in consistently providing me with these accommodations that reduce anxiety"). This is diametrically counter to Author A's experiences of widespread inaccessibility and exclusion of participants and researchers with communication disability (Author A: "We should not exclude such and such a group or person because 'it is too hard to reach' e.g., access costs too much, it is too complicated or heaven forbit , might not yield 'good' results because of the different ways people living with disability may speak/express and make meaning").

Informing domain 5 (i.e., involvement of research as participants) authors referred to strong engagement as research participants, as reminders of accessibility in disability research (Author A: "since I have such particular accessibility needs, I like to remind researchers that they need to provide those formats for me"), and enjoyment in contributing to the research of others (Author B: "I have participated in many research projects… these include: completing a survey for The University of Sydney power sharing in co-production study that aims to produce an evidence-based resource which is informed by the experiences of people with knowledge and expertise; being interviewed (with accommodations in place) for the University of New South Wales System-wide Disability Research Capacity in Australia study; and contributing my narrative about my experiences as a researcher with lived experience of disability to the 'ableism elephant in the academy' study").

For domain 6 (i.e., scholar activism) both researchers acknowledged their activist roles in supporting social justice messages about the need for inclusive research (Author A: "the work/research we do should be socially just and address areas of community concern"). Theme differences for this domain include activism strategies (Author B policy background and focus - "deeply drawing on my lived experience, I have made and continue to make important policy contributions in support of a positive workplace culture") and aspirations (Author A reminding university leaders about ongoing accessibility issues for self and others - "reminding people about accessibility for everyone not just me").

Common to domain 7 (i.e., multiple roles and identities) authors recognised their multiple roles as researchers, parents, and partners (Author B: "on a personal note, I sometimes find it hard to juggle multiple roles and identities (i.e., researcher, father, husband"). Author A discussed a lack of recognition of role aspirations ("people generally have low expectations of what people with disability can do…in fact, one can have multiple roles… e.g., partner, mother, parent, provider of services, recipient of services and so on"). Author B made specific mention of the role of stress and desire for balance ("a healthy balance…is the way forward").

For domain 8 (experiences with ableism) both authors cautioned about sites of ableism and of people who discriminate (Author B: "I have been fortunate in the university to have not experienced the ableism that I at times encountered when working in the public service"). Author A however, with the same employer, reported ongoing experiences of ableism with their current employer ("ableism is a constant, ever-present contingency"). This illustrates how a system-wide culture of inclusion is still elusive.

In the ninth and final domain of covid-related experiences, both authors recalled mixed Covid-related experiences. Author A referred to covid-related ableism and inaccessibility ("I found there was not a single reliable pathway for information for people with disability"), while Author B raised teleworking benefits following the pandemic ("Covid has played a big role in normalising working from home").

Discussion

In the discussion to follow and addressing our research aim, we will critically cover inclusive qualitative research design measures for studies that are co-produced by deafblind and neurodivergent researchers. This discussion encompasses the co-design of accommodating data collection methods, managing conflicting accommodation requirements, recognising divergent experiences regarding pandemic-related changes in workplace practices, providing flexible research project timelines, and safely disclosing disability.

A need is highlighted among the literature for qualitative data collection to be accommodating of neurominorities (e.g., interviews conducted in familiar settings, seating arrangements to reduce the intensity of maintaining eye contact) (Taylor 2017, Szulc 2022). Deafblind researchers and study participants too require an array of individual access supports depending on their residuals of hearing and sight (e.g., sign and/or tactile language/s, assistive devices, interpreters, communication guides, safe interview spaces, extra time and appropriate funding to provide what is needed for inclusion (Watharow and Wayland 2022, Johnston 1989). Recognising accessibility and accommodation needs, opportunities exist for qualitative data collection instruments to be co-produced *with* people with disability (Mathews, Coyle, and Deegan 2015). Our lived experience research, however, has demonstrated capacity for flexible and accommodating qualitative data collection methods to be co-designed *by* a Deafblind researcher and a neurodivergent researcher in an equal and trusting partnership. Investment is nevertheless needed in future research to examine the possible extent to which trusting partnerships are established in deafblind and neurodivergent co-produced studies more broadly.

Navigating a diversity of disability support means remaining open to conducting qualitative research in ways empathetic to individual needs (Mellifont et al. 2019, Watharow and Wayland 2022). But what happens on occasions where the individual accommodation preferences of research team members are in conflict? In this co-produced study, compromise was successfully reached. Our exploratory research has demonstrated capacity for an accommodating communication strategy between a Deafblind and neurodivergent researcher to be constructed, negotiated, and implemented. Research is needed, however, to investigate the degree to which accommodations are successfully negotiated in co-produced disability studies involving researchers with different disability types (i.e., disability types other than deafblind or neurodivergent).

