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Shifting power to people with disability in co-designed research

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ABSTRACT

This paper explores tensions navigated by researchers and project leaders when involving people with disability as experts in co-design and in the core team. Part of an evaluation aiming to improve paid employment of people with intellectual disability is used to consider this work. Assemblage analysis of the data assisted in identifying a range of material and social conditions, flows, and factors that de- and re-territorialise power in the co-design process. The expertise of people with disability informed research design. Structural conditions of funding and institutional support were foundational to the co-design. These included accessible practices, core roles for people with disability and resolving ableist conditions. Power shifts were easily undermined by institutionalised norms that disrespected the co-design contributions. When people in decision-making positions and allies recognised the value of codesigning research, it was key to centring valuable knowledge in articulating key issues, methodology, and analysis.

ARTICLE HISTORY

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KEYWORDS

Co-design; assemblage method; inclusive research; disability; power shift

Points of interest

- It is increasingly expected that people with disability will be involved as researchers and decision-makers in projects. This kind of co-design in research is very popular.
- When governments or organisations ask researchers to complete research quickly, people with disability are less likely to be involved in designing the research from the start.

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- This reduces how much power they have as members of the research team.
- Our research found that people with and without disability needed to work together to resist when co-design work was not treated with respect by people or systems.
- Allies need to work to make co-design positions more secure. For example, people with disability need to be in decision-making positions before research proposals are developed.

Introduction

Co-design is increasingly utilised in disability research and project work as an essential component of ethical and respectful work grounded in human rights. Certainly, it can be challenging to do co-designed research in time-bound commissioned work done in community, government, or academia where aims are often established before involving people with disability in expert positions. Nind highlights the importance of ‘managing the power dynamics when there are researchers from inside and outside the academy with different claims to authority’ (2017, 284). This paper takes up this challenge and explores some of the tensions navigated by researchers and project leaders when involving people with disability within a commissioned research project.

In this article, we provide examples by drawing from an evaluation of a community project that aimed to improve paid employment of people with intellectual disability, as a case example. The documents from early stages of the project (such as the research proposal, baseline report, minutes, and emails between project leaders and researchers) were analysed using assemblage analysis. A range of material and social conditions and flows were identified as key factors that de- and re-territorialized the codesign process. The paper concludes with implications and discusses future directions for code-signing commissioned research and practice.

In this paper we use the term people with disability, consistent with the preferences of self-advocates in Australia. They include the researchers, policy makers, employers, employees, and co-designers. Some people prefer identity-first language, such as ‘disabled woman’, with the view that this enables recognition of the experience of disability as a core part of identity.

Background

Co-design and inclusive and participatory research

Codesign, first developed by the design and technology sectors who saw the value of co-producing with end-users when designing products (Evans and

Terrey 2016), now has established roots in social sciences too (Durose et al. 2017), it is increasingly adopted by government agencies and academics world-wide, and the Australian context is no exception (Bigby, Frawley, and Ramcharan 2014; Blomkamp 2018; Chalachanová et al. 2020; Evans and Terrey 2016; Rieger 2020). Co-design enables social issues to be examined in collaboration with community affected by these issues in an ethical way. Taking a collaborative approach allows for a deeper degree of reflection, creativity, and pooling of knowledge from various members representing different backgrounds and interests (Trischler, Dietrich, and Rundle-Thiele 2019, 1595).

In disability studies, researchers may draw on related fields of inclusive participatory research as well as coproduction and codesign. Inclusive research is concerned with diverse range of data collection often not traditionally used in the social sciences, such as photo elicitation (Hollinrake, Spencer, and Dix 2019), pictorial mapping (Robinson et al. 2020), and walk-along interviews (Robinson and Graham 2021). In fact, flexibility in data collection and analysis is a central aspect of inclusivity and serves as a way to resist against ingrained ableist structures and 'traditional' methods which sometimes do a disservice to people with disability (Coverdale, Nind, and Meckin 2021; Nind and Vinha 2014; Roy, Mcvilly, and Crisp 2021). Co-design is often defined as one of the first stages of co-producing work. While the two concepts are arguably different (SCIE 2015), the concept of co-design is increasingly used interchangeably with co-production, and inclusive research, especially in the policy context (WACOSS 2017). A range of methodological approaches may be employed. These methodologies are inter-related, stemming from the shared goal of doing research 'with' community instead of 'on' community.

