



Article

Structures of Oppression or Inclusion: What Systemic Factors Impact Inclusion in Disability and Rehabilitation Research?

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Abstract: This manuscript considers the drivers towards inclusive research in the field of disability and rehabilitation; including some of the tools and frameworks that may support its realisation. We, a group of researchers engaged in rehabilitation research from lived experience and ‘conventional’ (non-lived experience) positions, reflect on our collective endeavours to bring about inclusion in research and specify the systemic factors constraining inclusion in research. We conclude by asking the following: how might we reimagine systems where the mechanisms of research production are in the hands of those impacted by the research, and where are intersectionalities both sought and valued?

Keywords: inclusive; disability; rehabilitation; research



Citation: Layton, Natasha, Rachele A. Martin, John A. Bourke, and Nicola M. Kayes. 2024. Structures of Oppression or Inclusion: What Systemic Factors Impact Inclusion in Disability and Rehabilitation Research? *Social Sciences* 13: 229. <https://doi.org/10.3390/socsci13050229>

Academic Editors: Patricia O'Brien and Barbara Fawcett

Received: 31 January 2024

Revised: 23 March 2024

Accepted: 4 April 2024

Published: 23 April 2024



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1. Introduction

In 2022, O'Brien asked the question, ‘Is the road more or less well travelled?’ The resulting Special Issue and published book explored the epistemological leadership of intellectual disability researchers and asked how inclusive research might be realised in different fields (O'Brien 2022). This work considers the drivers towards, and barriers to, inclusive research in the fields of disability and rehabilitation.

1.1. Positionality and Scope of This Paper

We are a group of researchers engaged in disability and rehabilitation research. We bring diverse perspectives to our research endeavours, including lived experience of disability (JB), occupational therapy (NL), physiotherapy (RM), and health psychology (NK). We share values of social justice and inclusion and a commitment to equity in access, experience, and outcome. In this paper, we ask how we might know what voices are included in our research and critically examine some tools proposed to support inclusion in disability and rehabilitation research, identifying what good might look like. In terms of scope, this paper is not intended as an exhaustive review of existing theory, evidence, and tools relevant to inclusion in disability and rehabilitation research. Rather, we relate our own research experiences which speak to the structural barriers and systemic factors that enable, or constrain, inclusion in research in our field in Australia and New Zealand. We would add a note of explanation on our focus on disability as a hallmark of inclusion, versus inclusion more broadly. Inclusion, or exclusion, is likely an intersectional experience, for example, for rainbow communities and different gender identities, migrant and ethnic

communities, with many more factors contributing to the rich breadth of the human experience (Smith et al. 2024). In this paper, we refer to examples primarily relevant to inclusion in research for disabled¹ people to exemplify our points and as one example of a community who have been historically excluded, marginalised, and disadvantaged. We suggest many of the issues highlighted extend to other routinely excluded communities. Finally, we do not consider ourselves an authority on inclusion in research and recognise that the arguments we offer here are inherently partial, informed by our own perspectives and experiences. Notwithstanding these limitations, we hope the arguments and examples presented provoke critical discussion and reflexivity and contribute towards a culture of inclusive research in disability and rehabilitation.

1.2. What Is Meant by Disability and by Rehabilitation?

Our work as practitioners and researchers is, at times, within disability services structures, rehabilitation structures, or both. These contexts influence our practice, research, and efforts toward inclusion and so here we provide a brief background of each and how their epistemologies both intersect and depart. Disability, according to the *World Report on Disability* (World Health Organisation 2011), is ‘part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life, and those who survive [sic] to old age will experience increasing difficulties in functioning’ (p. 3). According to the World Health Organization International Classification of Functioning, Disability and Health, the experience of disability arises from the interaction of impairments, activity limitations, and participation restrictions (World Health Organization 2001). Rehabilitation is ‘a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment’ (World Health Organisation 2017, p. 2). Global efforts to improve access to rehabilitation are underway (Heinemann et al. 2020) based on the premise that rehabilitation ‘may benefit any person with a long-lasting disability, arising from any cause, may do so at any stage of the illness, at any age, and may be delivered in any setting’ (Wade 2020, p. 571).

These definitions suggest that impairment and the resulting disability, operationalised as a decrement in functioning, can be addressed through the provision of rehabilitation. However, the disability academy describes tensions between this normalising discourse of rehabilitation and disability identities, providing a rich description of human engagements with difference. The biomedical approaches that have underpinned much of rehabilitation practice are critiqued as representing a limited lens on human functioning and wellbeing (Wade 2015). Failing to capture psychosocial and relational dimensions does not tell the whole story; see, for example, (Bright et al. 2023; Fisher and Goodley 2007). Rehabilitation has also (by and large) failed to consider the needs and aspirations of people over the whole of their lives. Rather than adopting a holistic approach that encompasses alterations in environments, personal factors, and resources over the lifespan, rehabilitation has predominantly been dispensed through isolated intervention episodes triggered by emergent or pivotal shifts in individuals’ health conditions (Palisano et al. 2017).

The systematic emergence of counter models (Brisenden 1986) and narratives (Shakespeare 2006) provide signposts regarding the imperatives of people living with disabling impacts or impairment. Shakespeare describes rehabilitation as ‘a controversial subject in disability studies, often discussed in terms of oppression, normalisation, and unwanted intrusion’ (Shakespeare et al. 2018, p. 61) but argues access to rehabilitation is a human rights issue of critical importance. Critical rehabilitation discourse is bridging this epistemic schism (Gibson 2016; Gibson et al. 2020). However, it remains an aspiration rather than routinely embedded in everyday practice (Gibson et al. 2020; Kayes and Papadimitriou 2023). Inclusive research, which values and legitimises the expertise of people with lived experience in knowledge production and dissemination, may be a critical step in realising these aspirations for person-centred and inclusive rehabilitation.

Epistemologies of resistance recognise that multiple voices are not heard within power structures within society, including the construction of knowledge through research (Barnes

1996; Fawcett and Hearn 2004). Implications of the partial representation of people with various lived experiences who have been typically underrepresented and undervalued are profound in terms of making decisions regarding agendas, priority setting, determining valued outcomes (Rist et al. 2008) and the representation of human diversity within society (Dirth and Branscombe 2017).

