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Inclusive Research in Health, Rehabilitation and Assistive Technology: Beyond the Binary of the 'Researcher' and the 'Researched'

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Abstract: The principle of 'working with, not on' people with disabilities is widely espoused within inclusive research, yet historically such opportunities have not been fully realized. This paper speaks from the perspective of users of health, rehabilitation, assistive technology services, and the academics with whom they collaborate. We draw on Australia's Disability Inclusive Research Principles to reflect on the practice of inclusive research across the areas of assistive technology policy, digital information, and health access, as well as the co-design of allied health resources. We consider and provide examples of how power and knowledge play out in health and rehabilitation, the developing discourse around consumer co-design and co-production, and the challenges of enacting inclusive research. This paper is about shared power in the mechanisms of research production and our journeys towards it. Engaging in inclusive research has enabled us to assume roles beyond the binary of the 'researcher' and the 'researched'. We conclude by proposing an adaptation of the ladder of participation for inclusive research.

Keywords: inclusion; research methods; health; rehabilitation; assistive technology; consumer-led

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1. Introduction

To understand 'what is' (ontology), strategies and methods are used to uncover sources of knowledge (this is 'how we know', or epistemology). Different fields of research tackle this in different ways. This paper considers knowledge from the perspective of academic researchers working in the area of health, rehabilitation, and information, communication, and assistive technologies, where traditionally the evidence has been largely based on medical and socio-technical approaches. Challenges to the mainstream scientific world view come from the disability academy and from indigenous ways of knowing. These counter views suggest that professionalism may be oppressive, that scientific knowledge is partial, and that lived experience is often unheard (Friere 1972). Contrasting perspectives include social, critical–realist, and other models of disability and culturally sound ways of knowing (Friere 1972; Thomas 2007; Corker and Shakespeare 2002).

On a practical level today, this translates into a range of guidance to bridge these different approaches and inform practice in health and disability research. For example, frameworks such as the World Health Organization International Classification of Functioning, Disability, and Health (WHO ICF) (WHO 2001), combine medical and social views into a biopsychosocial model. Following, as a signatory to the United Nations Convention on the Rights of Persons with Disability (Stein et al. 2009; United Nations 2006), Australia's health, rehabilitation, and disability sectors are moving to enshrine consumer centeredness in service design and delivery (ACSQHC 2012; Department of Health 2018). Parallel fields, such as design and social science, have engaged over decades in co-design (Arnstein 1969; Jasanoff 2004; NCOSS 2022) as a paradigm and method to include multiple voices and share power. Co-design tools (People with Disabilities Western Australia 2020) and projects (Bould and Callaway 2021; Layton et al. 2021) are emerging for disability in Australia.

From the perspective of health and rehabilitation, but turning to research (rather than practice), evidence-based practice principles explicitly call for a triumvirate of best quality evidence, professional expertise, and consumer and community knowledge (Sackett et al. 2000). The consumer aspect, however, remains under-realized (Hill 2011) and may be difficult to enact in some organizational settings (Lofgren et al. 2011). For example, challenges have been noted with enacting co-design/consumer involvement in health research, including limited or tokenistic roles, limited time allocation for authentic engagement, and difficulty acquiring tacit research skills and knowledge (Slattery et al. 2020).

The field of intellectual disability research has a relatively long engagement with inclusive research principles (Johnson and Walmsley 2010; O'Brien et al. 2014; Riches et al. 2020), including a consensus statement on how to conduct inclusive health research with the intellectual disability community (Frankena et al. 2019). Academics propose potential models (Bigby et al. 2014) and principles (Disability Inclusive Research Collaboration 2012) for inclusive research. Arguably, the inclusive research paradigm for intellectual disability is further developed than inclusive research in rehabilitation and health. Indeed, as intellectual disability research is largely published in separate journals and not in journals on rehabilitation research and practice, we suggest that health and rehabilitation researchers who would benefit from epistemologies on 'working with the experts', are not hearing about them.