The principles underpinning co-design are based on the idea of setting research agendas in collaboration with people with disability, strengthening research quality, and ensuring the outcomes remain central to people's priorities and interests (Blomkamp 2018; Hollinrake, Spencer, and Dix 2019; Puyalto et al. 2016; Robinson et al. 2020; Strnadová and Walmsley 2018). Factors known to contribute to an inclusive research team include principles, such as (but not limited to) leadership and good management, diversity of team members strengths, and availability of peer mentoring and opportunity for skill development of both those with and without disability (Johnson 2009; Nind et al. 2016; Strnadova et al. 2014).

Co-design can provide authenticity of knowledge and allows researchers to understand the problems and frame solutions to social problems (Hollinrake, Spencer, and Dix 2019; Roy, Mcvilly, and Crisp 2021) by acknowledging lived experience and diverse ways of knowing (Evans and Terrey 2016; Hadley et al. 2022; Palmer et al. 2019). It has been argued that in order for co-design and co-production to be enacted, mutually beneficial and reciprocal relationships between researchers and co-design members need to be

developed over time (Aldridge 2017; Armstrong et al. 2019; Chalachanová et al. 2020; Nind 2017; Roennfeldt and Byrne 2021).

Much of the literature discusses the benefits of co-design and argues for its use, there has been a dearth of literature outlining what preconditions, factors and elements facilitate or constrain co-design in the Australian context of short-term government funded projects. This article aims to contribute to the literature in the context of Australian disability policy.

Current policy context: NDIS and employment opportunities for people with disability in Australia

The introduction of the National Disability Insurance Scheme (NDIS) in 2013 changed the landscape of disability support in Australia, aiming to enable people with disability to have more control to organize their supports and disability resources as needed (Reddihough et al. 2016). One of the ways in which the NDIS aims to support people with disability is through the facilitation of employment (NDIS 2021). In addition, the Department of Social Services provides Information Linkages and Capacity Building (ILC) grants 'to organisations to deliver projects in the community that benefit all Australians with disability, their carers, and families.' (DSS 2021).

One such ILC project was the 'The Road to Employment' (RTE) project. This project aimed to address barriers to disability employment (including tackling negative attitudes held by employers about disability (Hemphill and Kulik 2016). Despite Australian employers' attitudes towards hiring people with disability becoming more favourable, actual hiring has declined (Hemphill and Kulik 2016). This decline suggests that employers need to learn from people with disability and their allies and advocates about how to improve employment opportunities. The RTE project aimed to capacity build community and focus on challenging attitudes as part of improving employment.

This combined focus on inclusion in policy intentions, co-design, and inclusive research to shift more control to people with disability is a fertile context for this article. The gaps between intention and practice inform the development of the research question for the article: How can the use of co-design shift power towards people with disability within commissioned research?

Case example

The case study for the analysis was research about the project Road to Employment (RTE), which is managed by a non-government organisation, Julia Farr Association Purple Orange, in Adelaide, Australia. The project objectives are to (a) increase confidence and capacity of people with disability to gain employment and for families of children and young people with disability to

include a vision of paid employment; (b) increase confidence and capacity of employers across a range of industries to create inclusive recruitment processes and workplaces; and (c) improve inclusive workplace practices and increase employment outcomes for people with disability across a range of industries.

The project has three activities to meet these objectives: (1) Capacity-building workshops with students, family members, and teachers; (2) Business Mentoring Services to assist businesses to build welcoming and accessible workplaces; and (3) Communities of Practice (COP) for finance and aged care industries. The COPs are working to reduce barriers to employment for people with disability in each industry. The COPs are co-chaired by a person with disability and have people with diverse employment experience (employees, community members, government representatives, academics, CEOs).

There were several layers of co-design in this project, at work in both the research and the project:

- co-design research (the subject of this article)
- co-design project (the employment project case study)
- co-design activities (e.g. meetings, workshops, community of practice groups).

The research co-design practice can be seen in framing and methods. The research tender specified co-design methods. The research was conducted by researchers from two Australian universities comprising academics at a range of different career levels, with and without disability.

The RTE project co-designed the activities, with particular emphasis on leadership and meaningful involvement by people with disability. People with disability were employed as staff in the RTE project and industry workplaces; and involved as experts through the Communities of Practice.

In this paper, we analyse these aspirations and the practice of the research co-design. Data are from the research proposal, research baseline report, meeting minutes, and emails between project leaders and researchers. The process of analysis focused on the roles of the people with disability in the research team, the project team, and the co-design groups.