Rehabilitation services are commonly delivered through health systems, and some developments in health research are indeed positive. Research texts acknowledge biopsychosocial and critical alternative models of human functioning (Hathcoat et al. 2019). In health settings, ‘patient voices’ are built into structures through ‘patient mandates’ (Finset 2017; Te Tāhū Hauora Health Quality & Safety Commission 2022). In health research, lived experience expertise is frequently sought by funding bodies, and there is growing interest in research methods enabling research ‘with’ rather than ‘on’ participants (Kayes et al. 2019). The inclusion of people with various lived experiences is also promoted as one way to improve the translation of research knowledge into healthcare practice (Grindell et al. 2022) with networks such as the Cochrane Consumer Network (Cochrane Collaboration n.d.) focusing on knowledge translation for the users of health.

We suggest the initiatives described above provide many signals regarding ‘what good would look like’, yet responses resemble compliance rather than system transformation. Therefore, it is timely to examine research inclusion from our standpoints as disability and rehabilitation researchers and consider whether our field is making substantive progress towards ‘inclusion’ in research.

1.3. Intersectionality

A key metric for research is the production of research outputs, including reports and peer-reviewed artefacts. Therefore, one measure of representation, although rather blunt, might be the proportion of research authors identifying as experiencing disability. This question of the proportion of research authors identifying as experiencing disability immediately requires us to acknowledge the multiple dimensions of identity that people hold, the subjectivity and contested nature of identity, and the limiting binary of ‘disabled/non-disabled’ inherent in this question (Patston 2007; Smith et al. 2024). Given the history of marginalisation and exclusion experienced by people experiencing disability (Charlton 2000), it would hardly be surprising if some researchers choose not to articulate the dimension of disability experience (Brown 2020; Griffiths 2020). Authors experiencing disability may or may not identify as such and, where they do, may use inconsistent nomenclatures (what it is called) and locations (where it is written). The lack of common or agreed terminology is illustrated in Table 1 of phrases used within academic databases.

Table 1. Key phrases and words used within the literature.

Phrase
researchers with disability
disabled researchers
researchers with lived experience of disability
lived experience of disability
citizens with disability engaged in research
partnership with citizens with disability
lived experience led research
researchers with lived experience
co-researchers with disability

This situation calls for a critical examination of authorship, both to examine what identities are privileged and made to matter in peer-reviewed publication processes (implicitly or explicitly) and to mitigate the risks of disclosing one’s status as disabled. The development of reporting guidelines for research inclusion, for example, requiring that researchers include a positionality statement as standard, may be indicated.

An array of guidance relevant to inclusion in rehabilitation research can be found in allied fields and has the foundational concept of a hierarchy of participation in common. Since Arnstein’s 1969 ladder of citizen participation (Arnstein 1969), hierarchies have been described for public participation (informing; consulting; involving; collaborating; and empowering) (IAP2 2018) for inclusion of people with disabilities in research (as participant, consultant, collaborator, colleague, or director of research) (Layton et al. 2022), and to guide culturally responsive ethical engagement (Hudson et al. 2010) (Table 2).

Table 2. Hierarchies of research inclusion.

International Association for Public Participation (IAP2) (IAP2 2018) Source: Social Sciences	Ladder of Inclusive Research (Layton et al. 2022) Source: Disability	Te Ara Tika Framework (Hudson et al. 2010) Source: Māori ethics
 <ul style="list-style-type: none"> • Empowering: the public is not only involved in all steps of the process, but the final decision sits with the public. • Collaboration: partner with consumers in all aspects of decision making, including engagement in the final decision. • Involving: work directly with the public throughout the process and ensure public perspectives are included. • Consulting: obtain public feedback, acknowledging concerns, but not necessarily incorporating this within decision making. • Informing: share information and support understanding of decision making. 	<ul style="list-style-type: none"> • A director of research, in charge of research production: person commissions research and directs researchers in methods/research question/study design/outputs and dissemination. • Research colleague: person is an equal partner in establishing outcomes/findings/method/study design/research question. • Research collaborator: person collaborates about outcomes/findings/method/study design/research question. • Research consultant: person is consulted about outcomes/findings/method/study design/research question. • Research subject: person being researched is asked questions decided by others. 	<ul style="list-style-type: none"> • Best practice: Kaupapa Māori Research addressing questions determined by Māori, for Māori; Māori lead and govern the research and lead research planning, development and execution; the research team and research participants are typically all Māori; Māori values underpin the research process, Māori research methods are used, and Māori knowledge is produced; data are owned by Māori and Māori determine how the findings will be used for the benefit of Māori; research meets expectations and quality standards set by Māori. • Good practice: Māori-Centred Research which aligns with Māori aspirations, and which is relevant to and addresses a question important to Māori; meaningful relationships are established with Māori communities and shape the research direction and process; Māori are typically senior members of research teams; research processes are informed by Māori cultural protocols; Māori-specific analyses are undertaken and produce Māori knowledge, albeit measured against mainstream standards for research. • Minimum standard: Research involving Māori which may or may not have direct relevance to Māori; Māori are involved as participants; researchers consult Māori and seek to protect the rights and interests of Māori; research processes are culturally sensitive; ethnicity data may be sought and analysed.

2. Analysis of Structural Barriers

Our collective experiences as researchers in disability and rehabilitation suggest that aspirations to enact inclusion are impeded by structural barriers (see also Williams et al. 2020). Figure 1 lists observed structural barriers to inclusive research. These are discussed in more detail below, alongside examples which demonstrate the opportunity for reimagining disability and rehabilitation research systems and creating the context for inclusive research practices.