One of the positives of global pandemic disruptions was a normalisation of remote working through an increased use and acceptance of online communications. This position is supported in the literature with Covid-19 described as encouraging workplace adjustments including teleworking as part of a ‘new normal’ (Agba, Agba, and Chukwurah 2021, Raghavan, Demircioglu, and Orazgaliyev 2021, Como and Domene 2023). Our study cautions, however, that online communications are not accessible or inclusive of everyone (in this case, a Deafblind researcher). Such cautioning is supported by Dobransky and Hargittai (2016) in their discussion about online communications whereby some people with disability can be excluded more so than others. Nonetheless, we have demonstrated in our case study that new knowledge is realisable with open minds and flexible accommodations across all stages of research which can satisfy the needs of researchers with differing professional backgrounds, disabilities, and requirements.

Anxiety-related work attributes of inspiration, motivation, and perseverance are each reported among the literature (Sweeny and Dooley 2017, Brooks et al. 2016, Eysenck 1997, Bertilsson et al. 2015). Recognising these performance-related attributes of neurodivergence, we argue it ableist to assume that all researchers with disability will take longer to complete research tasks than their non-disabled research colleagues. However, we also note scholarly depictions emphasising the time needed for Deafblind researchers to organise access, book interpreters, and arrange other communication supports (Kusters, De Meulder, and O'Brien 2017, Stapleton 2015, Woodcock, Rohan, and Campbell 2007, Watharow and Wayland 2022). Moller (2003) too noted people living with deafblindness losing time in almost all activities and across almost all domains. We thus position traditional and inflexible framings of qualitative studies which place unreasonable deadlines upon deafblind or other researchers with disability (or which apply time as a key measure of research quality) as fundamentally discriminatory and exclusionary research practice.

Researchers should feel confident to proudly disclose their disability to research team members and more broadly should they wish to. As noted by Lindsay and Fuentes (2022), supportive colleagues, inclusive work settings, and the scarcity of discrimination collectively encourage people to disclose their disability in academia. Each of these factors supporting disclosure were replicated in our case study through a reported decision to disclose disability in the academy. Nonetheless, we recognise that any decision by a researcher to openly disclose their disability is a personal one and pressure should not be applied to do so.

Roadmap to inclusive research

Informed by our case study, we offer the following eight key directions about how to be inclusive of deafblind and neurodivergent researchers and study participants.

1. Recognise disability as part of the human spectrum and that deafblind and neurodivergent people have the right to lead, co-produce and participate in research.
2. Enact society's obligation to provide accessible and accommodating environments for researchers and study participants with disability: (e.g., information and inclusive practices - provide universal arial or calibri fonts, large and extra-large print, braille versions, video sign language, audio, visual descriptions, captions).
3. Redress the dominance of researchers without disability by opening career pathways for researchers with lived experience of disability. Specifically, make grant applications accessible and fund accessibility budgets for researchers, teams and participants.
4. Dismantle ableist barriers in academia (and beyond) by: using accessible onboarding procedures; having accessible documents, modules and processes; and funding disability supports required by researchers and study participants.
5. Address methodological barriers with creative modifications which support benefits of conducting research that is ethical and targeted (i.e., guided by the voices of lived experience); and requiring an insistence on: accessible data analysis

and collection measures, noting that software cannot be used by everyone, and providing flexibility in communication methods (e.g., accommodating neurodivergence where needed through communication by email and doing pre-recorded instead of live presentations).

6. Implement promptly the support needs of researchers, as inaction and delays are ways to marginalise and increase temporal and emotional burdens.
7. Keep learning: we need more conversations about how we live with disability and difference in navigating academia, research and life. Our allies need to keep listening, and oppressors need to learn too from the research work that we do to demonstrate and inform about our capabilities. We have found great value in leading and participating in research ourselves, to both experience the landscape of other people's research and to contribute the expert-knowledge of our lives.
8. And a final reminder: system transformation is the key - we are disabled by society as well as our bodies and minds (Shakespeare 2013). Therefore, the academy needs to engage with systemic issues and barrier removal, and not just individual accommodations.

Limitations

This co-produced study, addressing inclusive co-produced qualitative research involving deafblind and neurodivergent researchers, is constrained by its exploratory nature and the modest number of cases upon which it is based. Recognising that our themes are also represented by small numbers of quotations, Morse (2007) argued that qualitative researchers are interested in what the data tells us rather than how many. Morgan (2021) too noted the value of a theme is in its explanatory power and not the number of times it is counted in quotations. Nonetheless, we openly acknowledge that our results cannot lay claim to be representative of a wider population of Deafblind and neurodivergent researchers. Future studies with a broader selection of Deafblind and neurodivergent researcher populations are therefore needed to test and build on our preliminary evidence base. Finally, we recognise the possibility of recall bias in attempts to describe disability histories. Future studies could consider the inclusion of an independent reviewer to confirm the reports of each researcher/participant.

4. CONCLUSION

Our case study imparts timely messages which endeavour to promote the involvement of researchers and study participants who are deafblind or neurodivergent in qualitative research about disability. Co-produced disability studies that are inclusive and socially just need to be accommodating of personalised accommodation requirements throughout all stages of research. These requirements must be carefully planned and budgeted for, and not added as an afterthought or be forgotten altogether. Crucially, our co-produced qualitative research has demonstrated how diverse disability and impairment types with different needs can be consistently 'matched' with accessibility provisions allowing inclusionary knowledge building dialogue and practice to take place.

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