Methods

This article concentrated on the co-design during the research proposal and initial stage of the research (September 2020–January 2021). It is not about the RtE activities, which are ongoing at the time of writing.

The data for this article included program and research documents and emails about the research co-design. These documents pertained to tasks relevant to research co-design, and outputs from the co-design process, including the research brief from the NGO; the research proposal from the

universities; the drafts and final baseline report and minutes from the research, NGO, and employment groups. The emails were correspondence within the research team and between the researchers and the NGO used in the process of co-design.

Analysis and presentation

We have applied an assemblage analysis, following Feely's (2020) adaptation of Deleuze and Guattari (2004) work, which recognises that both semiotic and material factors are at play and in constant interaction with each other. Feely's three stages of assemblage analysis (2020, 7) are:

1. identifying components or relations relevant to co-design
2. mapping flows
3. exploring processes of 'reterritorialisation and deterritorialisation'.

Components are factors or conditions that enable or constrain the process of co-designed work, such as who was in the team, what kind of resources were available or needed, and where and how the project worked. **Flows** consider how these aspects and components relate to each other. For example, the macro level funding context surrounding commissioned work and the resulting effect this has on internal dynamics and relations within the team. **De- and re-territorialisation** refers to the analysis and discussion of how authority and power in the project shifts and continually changes depending on these components and how they interact in ways that facilitate and enable co-design or constrain it.

Assemblage analysis proved to be a particularly useful way to identify critical analysis of power relationships. The process for analysis consisted of coding and preliminary analysis of the data sources by two of the authors. The process was to first identify and code the three components in each document, then assemble the coding about same topic in other related documents. For example, in the first finding about socio-political context, starting with coding from the NGO documents about the topic, then assembling the coding about the components on the same topic from other documents.

The two authors cross-checked each other's coding and analysis and discussed discrepancies with a third author until agreement was reached for inter-rater reliability. This discussion process was repeated with the rest of the authorship team, requiring the first two authors to return to the documents to resolve discrepancies until agreement was reached. Reflective iterative dialogue was important because of the different positionalities of each of the authors within the research team, including disability, seniority, and work security.

Limitations

This paper reflects on the initial stages of a longer research project, and consequently, data had not yet been collected on some aspects of the research, such as the experience of members in the groups where co-design occurred. For this reason, the opinions of the people with disability in the groups about their experience of the meetings and activities were not available for analysis. Data were not available about some aspects of the co-design. For example, not all Community of Practice meeting minutes were available for review.

Findings about power shifts in co-designed research

The findings from this research project are presented and grouped according to Feely's (2020) three stages of assemblage analysis.

Stage one—identifying components and relations relevant for co-design

The first stage of Feely's assemblage analysis 'involves identifying the disparate components, forces or relations' that, in this case, constitute co-design of disability research (2020, 7). The document analysis and review of email communication identified societal and broader contextual conditions, institutional and project components, and inter-relational forces that affected the co-design in the research. These different components were visible across the research practices, for example, the Community of Practice group, and affected the way in which co-design could, or could not, unfold in the research.

Socio-political and funding context

In the analysis, we asked what components facilitated co-design and enabled people with disability more authority and a greater say. We looked for how co-design was referred to and implemented and searched for factors that enabled co-design. First, we looked at the components within the NGO. In the briefing documents provided to the research team, it was clear that the NGO prided itself on being a peer-led organisation founded on principles of co-design and co-production:

Our work is characterised by co-design and co-production and includes hosting a number of user-led initiatives ... Much of our work involves connecting people living with disability to good information and to each other. (Evaluation tender briefing document)

People with disability serve as members of staff and the board, and they are involved in a range of project activities and decisions. The NGO's values and core governing principle of co-designing with people living with disability is central to all of its activities and significantly shape the outcomes projects have in the community (JFA Purple Orange 2021).

The NGO's vision to ensure peer leadership of people with disability also meant that the evaluation tender briefing document included specific requirements for the successful researchers to 'apply co-design to all parts of the research' and 'ensure that activities are inclusive of people with disability'.