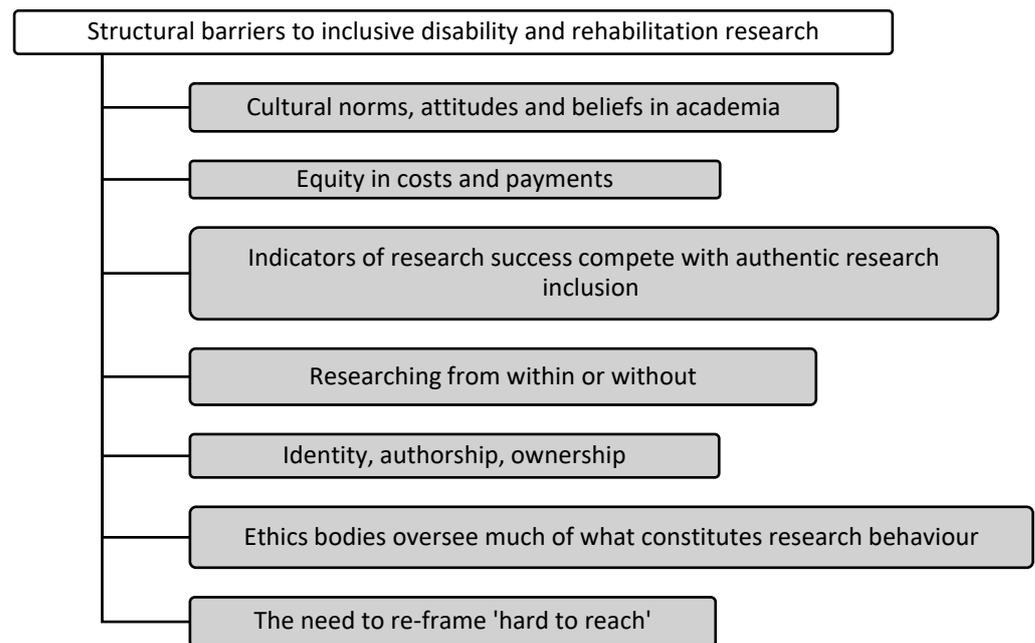


Figure 1. Structural barriers to inclusive rehabilitation research.

2.1. Cultural Norms, Attitudes, and Beliefs in Academia

Research is largely conducted with or by academic institutions. However, entry to academia is controlled through, for example, qualifications and subject to hidden curricula (Rossouw and Frick 2023). Institutional and collegiate norms and attitudes regarding, for example, academic workloads can bring about experiences of exclusion for academics experiencing disability. For example, the work of Brown et al. discusses challenges of interruptions, correct language, disclosure and emotional labour among academics living with fibromyalgia (Brown and Leigh 2020). Furthermore, the culture and institutional pressure in academia to complete work quickly is often contrary to slower participatory processes that typically require additional time and resources (Oliver et al. 2019). Conventional researchers who wish to conduct high-level participatory research can feel exhausted due to the often more labour-intensive work required of participatory research, which is often at odds with the ‘do more with less’ research environment (River et al. 2023). However, Williams et al. (2020) argues that the difficulty in conducting participatory research is not due to the process being inherently harder and more time intensive. Rather, it is more due to the academic context, which is incongruent with facilitating inclusive, participatory research (e.g., inflexible funding timelines, valuing of non-typical research outputs and metrics—see below).

In reimagined inclusive research structures, the mirror would be turned around to examine why the mainstream research structures fail to engage and accommodate a full diversity of humans, and what ought to change to enable their inclusion. If some populations do not engage with research, in what way is research seen as unattainable, unimportant, or irrelevant? What needs to change for research production to be attainable, relevant and a tool for epistemological justice? Promoting an academic culture that is more supportive of inclusive research could, for example, work to establish research metrics that support participatory research, acknowledge lived experience expertise in funding initiatives, and involve funding training initiatives that promote genuine partnerships (River et al. 2023). Intersectionality would be recognised as a feature of all researchers, and both sought and valued. It would be acknowledged as a dynamic concept and continuous reflexive steps undertaken to assure and uphold intersectional inclusion.

Williams et al. (2020) encourage a more structural analysis, questioning what research production processes and outcomes are seen as valuable within academia. For example, engaging in partnership-based research (e.g., co-production) is often thought of as a noble

pursuit, but one that requires the investment of much funding, time, and effort with no guarantee of academic outcomes (Oliver et al. 2019). Williams et al. (2020) challenge such positions, arguing these barriers result from the status quo academic context and are concerning ‘only if we accept that a narrowly defined output-focused culture is what academics should embrace’ (p. 7). It is imperative that we reimagine the ‘knowledge’ paradigm within disability and rehabilitation research. What researchers (who currently hold the power in terms of funding acquisition and momentum, etc.) value as ‘evidence’ will influence the degree to which they are able and willing to engage in inclusionary actions.

As an example of work that is seeking to reimagine inclusion, we are working with developers to extend the functionality of an existing accessible survey tool (<https://accessiblesurveys.com>, accessed on 30 January 2023) as part of a research project developing tools to more meaningfully include disabled people’s voices in policy (Martin et al. 2022). The tool was initially developed to collect quantitative data from disabled people; however, we have been collaborating to allow for the tool to also capture qualitative data. This has involved adding additional accessibility features (e.g., a voice memo function allowing participants to record their responses orally) and re-thinking how surveys can be used to support idea generation and diverse perspectives. Our key argument for developing this type of qualitative data collection tool is that in-person interviews or focus groups (which are currently the ‘go-to’ primary source of disabled person experiences) will always be limited in the range of perspectives they can gather due to pragmatic and cost considerations.

2.2. Equity in Costs and Payments

Living with disability incurs higher costs (Carers New Zealand 2010; Mitra et al. 2017). These costs may be visible and direct (such as attendant care costs, and the costs of disability accommodations such as assistive technology) or less visible (such as taking more time to complete tasks, which stretches paid time beyond ‘usual’ expectations of work speed). R.M. (author) has had the privilege of working closely with disabled colleagues from various organisations over the past decade:

“However, there are challenging implications in supporting capacity building and genuine partnerships with other disabled researchers. There has been a frequent need for my disabled peers to work flexibly and take unplanned leave for health-related issues. This contributed to a more limited ability to increase their hours of work to meet work deadlines—and at times, this engendered stress for my disabled peers and placed additional demands on me. Processes and systems that allow for, and provide resources towards, this need for flexibility and increased capacity at high-demand times, would support long-term, sustainable partnerships for all.”

Challenging such structural barriers and promoting higher levels of partnership and inclusion in rehabilitation research (which move beyond tokenism and consultation to involve genuine partnership or leadership of people with lived experience in research) can draw on examples such as the Raising the Bar model (River et al. 2023). The Raising the Bar model provides both lived experience and conventional researchers with the competencies and resources to undertake participatory research in egalitarian team structures. It has been successful in supporting lived experience and conventional researchers to successfully engage in high-level participatory research, helping to develop relational resilience in research teams, and establishing co-learning spaces that support lived experience researchers to challenge entrenched discourses and traditions of academia and negotiate new forms of non-traditional research outputs.