2. How Does This Influence Our Knowing and Doing?

Speaking as academics and practitioners working in health, disability, and academic structures (Authors LC, EB and LC), evidence-based practice principles enable us to include consumers' perspectives in our methods. However, often institutional and funder requirements—whilst calling for consumer representation—still require the demonstration and evaluation of research track records, performance metrics, and evidence of highly qualified team members whose research methods are seen as scientific. As our examples will show, 'scientific method' may unwittingly skew views of truth.

Speaking as consumers of rehabilitation, health, and assistive technology interventions, and as participants in research and lived experience experts on these topics (Authors RB and JB), we have some rights in relation to what our services should look like and some roles in how to design them. However, we find legitimate research roles are limited to being researched, being consulted, joining project advisory groups, or 'being examples'. The continuum of community and consumer engagement in health, rehabilitation, and assistive technology research has been well-documented. Within this, recognition that if we are to move beyond such limited roles of 'being researched and consulted' to true co-researcher roles and research leadership by people with lived experience expertise, the benefits will be significant. They also come with the requirement for more time and funding commitment for authentic participation (Manafo et al. 2018).

This paper aims to represent the varied perspectives of users of health, rehabilitation, and assistive technology services and the academics with whom they collaborate to: (1) reflect on the practice of inclusive research across health, rehabilitation, and assistive technology, using Australia's Disability Inclusive Research Principles; (2) provide examples to consider how shared power and knowledge play out in health and rehabilitation, and the developing discourse around consumer co-design and co-production; and (3) outline some of the challenges of enacting inclusive research.

3. What Do Disability Inclusive Research Principles Look Like in the Fields of Health and Rehabilitation?

We have selected a set of Inclusive Research Principles (DIRP) (Australian Disability Research Agenda Collaboration 2018) to guide our thinking about inclusive research. These principles were developed by the Disability Inclusive Research Collaboration (DIRCC), a group of organizations for people with disability, universities, and research centers in Australia that came together in 2014 at the University of Sydney for the Research rights: Disability—Inclusion—and Change Conference. The set of principles were developed to guide the organizing committee in developing the conference agenda, and were also presented in opening addresses (DIRCC 2012). We have reflected upon and developed plain language explanations of each of these principles (see Table 1 below).

Table 1. Disability Inclusive Research Principles with Plain Language Explanations.

Disability Inclusive Research Principles (Johnson and Walmsley 2010)	**Plain Language Explanations Developed by the Authors of This Paper**
Research that is informed by and/or led by people with disability	Research that is important to, and/or led by, people with disability - research looks at issues that are important to people with disability - research uses the lived experience of people with disability - people with disability are part of the research team - the leader of the research project is one person or a small group of people, Some or all of these people have a disability.
Ownership	Identifying who the research belongs to - everyone in the team needs to know what they are doing on the project - people with disability and the organization where they work should be included in every stage of the research process.
Inclusive and participatory	Research is inclusive and people with disability are part of the research team - researchers with and without disability work together - inclusive research begins at the start of the project - the team sets out the focus and the goals - everyone in the team can ask questions - everyone in the team is listened to and respected.
Co-presenting	Sharing of research activities and findings includes people with disability as co-presenters - people with and without disability talk about the research findings with other people.
Materials that are accessible	Information is accessible - all information about the research project is easy to read and easy to understand - pictures are used with words to explain things - captions and transcripts are used for videos.
A range of types of activities	Research activities are flexible - information and activities should be accessible to all participants - everyone should be able to have a say.
Research that transfers through to real life	Research should support people to have a better life - everyone must benefit from working on a project - it is important to check if the research is going well - inclusive research should help people with disability and disability organizations.
Re-defining what research is	Change what research is - think of different ways of doing research - there is a need to ask people with disability what would make inclusive research better.
“The right people asking the right questions and getting the right answers”	Think about the questions we should ask and who should be invited to answer these questions - the research questions should be important to people with disability - there is a need to think about who should be invited to take part in the research project (as research participants) - ensure all participants can have a say by making information accessible.
Consent	Consent - The research needs to be done in the right way - The research project should be reviewed by an ethics board. - The ethics board are separate from the research team - People with disability are asked if they want to take part in the research and it is their choice - They can change their mind and stop participation at any time.