Next, we looked at how the wider conditions of funding for the employment project affected the research co-design opportunities. Disability policy reforms like the implementation of Australia's Disability Strategy and National Disability Insurance Scheme (NDIS) reflect broader social-political conditions for co-design in projects and set out current expectations of good practice in the Australian disability community (Reddihough et al. 2016). The NGO project (and subsequent research) is funded through an Information, Linkages, and Capacity Building grant, administered by the Australian Government Department of Social Services. The conditions of funding for these grants also require demonstration of meaningful inclusion of people with disability in the design and delivery of the projects (DSS 2021). There is a movement and recognition in government, services, and broader community of the value of co-design and authentic inclusion of people with disability in project design, delivery, and evaluation and this is often seen as a strength in securing funding. Funding arrangements where co-design is specified as a requirement sets the standards for authentic co-design and is key to shifting power towards people with disability and ensuring they have a say in commissioned research.

Institutional and resource-related conditions

The second central component influencing shifts in power in the co-design concerned the institutional and resource related conditions. One example of institutional factors included the legislation and regulations in place about not meeting in person due to the COVID-19 pandemic.

The COVID-19 pandemic and the physical restrictions to meet in person, enforced by the institutions involved [NGO and universities] meant that several co-design activities and meetings had to be postponed or cancelled. (Baseline report)

While for some people the COVID-19 pandemic aided accessibility and meant that they could participate from the comfort of their own home if they had access to a computer, there are also many people who found online communications inaccessible.

The employment project and research about the project were also affected by conditions, such as limited time and finite resources for the project and research. These restrictions are common to most research and practice projects however they do create barriers, particularly when needing to build relationships and negotiate the time needed to truly work with people with disability in an authentic and collaborative way. To manage limited staff capacity and funding, the researchers opted for online meetings and email communication, over inter-state travel and in person meetings. These decisions had both benefits and costs to the participation of people with disability in the co-design process. For example, technology was useful to bridge barriers, such as distance, but raised other accessibility barriers that were difficult to resolve. This underlined the importance of having a collective of diverse people involved:

There's learning in the doing of things. In projects, you can bring a diverse group of people together – there are things you only learn by having been in the position of having been through it. (Amanda, NGO staff member with lived experience)

Online meetings and the increased reliance on this format due to the pandemic and associated regulations meant practices were not fully accessible to everyone involved in the research. Resolving these barriers took considerable time to negotiate as it required liaising between the federal government funded Employment Assistance Fund, university administration, and research team members and was only partially successful, as funding for accessible captioning was rationed, which meant relying on less accessible automated transcription services to fill gaps. The time and labour it took to negotiate these aspects of accessibility were aggravated by institutional, funding, and project budget limitations.

Institutional and project impact

When analysing material and semiotic forces it was evident that institutional and project conditions affected the way project resources could be activated over time in two distinct ways.

Firstly, the baseline report identified a dual challenge arising with the aspirations of co-design work. People with disability were present in the NGO staffing, governance, and research of the employment project from the start, although less represented in managerial or permanent positions. Their presence set a strong foundation for reliance on diverse skills and perspectives within the organisation and research team. However, it took longer for the employment project to identify people with disability for the Community of Practice groups. The delay may have impacted on how the co-design was practiced and research priorities set in the early stages.

[Co-design] is also a challenging aspect of the employment project. It takes time to identify industry champions [for co-design] and generate sustained interest and momentum in the project and implement actions. (Baseline report)

Secondly, the project conditions constrained the processes of co-designed work in the resourcing allocated for certain co-design activities. The review of project meeting minutes found that some co-design groups met infrequently. Hence, there was considerable time in between the co-design meetings, which restricted meaningful engagement in decisions about priorities and design choices.

Relations and attitudes

Relations and attitudes were another component affecting conditions of co-design in the research about the project. These factors affecting the co-design were visible in the dynamics of trust building and managing relationships or tensions; how diversity within the groups was recognised and valued; and in ensuring that there were conversations and dialogue to enable people to discuss beliefs that were helpful, or unhelpful, and respectively how beliefs shaped day-to-day practice in the co-design process.

[in the] big co-design group we have different opportunities to share experiences. It's not just same person reporting back each time. This creates opportunities for leadership. (Community of Practice member)

The co-design groups were formed in each part of the project and research, within the NGO staffing and governance, with the participants, and with the researchers. The inclusive approach to co-design meant recognizing that people are products of the society in which they are surrounded by and thus may have ingrained ableist beliefs and attitudes which may at times cause conflict between group members which needs to be managed. These exchanges were not usually intentionally disrespectful, but they reflected diverse beliefs and attitudes about disability that reinforced discriminatory power structures. The researchers and project staff actively negotiated these tensions. One of the researchers included a reflection in an email exchange with the research team after a co-design meeting that demonstrates the tension and the relationship management.