Ensuring full inclusion of disabled people in research frequently requires additional resource commitments. For example, as part of a realist evaluation of peer support for people with SCI, Burwood Academy Trust (2012) the lived-experience researcher who completed all the data collection and supported analysis required additional time to complete work, needed more researcher support for training, and had increased costs associated

with travel and accommodation associated with using a wheelchair and requiring personal care support. However, his contribution to the process and outcomes of the research were pivotal to its success. In reimagined inclusive research structures, funded equity measures are an integral part of funding applications and are paid at benchmark rates. Building on health economic efforts to enable ‘equal outcomes’, the concept of equity weights can be useful in expressing just how many resources are required to enable all parties to achieve an outcome. Therefore, equity weightings could be calculated for disabled researchers to achieve equal outcomes (Ong et al. 2009).

The continual development of equity and learning in inclusive research can benefit from respectful dialogue and iteration (Langley et al. 2022b). Having open discussions surrounding team expectations, roles and the realistic capacity of team members, alongside potential mitigation strategies, is beneficial (Hoekstra et al. 2022). Such dialogue can occur when starting projects, be monitored throughout projects, and when projects are finished to see what worked, what did not, and what could be conducted differently next time. Such reciprocal, two-way conversations, allowing for sharing and reflecting on diverse perspectives, can challenge research practices, cultures and structures—including understandings of what knowledge is and how different forms of knowledge are valued (Farr et al. 2021).

2.3. Indicators of Research Success Compete with Authentic Research Inclusion

Research structures drive researcher behaviour. For example, university ranking systems such as the Times Higher Education World University Rankings and QS World University Rankings shape what is valued and legitimised in academic institutions. Similarly, research performance frameworks, such as the Research Evaluation Framework (United Kingdom) and Performance-based Research Framework (New Zealand), define academic success and filter through to institutional promotion practices. These structures value peer-reviewed publications, impact factors, journal rankings, citation rates, and hierarchy in authorship status. The ‘publish or perish’ imperative is alive and well in academia and sustains a particular way of working that can compete with authentic and meaningful research inclusion. Individual success often overrides collective endeavour within these systems, and the priorities and outcomes privileged within academia can sit in contrast to those of the communities we serve.

For example, a colleague used his sabbatical to immerse himself in a rural and remote region of Aotearoa New Zealand. During this time, he worked closely with a non-government health organisation on a collaborative piece of research led by the community, for the community. He shared the report produced through this work, reflecting to the authors of this paper:

“Note my name is not on it, and it will not be in a peer-reviewed journal because it is their story and belongs to them. I have no doubt, though, that it will be used with great impact, and they have permitted me to disseminate it as I feel fit. This notion of supporting the agenda of others and fading into the background is indicative of the depth of the transformation that needs to occur.” (McKenna, Brian. 16 June 2023)

This research has the potential to have an important and meaningful impact on the community. However, ‘fading into the background’ is likely to have a detrimental impact on this researcher, given this piece of work cannot be ‘counted’ in his research metrics. He has made a conscious and deliberate decision to push against these structures so that the community could lead the research and determine what form the findings take and how those findings are made to matter in their community.

2.4. Researching from ‘within’ or ‘without’

Researchers within ‘the system’, that is, with recognised positions in research institutions, are afforded certain privileges which profoundly impact the capacity to ‘do research’. For example, the cost of accessing academic databases is prohibitive without library access.

Free versions of reference management systems and analysis software may not exist, may be less powerful, or indeed not interact with other systems. Access to data storage and shared work areas is problematic without a university email address. Similarly, the cultural norms of academia can be implicitly exclusive for those participating without the system. Research funding systems can sometimes be paradoxical in their workings—on the one hand, requiring the involvement of consumers as co-investigators while at the same time expecting those consumers to conform to academic norms. For example, requiring them to submit an academic curriculum vitae where peer-reviewed outputs, not lived experience or community networks and engagement, characterise research track record and competency. It can also be the case that conventional researchers may be more securely employed and named on a research grant. This could lead to tensions for lived experience researchers who might be intermittently employed or reimbursed, unnamed on research grants, and may find it difficult to raise issues about the budget (River et al. 2023). This likely has the effect of communicating to consumers that they ‘don’t belong here’.

In reimagined systems, the boundaries between being ‘within’ or ‘without’ can be addressed in several ways. Associating research projects done in partnership with disabled people with a university means that they can also access the support they require (e.g., librarian expertise). To optimise collaboration, freely available alternatives such as Mendeley for referencing, and MIRO (an online interactive whiteboard to support qualitative data analysis) mean that all partners can access this without cost.

Reimagined systems would create the context for all to feel they belong, and that there is a place for them. As an example, when designing methods for a project developing tools to better include disabled people’s voices in policy development (Martin et al. 2022) we focused on the attributes of engagement and participation we want to enable, rather than the impairments we might need to account for. As an illustration, when planning online interactive activities, we have brainstormed accessibility and inclusion requirements for optimising opportunities to build connections between participants, allow participants to connect ideas, and disagree or offer alternative solutions.

2.5. Identity, Authorship, Ownership

The wide array of terms for lived experience researchers has been canvassed above. Where an identity is established, it may not be present in the many existing author guidelines. For example, authors need an academic affiliation with a tertiary institution to publish in Australia’s *The Conversation*. Therefore, authoring with a consumer necessitates a byline elsewhere, and authors are less privileged as a result (see, for example, Callaway et al. 2017). Closed academic systems also mean that even when the research production is inclusive, the findings end up within a gated community, so the communities that have helped to produce the research cannot access the research to ensure their community benefits. So inclusive research doesn’t only require inclusion in knowledge production. It also requires communities to be self-determining in how that research is used. Guidance can be found in writings on indigenous data sovereignty (Prehn et al. 2023).

In reimagined systems, the fundamental principle is that anyone that the research is about has opportunities to engage within the research hierarchy. This expectation creates requirements for engagement (specified on a hierarchy and funded accordingly) and flips notions of identity, authorship and ownership such that there is an assumption people will be included, be authors, and be owners.

2.6. Ethics Bodies Oversee Much of What Constitutes Research Behaviour

Research ethics processes have an important role and function given they govern the standards of scientific research to protect the dignity, rights, and welfare of participants. However, it is important to recognise there are embedded assumptions in what constitutes ethical research, which can sometimes inadvertently result in exclusion. For example, ethical mandates which attribute vulnerability to populations can be paternalistic and limit choice and opportunity to participate in research. von Benzon and van Blerk (2017)

argue that “vulnerability is context-dependent” and “relational” with the circumstances and ways of engaging and working with people having great influence. They argue that attributing vulnerability to individuals or groups can be problematic, particularly if the desire to protect them from harm removes their choice and opportunity.