We will now present three research journeys from health and rehabilitation settings that we have led. Our reflections on the inclusive research principles are indicated in bold font:

Example 1. *Assistive technology: research that is directed by assistive technology users themselves.*

In the State of Victoria, Australia, an alliance of people living with disability, assistive technology practitioners, advocates, and academics (the 'Aids and Equipment Action Alliance') was formed in response to perceived policy failures in public provision of AT. This multi-stakeholder alliance **led a research endeavor** by commissioning the philanthropically funded project *The Equipping Inclusion Studies* (Layton et al. 2010). More than 50% of the alliance steering group for this research were people with lived experiences of disability. We ensured the **right people asked the right questions** by turning the purpose and mission of the Alliance (to provide evidence to influence government policy) into the research questions. We ensured the **research design** was participatory and inclusive through use of methods which sought the views of Victorian adults with a disability about AT needs and outcomes. Authors NL and RB were engaged in this research, and the experience of undertaking commissioned research and 'working for' people with disabilities profoundly shaped the research process (Layton et al. 2017). This happened in several ways. In terms of **consent**, standard ethics processes assume anonymity is required for people with disability, however the alliance took issue with this perceived conflation of disability and vulnerability, and sought ethics modification to enable people to be named and 'own their own data' (Layton and Wilson 2009). In terms of **inclusive and participatory approaches**, we wanted to use methods which ensure voices of people with disability are validated as data: the alliance felt this was important. It seemed self-evident that the research design must include everyone, and when it was discovered that fully accessible online survey methods did not exist, we created one (Gottliebsen et al. 2010). **Co-presenting** is essential: once the research was complete the roles of co-authorship, disseminator of findings, and knowledge translator, were actively taken on by alliance members alongside and beyond the academic researchers (Layton et al. 2012; Layton et al. 2014), and continues to date with a set of personal outcome tools under development by a consortia of AT users and research partners (Buchanan and Layton 2019; Layton and Callaway 2020). No presentation occurs without personal stories to contextualize the content, and sometimes it is necessary to redefine what research is. When we identified an inherent disability bias in standardized data collection instruments for quality of life, steps were taken to address this with instrument authors to both address the impact of this bias and to revise the tool (Layton and Wilson 2010).

Example 2. *Moving beyond the binary of 'therapist and the client', and the 'researcher and the researched'*

In Australia, there are a range of options people with disabilities may consider to meet their goals for community living across their lifespan, whilst addressing their disability-related support needs (Callaway et al. 2020). One of these is a coordinated approach to the provision of both highly-accessible housing and support, called Specialist Disability Accommodation (SDA). Authors JB and LC first met when a new approach to SDA provision had been developed and located on the border of a large University campus in the State of Victoria. This accommodation included a new collaborative model of allied health student fieldwork education through which tenants could work with students on their nominated personal goals. JB accepted an offer of tenancy at this SDA in 2015. At that time, LC was designing the model, supervising students delivering fieldwork hours, and establishing a framework for multi-stakeholder research evaluation to ensure research was **informed by people with disability** and other key stakeholders. From that time, JB and LC developed a collegiate and collaborative relationship, co-designing student education opportunities, and the evaluation framework. As JB notes: 'I think if people with disabilities want a brighter future, we should want to train others—I've personally learnt five times more than I give through this process'. Now into its seventh year, and expanded across regions of Victoria as well as into Tasmania, we draw on occupational therapy and lived experience expertise equally, and with mutual benefit, to inform both education and research design, translation and impact. The work is built on shared trust, and timely identification when things will or will not work, or have or have not worked, enabling honest and open conversations about this. This includes discussion about projects, and when JB feels he would or would not add value in contribution to research projects or student education activities.