I did have a very quick chat with [facilitator of the employment co-design group] after their meeting, and we both agreed that the meeting went really well. We acknowledged the ill-informed comments from several of the group members ... I highly doubt anyone would want to put in a complaint (of course that is my opinion from just reading the room). The comments, despite being offensive, were made from a place of ignorance.

The excerpt speaks to the need to actively manage relations and dynamics between co-design members, in particular avoiding and managing tensions and offensive comments, while also ensuring everyone has the opportunity to be involved and heard. Despite some short-lived tensions, across the co-design groups we found ample evidence of a culture of respect and valuing the voices of people with disability, which were an important factor in effectively supporting the groups.

Stage two—mapping social and material flows

In the second stage of assemblage analysis, we examined how the components identified in stage one—socio-political context, funding and time, resources, institutional regulations, technology, relations, and beliefs—interacted and reinforced one another, thereby facilitating or hindering the shift of power to people with disability in the co-design process.

Analysis of how the co-design groups functioned found that managerial practices created and enhanced conditions favourable to co-design. The actions of managers and group facilitators were key to setting up conditions conducive to co-design where people felt able to contribute with authority.

Accessible practices for all group members

Managers and group facilitators established practices and communication structures that were accessible to all members of the groups. Examples included informal and formal briefings and reflection before and after meetings, finding communication tools that were accessible to all, use of verbal and non-verbal cues to manage interpersonal dynamics during meetings, establishing ‘meeting rules’ that created safe spaces for questions and open discussion, and modelling appropriate meeting behaviour. An example of how equitable communication practices and technology enabled steering group members to communicate directly with the research team was email feedback by a lived experience steering group member.

So pleased that you are doing the formative evaluation with PO [the NGO]. I found myself quite moved when you were talking about working in solidarity with PWD [people with disability], and realised that I so seldom hear that approach articulated with such genuineness and lack of competition or condescension.

Core roles for people with disability

Having people with lived experience in all the research co-design was informed by the research funding agreement and organisational governance of the NGO, both of which prioritised the value of lived experience. The

involvement of staff with disability in the project and co-design groups was important for balancing power, authority, and relational dynamics in several ways. One practical example from the research team and co-design groups was the managers' focus on building capacity and supporting people with disability to lead meetings.

Other conditions that facilitated this approach were the socio-political conditions and expectations of representation of people with disability, discussed in Stage one of the analysis. Implementing these conditions of representation needed commitment from the group coordinators. That commitment was evident where coordinators worked to provide multiple avenues for participation of people with lived experience:

In the co-design working groups we ensure there are alternative ways of contributing ... and for people to be involved, in addition to attending or speaking at the meetings. This could be participants sending through a comment via email. ...We always have a conversation at the start of a meeting, asking what the attendees need to feel supported in the group...We also try and follow the agenda as much as possible, so people can prepare for it (coordinator).

Managerial practices created trusting, respectful, and safe environments. An example was email feedback from the NGO on the role of lived experience in the Baseline report.

Some great guidance here [in the Baseline report] in connecting with our steering group on the employment project.

Relations and attitudes

Across the co-design groups, we found many examples of a culture of intentional respect and valuing the voices of people with disability in the way the groups functioned. Despite this, the need to actively manage relations and interpersonal dynamics between co-design contributors was evident. The need was to ensure that everyone was heard and had opportunities to be involved and to manage tensions between competing values.

You've got increase the amount of time you're putting into the meetings to enable people to exhaust discussion; breaking down further into co-design groups to enable people to have more ease of input (staff member with lived experience).

People with disability had important, but not dominant voices in the co-design groups. While people were working towards a shared goal, individual views were aired at times which did not align with the project aim or purpose. When ill-informed or negative comments were made in these groups, it was often people with disability who identified and spoke up to counteract ableism. Project leaders and facilitators observed the power of people with disability in these situations and the confidence with which

people spoke up. They made decisions about when to name the negative views and the potential negative impact and evidently felt safe and supported to speak up with minimal repercussions.

The involvement of researchers with disability in the team shifted perceptions about the research in ways that would not have been possible for a team without lived experience expertise. For example, a theme in the baseline report was the importance of creating safe spaces and practices within the co-design groups. Advice from the research team, which was generated from the expertise of our team member speaking from both research and lived experience, was well received and carried forward into other parts of the employment project design.