Similarly, Eurocentric conceptualisations of what constitutes ethical behaviour can sit in contrast to what constitutes ethical behaviour from another worldview. Writing from the perspective of a Māori researcher, Linda Tuhiwai Smith (2006) reflects on ‘researching within the margins’ when the norms of research conduct have been established through other Western jurisdictions. She poses questions about some of the fundamental assumptions embedded in the assumed universality of some of our most basic ethical principles, such as respect, and artefacts, such as the consent form.

Our reimaged ethics bodies are informed by a ‘bottom-up’ or ‘community-up’ defining of ethical behaviours (Smith 2006). We provide some examples of ethical challenges and workarounds here. During one study (Layton et al. 2023), research participants requested to be named as ‘owners’ of the stories they were telling related to assistive technology use in their lives. An ethics revision was submitted to vary the standard clauses about non-identification and protecting potential re-identification. The ethics board queried the purpose of this change, stating, ‘Don’t they realise then people will know who they are?’. This query was felt to be highly patronising, by the research participants.

In another study, when seeking approval for an amendment to our data collection processes (to move from in-person to Zoom interviews during a COVID-19 lockdown), we were asked to provide ‘justification for undertaking this part of the research during a time when everyone, in particular those with added vulnerabilities, are under considerable stress’. In our response, we noted that our research sought to engage people from the access community as experts. We argued that a key principle that guides our research is to ‘make no assumptions’—including not assuming vulnerability as a starting point—and that we did not want to assume that people with access needs would not be able to contribute to this research at this time. Rather, we wanted people with access needs to have the opportunity to take part should they wish to, while proceeding with caution and ensuring the research process mitigated any perceived or real vulnerabilities. We noted that every situation is unique and specific to individuals and their families. We acknowledged that some people will be under stress, and their focus will rightly be on navigating their way through the lockdown period. However, others will be grateful for an opportunity to connect with the outside world and will be looking for opportunities to meaningfully and purposefully contribute to life beyond COVID-19. For the latter group, contributing to research where their opinions are sought and valued, could be a mechanism for achieving a sense of purpose.

In 2021, a group of leaders from non-government organisations supporting people with age-related neurological decline called for research that captured their experience of providing support to their communities during Aotearoa, New Zealand’s COVID-19 response. We took up the challenge and worked with these community leaders to design the research to capture their experiences. The organisational leaders were keen to ensure their experiences were captured so they could inform decisions and policy making when facing similar situations in the future. When we sought ethics for this community-initiated, designed and led research, we were asked by the ethics body to give further reconsideration and justification of this research given that at least one group of potential participants has already been surveyed a number of times. This had the effect of immediately minimising and belittling the communities’ endeavour to have a voice and felt entirely counter to an inclusive research approach.

2.7. The Need to Re-Frame ‘Hard to Reach’

We frequently define underrepresented populations in our research processes as ‘hard to reach’ (Shaghghi et al. 2011). However, in doing so, we attribute the problem to individuals, not the processes by which research typically seeks to reach those individuals

(van der Ven et al. 2022). A comparative example in health care occurs when health literacy is situated as an individual determinant of health and a barrier to accessing care. Countering this, there has been a call for a focus on the development of health-literate organisations, putting the onus on health organisations to design for and respond to the needs of people with limited health literacy (Palumbo 2016; Palumbo and Annarumma 2018). We similarly argue here that we need to move away from the narrative of ‘hard to reach’ people to talk about ‘hard to access’ research. This makes it clear that the problem lies with us. Our failure to design accessible research inevitably means that our research fails to adequately account for many perspectives.

Accommodations, that is, reasonable adjustments to enable a diversity of people to engage, exist for a multiplicity of use cases and contexts. They may involve products and technology, the built and sensory environments, or indeed, ensuring that multiple formats are presented to accommodate visual, auditory, motor, and cognitive preferences. Accommodations may include more time (for preparation and processing) and multiple formats for materials (visual, plain language, accessible to screenreaders and switching software) and for meetings (virtual, accessible spaces, flexible to accommodate care partners, transport, and fatigue). Inclusion is unlikely to be fully realised without budgeting for such accommodations—and expertise in identifying supports and setting these parameters lies with the experts by experience whose inclusion is sought. Such changes to the culture of research strike at the heart of addressing systemic factors involved in the inclusion of disabled people in research and demonstrate how the ‘bigger picture’ of rehabilitation research can change towards a more egalitarian imperative (Williams et al. 2020).

Van der ven suggests ‘Hard to reach’ populations are not really hard to reach, they just require a different mindset and skillset from the researcher’ (van der Ven et al. 2022, p. 193). We agree, and note the role of creative practices in co-production (Langley et al. 2022a), the development of research protocols to better include disabled people’s knowledge in health policy development (Martin et al. 2022), and the synergy between health planning and design fields in developing novel approaches to accessible and inclusive design, see, for example, Good Health Design (n.d.).

3. A Way Forward

As we have illustrated, tensions and challenges continually arise in inclusive research endeavours, often related to structural research processes such as compliance with various funding and ethical and institutional systems. Strategies are needed to relocate the onus of inclusion from people to systems. In the above, we have stepped through the structural barriers we perceive and made some suggestions as to how systems might be reimagined to create the conditions for inclusive research. Further leadership can be found in the literature, and specifically in two relevant frameworks presented here. The Dignity Framework, developed in an extreme citizen science context, offers four principles (human rights, elimination of barriers, diversity, and transparency) alongside four processes (vision, uncover, discuss, change) to support inclusion (Chapman et al. 2022). In parallel work from the intellectual disability sector over the past decade, ten Disability Inclusive Research Principles have been developed and used to guide the inclusion of intellectual disability researchers (Disability Inclusive Research Collaboration 2012). The principles offer clear direction around ownership of knowledge and power in establishing the rules of engagement with research, diversity of methods for data capture and dissemination, and consent. The structural barriers discussed above can readily be linked with aspirational principles from these frameworks (see Table 3). Drawing on the Dignity Framework principles (Column 2 in Table 3 below) and Inclusive Research Principles (Column 3) to critically examine and shape the structures and processes that shape disability and rehabilitation research practice may provide some starting points for mitigating these structural barriers. Doing so creates opportunities to reimagine egalitarian systems, and to question the duty holders involved in the status quo.

Table 3. Mapping structural barriers to principles for inclusion.