This approach has aided **redefining what research is**, with both process and outcome evaluation built into each placement block JB co-designs. Moving beyond this first phase of collaborative work, and the binary of 'therapist and the client' and the 'researcher and the researched', **ownership** has become central to our collaborative model of both research and education practice. JB draws on his lived experience expertise, and LC on her allied health research and practice knowledge, in combined presentations of these varied perspectives (see Figure 1). JB's lived experience expertise is drawn upon using a co-researcher approach, with human research ethics committee approvals in place and **co-presenting** of research evaluation findings (Callaway et al. 2017a, 2021).

Figure 1. Co-presenting [left to right] colleague LF (Acknowledging our colleague L.F.), and authors NL, JB, and LC at Occupational Therapy Australia—Victoria conference panel. Source: Personal photo of author NL.

The range of types of research activities undertaken has been expanded over the last seven years. JB has now delivered a number of paid co-researcher roles (National Disability Research Partnership 2021) and joint supervision of student project work, with both JB and LC holding roles on the new National Disability Research Partnership Community of Practice (www.ndrp.org.au (accessed on 12 January 2022)). For shared knowledge translation, activities have included joint conference presentations (Callaway et al. 2017a, 2021), invited guest lecture and/or speaker roles at universities, disabled person organization events or professional forums, and joint authorship in the media (Callaway et al. 2017a). Recognition and nomination for awards relevant to JB's individual performance have also been successful (see Figure 2).

Figure 2. National Year of Digital Inclusion Award Recipients, including JB (pictured at front, seated in a powered wheelchair). Source: https://www.godigi.org.au/blog/congratulations-our-national-year-digital-inclusion-award-recipients (accessed on 12 January 2022).

Throughout these range of activities, consideration of **materials (and methods) that are accessible** has been important. Strategies include requesting questions for JB prior to the event so he can use his preferred Augmentative and Alternative Communication (AAC) device to prepare responses; utilizing online forum text box chats for two-way communication between JB and LV (via direct message), or ourselves and the audience during live presentations; and scheduling JB as the first speaker during presentations so that he can then respond using his preferred AAC whilst others are presenting. Our shared aim is that the **research we deliver transfers through to real life**, linking to both practice and policy (Callaway et al. 2017a, 2017b).

Example 3. *Co-design of allied health resources.*

In 2020, the 'My Allied Health Space' team which includes authors NL, EB, JB and LC partnered with the Victorian Government Department of Health to develop digital resources with two overarching goals: (1) ensure people with disability and their supporters have access to information and resources to guide selection and evaluation of disability workforce over time; and (2) ensure health professionals can assess and grow their own work capability to work with people with disability.

Often website design does not offer digital or information access for some people, including those with disability. However, the Council of Australian Governments jointly signed a 10-year National Disability Strategy in 2010 which espouses the need for inclusive and accessible communities, including digital information and communication technologies. Emphasis in this project was on being **inclusive** and **accessible**, so the clarity of the message being communicated and the functionality of the information matched the user's requirements.

This project used consumer co-design principles with a cross-institutional, interdisciplinary team of academic researchers, people with disability and the health professionals working with them. To ensure **the right people asked the right questions**, regular team meetings were held to plan, explore, develop, and deliver both resources and checklists for people with disabilities and their families and friends, and training content for allied health professionals.

Inclusive and participatory approaches were utilized to ensure outputs **transferred through to real-life**. People with disabilities and health professionals worked with EB to lead the production of video training content. Information that was not accessible was identified. For example, the term 'Aboriginal self-determination' was not familiar to one person with disability. They said: *"I've never actually had to think of it as Aboriginal self-determination. I consulted with some Elders in my community and we decided to put it as an Aboriginal perspective the topic should be 'being supportive of Aboriginal sovereignty as an allied health worker'"*. Their video content aligns with many of the Disability Inclusive Principles, when asked what was most important to them when working with allied health professionals:

> *. . . being listened to, to be understood, and have a right to interact on our terms, and have the outcomes we choose in a timeframe we choose. We need to sit and talk as equals respectfully. We don't need to be talked down to. We also need to feel relaxed, and know it's okay for us to speak up. After generations of control of our people, and being kept away from education and its benefits, we still feel the effects . . . We don't expect much, but what we do expect is respect, dignity, understanding, and choice. You need to talk to us mobs in the terms we understand. We don't understand everything you are talking about, so talk to us in our words, don't use your jargon, bring it down, right down, to an equal level where we get it, we understand and we feel comfortable.*

An advisory committee was also formed for the duration of the design process. This committee included people with disability, Victorian government representatives and allied health and disabled persons' organization representatives. The project also received approval from Monash University Human Research Ethics Committee, and **consent** was received from 30 people with disability, 150 health professionals and 54 allied health educators who contributed to co-design workshops over a period of eight months to inform iterative design of the digital resources. Feedback from each workshop was incorporated into subsequent design iterations until consensus on design was gained via informants across the two stakeholder groups.

The features of My Allied Health Space (www.myalliedhealthspace.org (accessed on 12 January 2022)) offer **a range of types of activities** which include: (1) dual website and information sheet view options (standard or Easy Read view) so the user can choose their preferred or the most accessible digital information style; (2) multiple mixed information resources (captioned video, image and written content) so that the user has choice of a range of information resources and tools, offered in varied formats; (3) AAA-**accessibility** to respond to the circumstances of a range of people who may use varied and alternative methods for digital access (e.g., screen reader; voice control for direct access; eye gaze or switch control of computer systems); and (4) a comprehensive, interactive learning management system for allied health professionals broken into multiple modules for self-paced learning. These approaches have led to a user-centered design being delivered, with **ownership** shared across all team members. All have been listed as contributors on the website, along with the logo of the organizations in which they work.

The narratives above have summarized a range of strategies to enact and deliver disability inclusive research.

What may be the challenges of enacting inclusive research?

Checklists and outputs are unlikely to ensure the principles of inclusion are met, and indeed we must ensure that signaling a few markers of inclusion will not pass muster. We work in the health and rehabilitation space, and conducting inclusive research within biomedical paradigms brought us face to face with a range of boundary issues/pragmatic constraints. We describe two of these here, related to **co-presenting**; and to **redefining what research is**, where we observe we were unable to fully realize inclusive research principles.

The lived experience experts of My Allied Health Space were listed as co-authors on one abstract (Callaway et al. 2021a) but not on another (Callaway et al. 2021b) with both papers presented by only one listed author. This is due to two factors. Firstly, presenters at conferences are usually required to register to attend, and registrations are costly and most often are out of pocket expenses of the presenter(s). Secondly, the strict time limit of presentations, eight minutes, and 15 min respectively, make co-presenting by multiple speakers problematic (even with pre-recording presentations, which was the case for these conferences occurring during the height of the COVID-19 pandemic in Victoria). For another project, authors EB and LC included two people with disability as co-presenters for a conference, and were subsequently sent instructions as to the format of the recording, which included uploading two separate files, a PowerPoint, and a video of the presentation. It was not possible for all four co-presenters to be in the same room, as one presenter was in hospital. This co-presenter sent an audio file for their part of the presentation. Strategies were required to ensure inclusion of another co-presenter. They needed to record in bitesize segments, and were more comfortable with audio than a video recording. For consistency EB also recorded audio, so there was no video of any of the presenters. The audio files were edited together to give the impression that we had all presented together, and to ensure the presentation was within the time limit, short or long pauses were cut from the recording, and the speed of some audio clips were slightly adjusted. After uploaded the two files we received the following reply:

> *Thanks for your presentation. It is excellent. I do however, need a separate video file and ppt [PowerPoint] file for consistency. All other presenters have sent the two separate files. Sorry for the inconvenience, but can you please send the two files separately, as per the instructions.*

The strategies we used for inclusion of all speakers were explained to the conference organizers, and they were apologetic, and they said we did not need to redo a videoed version of the presentation. This flexibility is needed for all conferences to ensure inclusion of people with disabilities.