Use and impact of technology

Technology was a mostly useful material condition for co-design in the research about the employment project. Technology was used by the co-design groups to share information, schedule and hold meetings online and in person, to record or document activities. Technology was mostly useful to bring people together, especially during the COVID-19 lockdown periods. At times, however, it was a barrier to the quality of interactions, reflected in this researcher email.

[The research team] had the benefit of a face-to-face discussion yesterday, communication is often difficult over emails 😞

Online meetings and email communication were helpful to support the co-design groups and enabled the research team to work efficiently. The technology also had limitations, particularly the confidence of members using online meeting platforms and problems with accessibility (e.g. captioning). Some online meetings increased access barriers and restricted researchers' full participation without additional access to captioning, which meant the technology constrained the co-design. Efforts in this case to use online meetings and prioritise the voice of lived experience were undermined through institutional (university) access funding restrictions and project budget limitations.

This second part of the analysis showed that while people grasped multiple opportunities to use co-design for impact in the project, managerial practices were pivotal as an enabling force to facilitate the conditions for co-design.

Stage three—the shifting or maintaining of power

In this third stage of the analysis, we examine how and when the conditions and flows that supported co-design shifted power to people with disability, and when they retained existing power imbalances.

Strengthening authority of people with disability in decision making

The interactions in the forces and flows were evident across practices, relationships, and institutional conditions. The co-design activities and relations in the research about the project involved people with disability using ways of relating that aimed to be accessible. These practices resulted in times when the voices of people with disability were prioritised. For example, a member of a Community of Practice reflected on how they used their experiences of past discrimination as reflective opportunities to shift attitudes in their group and improve shared expectations:

being able to provide those insights to the discussion group [allows us to] work through that and go, “Okay, here’s a problem, guys, how do we all fix it?”

An example of managerial practices to prioritise lived experience in the co-design is illustrated in the following email exchange within the research team initiated by a researcher with disability. The benefit of this approach was that new ways of thinking about the research arose.

I wondered if the role and employment status of people with disability in relation to others around the table may also help buffer some of the emotional labour (the cost of being a person with disability countering thoughtless comments about people with disability in room). It sounded like [in the group] there was a coming together of professionals (and people with disability organically, identified as both professional & people with lived experience). I think this counters tokenism and promotes relational respect of views, and the sharing around the table too, and reduces divisiveness.

The researcher reflected on the ‘status of people with disability in relation to others’ in the employment project, and by doing so, raises questions about the effect of the co-design process itself. It is a critical remark which prompted researchers to question power and the conditions that enabled the authority and privileging of people with disability. The analysis of email communication demonstrated that while all researchers were listened and valued, there was also a sense of prioritising and valuing the authority of lived experience researchers and the effect this has on interpretation of key issues in dialogue and reflection.

These shifts in expertise led to practice implications in the early research report about promoting a culture where people with disability felt supported across the employment project. Examples from the co-design groups were about who should first respond to questions in the group, or which ideas for action were shortlisted and followed through by the group. Together with the other managerial practices (regular opportunities for reflection, feedback, working to improve accessibility of communication) and a culture of mutual respect, the research team approached co-design as both a principle and process.

While these were intentional efforts to value the experiences of people with disability, the power shifts remained fleeting and did not challenge existing hierarchies. Intentional actions needed to be taken and re-taken (as detailed above) for new authoritative voices to be heard, by the people who held positions of power. It requires a degree of conscious questioning of power and ongoing action to disrupt 'who' has power.

Institutional and project constraints—time, resourcing, technology

Lastly, we examine the conditions and flows that undermined the effectiveness of managerial practices intended to shift power within co-design. Institutional and project constraints were sometimes counterproductive to shifting power and instead reinforced dominant and ableist norms.

In the research team, it was evident that we needed a more nuanced framework than 'lived experience' to understand and articulate multiple power structures and the ways they intersected across research and projects. For example, the researchers with disability who had experience in using the employment support we were researching were less involved at the start of the research design, setting up the conceptual framework, and writing the research application. Similarly, university researchers with lived experience working in casual positions only came into the project once it had already been established. Due to their absences in the early stages, there were limited opportunities to shape the research design, the scope, or resourcing of some research activities.

We found that some co-design practices, for example, the structure and frequency of meetings, potentially constrained the input of people with disability. Co-design groups that only met occasionally likely constrain authoritative influence for people with disability in the project.