Structural Barrier	Principles Which, If Enacted, Could Address Structural Barriers	
	Dignity Framework (Chapman et al. 2022)	Disability Inclusive Research Principles (Disability Inclusive Research Collaboration 2012)
Cultural norms, attitudes and beliefs in academia.	Principle 1: Grounding research in a human rights conceptualisation of disability.	<ul style="list-style-type: none"> • Research that is informed by and/or led by people with disability—the need for research, and its design must be identified and led by people with disability. • Ownership—the research process, its design, management, implementation and findings must be owned by people with disability and their representative organisations.
Indicators of research success compete with authentic research Inclusion, Identity, authorship, and ownership.	Principle 2: Eliminating barriers to participation—intersectionality and authenticity.	<ul style="list-style-type: none"> • “The right people asking the right questions and getting the right answers”—inclusive disability research must be careful to ensure that research questions are relevant and important to people with disability (determined/informed by them), and that answers are sought from the correct sources using the best inclusive methods (identify “right people”).
Researching from ‘within’ or ‘without’.	Principle 3: Diversity in engagement—accessibility and inclusion.	<ul style="list-style-type: none"> • Inclusive and participatory—the research process, and its methodologies, must ensure that people with disability, about whom and for whom the research is designed, play a central role as researchers and as research participants; and the voice of people with disability is validated as data. • Co-presenting—people with disability must be provided with opportunities to present research findings. • Materials that are accessible—information about the research process, research tools, and research reports must be provided in ways and in formats that are accessible. • A range of types of activities—adjustment must be made to the design of research to render research appropriate to the participants and accommodate a variety of approaches (research design reflects the diversity of potential research participants). Good research design must emphasise the need for a variety of approaches to ensure that a diversity of views is researched. • Consent—researchers must apply processes of ethics approval that ensure that people with disability are included in the research as willing and supportive participants.
Ethics bodies oversight much of what constitutes research behaviour.		
Need to re-frame ‘hard to reach’.		
Lack of equity in costs and payments.	Principle 4: Transparent ways of working.	<ul style="list-style-type: none"> • Re-defining what research is—inclusive disability research is part of the universal research endeavour, and as such must contribute to ongoing discussions about the role and form of research in general. • Research that transfers through to real life—research by and with people with disability must provide tangible benefits to individuals and the constituency of people with disability, and work toward greater inclusion of people with disability in the community.

In applying these recommendations, we promote two cautions. First, we acknowledge the diversity of disability, capabilities, needs and preferences. We are mindful that it is not uncommon for strategies seeking to support access and inclusion to inadvertently marginalise some sub-groups. For example, when access initiatives prioritise physical impairment to the detriment of sensory impairment. We conceptualise access and inclusion in its broadest sense, i.e., as a physical, emotional, cognitive, and temporal experience. As such, we acknowledge the examples, recommendations and solutions proposed above are not a panacea—they are not going to be the right thing, for all people, in all circumstances, all the time. Rather, we suggest instead that the above is viewed as a menu of possibilities, but also that the most meaningful solutions will reside within the people with whom you

are seeking to include. Second, an ongoing challenge to researchers and practitioners is to ensure the meaning and intent of principles are not lost during their operationalisation. It remains essential that all frameworks, principles, or ladders are utilised critically, reflexively, and with a mind to avoiding unintended consequences.

4. Conclusions

Structural barriers constrain many aspects of inclusive research. Signposts can be found from parallel disciplines, some of which are canvassed here and in other Special Issue papers. As global rehabilitation policy moves to a more encompassing position regarding all people with functional impairment at any point in their life cycles and health journeys, we suggest it is timely for rehabilitation systems to consider and adopt successful inclusive research practices and the epistemological positions which enable them to be imagined.

A reimagined system understands that research is too important to leave in the hands of conventional researchers alone. It values and recognises intersectionality, where people with diverse perspectives, in the spirit of appreciative inquiry, can locate themselves and their vantage points and limitations. This likely leads to the seeking of missing voices, and the formation of a research community, thereby bringing the mechanisms of research production within reach of those whom the research is about.

Author Contributions: Conceptualization, N.L., N.M.K. and R.A.M., writing—original draft preparation, N.L., R.A.M. and N.M.K.; writing—review and editing, J.A.B., N.L., R.A.M. and N.M.K. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding.

Institutional Review Board Statement: Not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: No new data were created or analyzed in this study. Data sharing is not applicable to this article.

Conflicts of Interest: The authors declare no conflicts of interest.

Note

¹ We use the terms ‘disabled’ or ‘people experiencing disability’ as that has been the preference of people we have engaged with in our research to date and who have strongly identified with the social model of disability.

References

- Arnstein, Sherry R. 1969. A ladder of citizen participation. *Journal of the American Planning Association* 35: 216–24.
- Barnes, Colin. 1996. Disability and the Myth of the Independent Researcher. *Disability and Society* 11: 107–10. [CrossRef]
- Bright, Felicity A. S., Claire Ibell-Roberts, and Bobbie-Jo Wilson. 2023. Psychosocial well-being after stroke in Aotearoa New Zealand: A qualitative metasynthesis. *Disability and Rehabilitation*, 1–14. [CrossRef] [PubMed]
- Brisenden, Simon. 1986. Independent Living and the Medical Model of Disability. *Disability, Handicap & Society* 1: 173–78. [CrossRef]
- Brown, Nicole. 2020. Disclosure in academia: A sensitive issue. In *Ableism in Academia: Theorising Experiences of Disabilities and Chronic Illnesses in Higher Education*. Edited by Nicole Brown and Jennifer Leigh. London: University College London, pp. 51–71.
- Brown, Nicole, and Jennifer Leigh. 2020. *Ableism in Academia: Theorising Experiences of Disabilities and Chronic Illnesses in Higher Education*. London: University College London.
- Burwood Academy Trust. 2012. *Evaluating the Effectiveness of Peer Support Services for People with Newly Acquired Spinal Cord Impairment*. New Zealand: Burwood Academy Trust.
- Callaway, Libby, Kate Tregloan, and Jonathan Bredin. 2017. NDIS housing rules for people with a disability could be life-changing. *The Conversation*. Available online: <https://theconversation.com/ndis-housing-rules-for-people-with-a-disability-could-be-life-changing-74692> (accessed on 30 January 2023).
- Carers New Zealand. 2010. *Cost of Disability Report*. Auckland: Disability Resource Centre Auckland, Inc. (DRC Auckland) & University of Auckland’s Centre for Health Services Research and Policy (CHSRP).
- Chapman, Kelsey, Angel Dixon, Kevin Cocks, Carolyn Ehrlich, and Elizabeth Kendall. 2022. The Dignity Project Framework: An extreme citizen science framework in occupational therapy and rehabilitation research. *Australian Occupational Therapy Journal* 69: 742–52. [CrossRef] [PubMed]
- Charlton, James I. 2000. *Nothing about Us without Us: Disability Oppression and Empowerment*. Berkeley: University of California Press.