Technology, as identified in the conditions (Stage one) and assemblage flows (Stage two) of the findings, was identified as helpful for communication across different locations and facilitating groups to meet online and also meant managers could work with limited research and project budgets. When technology presented new access barriers (e.g. captioning costs), these barriers undermined efforts to shift power to people with lived experience.

Discussion

The article addressed the question of how the use of co-design can shift power towards people with disability within commissioned research. The question was applied to research about a disability employment project, where people with and without disability were involved in the research and project. The analysis used assemblage methodology to analyse the ways that

power was shaped in the co-design process (Feely 2020). The analysis found that the structural conditions of funding and institutional support for co-design were foundational to setting up conditions conducive for co-design. Managerial practices and management of social flows (counteracting ableism, offering support, and setting up positive norms in group) and material flows (e.g. accessibility requirements funded and established roles for people with disability) were key enablers that shaped and influenced positive experiences of co-design (Fitzpatrick et al. 2023; Nind et al. 2016). However, progress was easily undermined by institutional processes and attitudes when they did not respect the value of lived experience.

The requirement outlined in the research funding meant the research team, approach, and methodology must be inclusive of people with disability. This was a key facilitator in strengthening power of people with disability. These funding conditions are reflective of wider recognition of the strength of co-designing with people with disability in policy (Aldridge 2017; Chalachanová et al. 2020). Project managers and group coordinators also had a key role in instigating intentional efforts to recruit people with disability with expertise to all co-design groups and setting standards and conditions of co-design in practice. Their commitment to these co-design processes meant that they had resolve to address problems in power dynamics and disrespectful interactions when they arose.

Recognising ableist norms in project work: everyone's work to counteract

The analysis identified project conditions and factors that strengthened positioning of people with disability in the research co-design but also restricted their influence in the way time and resources were managed. As other researchers have noted traditional research practices are often operationalized in ways that limit the authority of people with disability and inhibit power in decision making (Durose et al. 2017; Voorberg, Bekkers, and Tummers 2015). In this project, these norms include time constraints, inaccessible practices, underfunded provision for accessibility, insecure employment, and prior research experience. Often these factors are ingrained in institutional structures and are taken for granted. Many who work within these conditions may not notice how these conventional project norms and expectations impact their work environment and colleagues with disability in ways that perpetuate ableism (Nario-Redmond 2019).

Taken together, these factors meant that some of the people with disability were less involved in initiating activities, such as setting up the project, and were not part of writing the research proposal. They were involved within these processes after the structures were established. Their late entry had an impact on their authority, as it was harder to change terms and conditions that are already been established. These constraints

affected the capacity of team members to invest in secure relationships and contribute to information sharing, decisions, and actions. The adoption of a co-design approach opened space to interrogate and counteract these unexamined ableist norms of project management (Campbell 2019). Part of creating an affirmative environment meant project managers acknowledged and responded to these constraints affecting people with disability and were cognisant of these while facilitating the goals of co-design. A reflective dialogue about these constraints contribute to a sense of solidarity and reciprocity and create conditions where its safe for people with disability to speak up, negotiate issues, and share their knowledge (Locock et al. 2022).

Inclusive recruitment and hiring policies and practices meant that people with disability were in positions where they had autonomy and influence in the research, but these policies alone do not ensure a cultural shift (Puyalto et al. 2016; Strnadová and Walmsley 2018). Across both the co-design research and project groups, continual reflection was needed, particularly in managerial positions, about how the authority of people with disability was valued in process (e.g. meetings) and outputs (e.g. documentation). In addition to reflection and dialogue, action and practices were also vital, ensuring the views of people with disability were prioritised intentionally, and that people with disability were employed. Affirmative employment policies and practices were important to achieve this.

The analysis of these inclusive practices aligns with findings from other studies about co-design. They demonstrate processes to build trust within and between groups, reassure members that it is a safe space where negative attitudes and practices can be counteracted and where people with disability are valued as equal contributors and colleagues (Aldridge 2017; Armstrong et al. 2019; Chalachanová et al. 2020; Nind 2017; Roennfeldt and Byrne 2021).

We identified three key factors that shaped co-design to create or hinder opportunities for shifting power. The factors were socio-political and funding conditions, relations and attitudes of groups and individuals, and co-design processes. They all have implications for policy and practice in co-design practice.

Socio-political and funding factors

Co-designed research can be empowering for people with disability, and de-territorialise current spaces and processes when it occurs at all stages of the research. This means including people with disability from the beginning and maintaining relationships throughout the research. This timing is a challenge in commissioned research, where funding does not flow until after

grants are awarded. Yet the quality of research proposal relies on the involvement of people with disability in the future research team.

Co-design takes time and money to do well. While co-design is increasingly recognised as a feature rather than a constraint (Blomkamp 2018; SCIE 2015), accounting for it in research budgets and timelines remains challenging. Many research funders seek cost-effective research, alongside co-design with people in research that affects them. The involvement of researchers with disability, especially in action research or in projects that aim to change policy, can mean that research is more likely to be well-targeted and effective in terms of impact and cost (Palmer et al. 2019; Roy, Mcvilly, and Crisp 2021).

The COVID-19 pandemic and geographical distance had a particular bearing on the way we engaged in this research. Technology was essential for practical purposes, and also facilitated relationship building between all group members in the research and project teams, particularly through email and online meetings. Email ensured that any observations were shared with all group members, ensuring they were included, and contributed to the richness of project data, analysis, and reflection. Online meetings bridged geographic distance and lockdown restrictions. However, some technologies were partly inaccessible to some members, due to imperfect accessibility features in software and limits to funding available for human-assisted alternatives. As more meetings are held in virtual or blended modes, not just because of COVID-19 restrictions but also because of new ways of working and collaborating, the implications for increasing access are important across groups.

Relations and attitudes of groups and individuals

Perhaps one of the important findings of co-designed disability research is that considering cultural safety is essential when working with people with disability. This consideration is one that arguably all disability research projects must engage with to avoid harm. Cultural safety has grown from, and is most often applied to, First Nations and LGBTQ+ contexts and is extending to disability research. It is not up to researchers with disability to change themselves and their practices to fit in; researchers should be working to 'crip' institutions and research practices in ways that 'acknowledge, reflect on, and address bias that could make people from other cultures feel unsafe engaging a system or service' (Hadley et al. 2022, 4). In this project, senior researchers attempted to equalise the power relations within the research team by sharing tasks, creating opportunities for authorship, reframing meeting processes to support access, and managing funds to maximise co-design processes. However, the reflective analysis found that our progress is fragile and easily undermined, often by our own and others' inadvertent lack of learning from reflections about the co-design.

Reflections on using assemblage analysis

Applying Feely's (2020) assemblage process was useful to analyse the material and socio-political factors that facilitated and hindered the development of co-designed research. The framework highlighted factors that we might otherwise not have noticed, but that were integral to the study of co-design. Sometimes it was difficult to tease out the different factors, flows, and shifts in power or not, as some findings seemed to fit into multiple categories. One of the ways we simplified the framework was to use the term 'shifting power' instead of 'deterritorialisation' (a term coined by Deleuze and Guattari 2004). 'Deterritorialisation' was difficult to understand and we wanted our research to be accessible, including explaining the concepts. The term 'shifting power' was the part of assemblage we were most interested to analyse.

Conclusion

The analysis found that the expertise of people with disability were included in each stage of the project and research, but more participation was evident in the later stages than the earlier ones. Structural conditions of funding and institutional support for co-design was foundational in setting up conducive conditions for co-design. Findings from this paper demonstrate the importance of including people with lived experience in professional capacities earlier in co-design. Early engagement to influence the framework requires established relationships, resources, or decision-making positions to cope with time constraints on contracted research.

The combination of structural, socio-political, and funding factors make it more difficult for people with disability to influence commissioned research in its developmental stages and may inherently privilege the voices of managers and coordinators (who are more likely, albeit not always, to be people who do not have lived experience of disability). People with disability were involved across all levels of this project and research evaluation. Ironically, like other research, people whose lived experience had the most direct connection with the aims of the employment project were less likely to experience the structural conditions that supported their influence in the design of the research. These conditions were secure employment, seniority of position, and influence in their organisation. The effect of this common structural barrier was that while highly valued and valuable, their participation was invited rather than underpinning the research, and their contributions informed the methods rather than the framework of the research.

Projects are not co-designed by virtue of being labelled as such; rather they must afford researchers, project members, and other contributors with disability equal places in the process to decide on project and research directions and methods. Generating change through co-design demands more of

us acknowledge ableist norms and structures and build structural change that supports the empowerment of researched communities through co-design processes that lend credibility as a legitimate and emancipatory way to perform research and evaluation.

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