- Cochrane Collaboration. n.d. Cochrane Consumer Network. Available online: <https://consumers.cochrane.org/> (accessed on 30 January 2023).
- Dirth, Thomas P., and Nyla R. Branscombe. 2017. Disability Models Affect Disability Policy Support through Awareness of Structural Discrimination. *Journal of Social Issues* 73: 413–42. [CrossRef]
- Disability Inclusive Research Collaboration. 2012. Available online: <https://cdis.org.au/> (accessed on 30 January 2022).
- Farr, Michelle, Philippa Davies, Heidi Andrews, Darren Bagnall, Emer Brangan, and Rosemary Davies. 2021. Co-producing knowledge in health and social care research: Reflections on the challenges and ways to enable more equal relationships. *Humanities and Social Sciences Communications* 8: 105. [CrossRef]
- Fawcett, Barbara, and Jeff Hearn. 2004. Researching others: Epistemology, experience, standpoints and participation. *International Journal of Social Research Methodology* 7: 201–18. [CrossRef]
- Finset, Arnstein. 2017. Patient Participation, Engagement and Activation: Increased emphasis on the role of patients in healthcare. *Patient Education and Counseling* 100: 1245–46. [CrossRef]
- Fisher, Pamela, and Dan Goodley. 2007. The linear medical model of disability: Mothers of disabled babies resist with counter-narratives. *Sociology of Health & Illness* 29: 66–81.
- Gibson, Barbara. 2016. *Rehabilitation: A Post-Critical Approach*. Boca Raton: CRC Press.
- Gibson, Barbara E., Gareth Terry, Jenny Setchell, Felicity A. S. Bright, Christine Cummins, and Nicola M. Kayes. 2020. The micro-politics of caring: Tinkering with person-centered rehabilitation. *Disability and Rehabilitation* 42: 1529–38. [CrossRef] [PubMed]
- Good Health Design. n.d. Available online: <https://www.goodhealthdesign.com/projects/accessible-co-design> (accessed on 30 January 2023).
- Griffiths, Elisabeth. 2020. “But you don’t look disabled”—Invisible disabilities, disclosure and being an ‘insider’ in disability research and ‘other’ in the disability movement and academia. In *Ableism in Academia: Theorising Experiences of Disabilities and Chronic Illnesses in Higher Education*. Edited by Nicole Brown and Jennifer Leigh. London: University College London.
- Grindell, Cheryl, Tom Sanders, Remi Bec, Angela Mary Tod, and Daniel Wolstenholme. 2022. Improving knowledge mobilisation in healthcare: A qualitative exploration of creative co-design methods. *Evidence & Policy* 18: 265–90. [CrossRef]
- Hathcoat, John D., Cara Meixner, and Mark C. Nicholas. 2019. Ontology and epistemology. In *Handbook of Research Methods in Health Social Sciences*. Edited by Pranee Liamputtong. Singapore: Springer Nature.
- Heinemann, Allen W., Michael Feuerstein, Walter R. Frontera, Steven A. Gard, Leonard A. Kaminsky, Stefano Negrini, Lorie Gage Richards, and Catherine Vallée. 2020. Rehabilitation Is a Global Health Priority. *BMC Health Services Research* 20: 143. [CrossRef]
- Hoekstra, Femke, Lee Schaefer, Peter Athanasopoulos, SCI Guiding Principles Consensus Panel, and Heather L. Gainforth. 2022. Researchers’ and Research Users’ Experiences With and Reasons for Working Together in Spinal Cord Injury Research Partnerships: A Qualitative Study. *International Journal of Health Policy and Management* 11: 1401–12. [CrossRef] [PubMed]
- Hudson, Maui, Moe Milne, Paul Reynolds, Khyla Russell, and Barry Smith. 2010. *Te Ara Tika Guidelines for Māori Research Ethics: A Framework for Researchers and Ethics Committee Members*. Auckland: Health Research Council of New Zealand.
- IAP2. 2018. *IAP 2 Public Participation Spectrum*. Denver: International Association for Public Participation.
- Kayes, Nicola M., and Christina Papadimitriou. 2023. Reflecting on challenges and opportunities for the practice of person-centred rehabilitation. *Clinical Rehabilitation* 37: 1026–40. [CrossRef] [PubMed]
- Kayes, Nicola, Rachelle A. Martin, Felicity A. S. Bright, Paula Kersten, and Alex Pollock. 2019. Optimizing the real-world impact of rehabilitation reviews: Increasing the relevance and usability of systematic reviews in rehabilitation. *European Journal of Physical and Rehabilitation Medicine* 55: 331–41. [CrossRef] [PubMed]
- Langley, Joe, Nicola Kayes, Ian Gwilt, Erna Snelgrove-Clarke, Sarah Smith, and Claire Craig. 2022a. Exploring the value and role of creative practices in research co-production. *Evidence & Policy* 18: 193–205. [CrossRef]
- Langley, Joe, Sarah E. Knowles, and Vicky Ward. 2022b. 3.3 Conducting a Research Coproduction Project. In *Research Co-Production in Healthcare*. Wiley: New Jersey, pp. 112–28.
- Layton, Natasha, Em Bould, Ricky Buchanan, Jonathon Bredin, and Libby Callaway. 2022. Inclusive Research in Health, Rehabilitation and Assistive Technology: Beyond the Binary of the ‘Researcher’ and the ‘Researched’. *Social Sciences* 11: 233. [CrossRef]
- Layton, Natasha, Ricky Buchanan, and Erin Wilson. 2023. Occupy Research. In *‘And a Seed Was Planted’ Occupation Based Social Inclusion*. Edited by Nick Pollard, Hanneke Van Bruggen and Sarah Kantartzis. London: Whiting and Birch, pp. 135–49.
- Martin, Rachelle A., Angelo P. Baker, Kirsten Smiler, Lesley Middleton, Jean Hay-Smith, Nicola Kayes, Catherine Grace, Te Ao Marama Apiata, Joanne L. Nunnerley, and Anna E. Brown. 2022. Flourishing together: Research protocol for developing methods to better include disabled people’s knowledge in health policy development. *BMC Health Services Research* 22: 1252. [CrossRef]
- Mitra, Sophie, Michael Palmer, Hoolda Kim, Daniel Mont, and Nora Groce. 2017. Extra costs of living with a disability: A review and agenda for research. *Disability and Health Journal* 10: 475–84. [CrossRef]
- O’Brien, Patricia. 2022. Inclusive Research: Is the Road More or Less Well Travelled? *Social Sciences* 11: 582. [CrossRef]
- Oliver, Kathryn, Anita Kothari, and Nicholas Mays. 2019. The dark side of coproduction: Do the costs outweigh the benefits for health research? *Health Research Policy and Systems* 17: 33. [CrossRef]
- Ong, Katherine S., Margaret Kelaher, Ian Anderson, and Rob Carter. 2009. A cost-based equity weight for use in the economic evaluation of primary health care interventions: Case study of the Australian Indigenous population. *International Journal for Equity in Health* 8: 1–48. [CrossRef]

- Palisano, Robert J., Briano Di Rezze, Debra Stewart, Peter L. Rosenbaum, Oksana Hlyva, Matthew Freeman, Tram Nguyen, and Jan Willem Gorter. 2017. Life course health development of individuals with neurodevelopmental conditions. *Developmental Medicine & Child Neurology* 59: 470–76. [\[CrossRef\]](#)
- Palumbo, Rocco. 2016. Designing health-literate health care organization: A literature review. *Health Services Management Research* 29: 79–87. [\[CrossRef\]](#)
- Palumbo, Rocco, and Carmela Annarumma. 2018. Empowering organizations to empower patients: An organizational health literacy approach. *International Journal of Healthcare Management* 11: 133–42. [\[CrossRef\]](#)
- Patston, Philip. 2007. Constructive Functional Diversity: A new paradigm beyond disability and impairment. *Disability & Rehabilitation* 29: 1625–33.
- Prehn, Jacob, Riley Taitingfong, Robyn K. Rowe, Ibrahim Garba, Cassandra Price, Maui Hudson, Tahu Kukutai, and Stephanie Russo Carroll. 2023. *Indigenous Data Governance and Universities Communiqué*. Melbourne: Global Indigenous Data Alliance.
- Rist, Pamela, Damean Freas, Greg Maislin, and Margaret Stineman. 2008. Recovery from Disablement: What functional abilities do rehabilitation professionals value the most? *Archives of Physical Medicine and Rehabilitation* 89: 1600–6. [\[CrossRef\]](#)
- River, Jo, Brett Bellingham, Sophie Isobel, Katherine Gill, Katherine Boydell, Liam Conlon, Mark Goodhew, Natalie Cutler, and Holly Kemp. 2023. Raising the Bar: A Qualitative Study of a Co-Produced Model for Promoting research Partnerships in Mental Health. *International Journal of Qualitative Methods* 22: 16094069231213268. [\[CrossRef\]](#)
- Rossouw, Nina, and Liezel Frick. 2023. A conceptual framework for uncovering the hidden curriculum in private higher education. *Cogent Education* 10: 2191409. [\[CrossRef\]](#)
- Shaghghi, Abdolreza, Raj S. Bhopal, and Aziz Sheikh. 2011. Approaches to Recruiting ‘Hard-To-Reach’ Populations into Re-search: A Review of the Literature. *Health Promot Perspect* 1: 86–94. [\[CrossRef\]](#) [\[PubMed\]](#)
- Shakespeare, Tom. 2006. *Disability Rights and Wrongs*. New York: Routledge.
- Shakespeare, Tom, Harriet Cooper, Dikmen Bezmez, and Fiona Poland. 2018. Rehabilitation as a Disability Equality Issue: A Conceptual Shift for Disability Studies? *Social Inclusion* 6. [\[CrossRef\]](#)
- Smith, Emma M., Natasha Layton, Em Bould, and Annalu Waller. 2024. Diversity beyond disability in assistive technology. *Assistive Technology* 36: 1–2. [\[CrossRef\]](#) [\[PubMed\]](#)
- Smith, Linda Tuhiwai. 2006. Researching in the Margins Issues for Māori Researchers a Discussion Paper. *AlterNative: An International Journal of Indigenous Peoples* 2: 4–27. [\[CrossRef\]](#)
- Te Tāhū Hauora Health Quality & Safety Commission. 2022. *Te Tikanga Mō Te Mahi Tahi a Ngā Hinonga Hauora Ki Ngā Kiritaki Me Ngā Whānau: Code of Expectations for Health Entities’ Engagement with Consumers and Whānau*. Wellington: Te Tāhū Hauora Health Quality & Safety Commission.
- van der Ven, Lillian, Jeroen van Baar, Rein Wispelweij, and Marielle Jambroes. 2022. How to involve ‘hard to reach’ population groups in research projects. *European Journal of Public Health* 32 Suppl. S3: ckac129.476. [\[CrossRef\]](#)
- von Benzon, Nadia, and Lorraine van Blerk. 2017. Research relationships and responsibilities: ‘Doing’ research with ‘vulnerable’ participants: Introduction to the special edition*. *Social & Cultural Geography* 18: 895–905. [\[CrossRef\]](#)
- Wade, Derick. 2015. Rehabilitation—A new approach. Part two: The underlying theories. *Clinical Rehabilitation* 29: 1145–54. [\[CrossRef\]](#) [\[PubMed\]](#)
- Wade, Derick T. 2020. What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clinical Rehabilitation* 34: 571–83. [\[CrossRef\]](#)
- Williams, Oli, Sophie Sarre, Stan Constantina Papoulias, Sarah Knowles, Glenn Robert, Peter Beresford, Diana Rose, Sarah Carr, Meerat Kaur, and Victoria J. Palmer. 2020. Lost in the shadows: Reflections on the dark side of co-production. *Health Research Policy and Systems* 18: 43. [\[CrossRef\]](#)
- World Health Organization. 2001. *International Classification of Functioning, Disability and Health: ICF*. Geneva: World Health Organization.
- World Health Organisation. 2011. *World Report on Disability*. Malta: WHO.
- World Health Organisation. 2017. *Rehabilitation 2030: A Call for Action*. Geneva: World Health Organisation.

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