This principle is echoed by RB, a disabled woman[1] with lived experience of being bedridden and homebound (www.notdoneliving.net/just-invisible.html (accessed on 12 January 2022)). RB states,

> *If you were talking to people about making a conference accessible, people will talk about interpreters, ramps, things like that. Or a deafblind person who needs tactile interpreting. Or a person with intellectual disability who needs cognitive accessibility. But I need virtual accessibility . . . and to drop me . . . just because I am the only one talking about it, its terrible.*

The exclusion of people who, in research terms, may be an 'n of 1' serves to further marginalize the person who is most marginalized in the first place'.

This point brings us to fundamental questions about how to enact the principle of '**redefining what research is**' uncovered an epistemological tensions (Hathcoat et al. 2019). As RB describes her experiences as a research 'outlier':

> *When you come to me with a questionnaire, and it says to me, is my answer a or b, and I say well actually my answer is c,d,e,f and sometimes z, then I don't want the researcher to say well sorry that's impossible, I want them to say 'hey wow—you are the person with the disability' . . . my lived experience is real, I want to be believed as a person with disability and if what I say doesn't fit with your paradigm, that means your paradigm is wrong. If what I say is something that your theory says is impossible, that doesn't mean that my experience hasn't happened, it means your theory needs to be revised, and that what collaborative research is about—that my experience is just as important as your theory or your paradigm.*

As a researcher trained in psychology and health systems research, EB reflects upon RB words and highlights some potential areas in need of change.

> *When learning about how to do good research, you are told about all the steps you need to take to ensure rigor in the planning, execution and reporting. You learn about the pros and cons of each methodology. For surveys, the advantages are that they enable you to obtain a large amount of data from a representative sample, so that the results are generalizable to a specific population. One of the disadvantages of surveys being that*

> *the data is unlikely to contain the same level of depth as interviews or focus groups. You learn how to analyze data, and in the case of closed-ended questions, where respondents select 'other', about techniques you can use to interrogate those responses to identify themes, or the most common responses. You learn that it is not a requirement to provide every possible breakdown of the data, rather you need to present the highlights, or those findings that are statistical and/or have practical significance. So, consequently, if only one participant answers 'z', their response gets left out of the findings. The same is true in research using interviews or focus groups as the methodology. Thematic analysis of the data similarly requires the researcher(s) to examine the data to identify common themes that come up repeatedly. However, there are instances where a response is a one-off, there is no theme, and whilst it is not included in the findings I can see how this could lead participants such as RB feeling that their voice had not been heard, or worse still completely ignored when reading the findings.*
>
> *RB also mentioned the need for theories to sometimes be revised, which can often be easier said than done, as people (i.e., reviewers, editors) can be much more accepting of 'confirming' evidence. For example, . . . a review in 2005 found significant results are more likely to be published (Dubben and Beck-Bornholdt 2005). The source of this problem is unknown, is it failure of the researcher(s) to write up the study, failure to submit for review, or failure for the paper to be accepted by a journal. Consequences of leaving non-significant findings unreported, apart from an unproductive expenditure of time and funding, are the potential to impede progress, prevent the creation of new theories or the revision of existing theories. Ferguson and Heene (2012) reported that publication bias can lead researchers to conduct studies and analyze results in ways that minimizes the danger of non-significant results. This too, is something I have encountered in the very early stages of my research career. I recall running an experiment and analyzing the data and the results being insignificant. However, rather than our data and findings offering the potential to revise an existing theory, I was told that our non-significant findings were due to having some outliers in the sample. I was subsequently asked to re-advertise and repeat the study with some 'replacement' participants, and re-run the analysis. In such a pursuit to obtain statistically significant findings that support an existing theory, it seemed like we were potentially removing important information about the variability we had encountered, and overestimating the true effect of the existing theory.*

These examples and directions are drawn together in the discussion, with a proposed way forward.

4. Discussion

We agree with the question posed by Milner and colleagues that 'academic researchers might want to check how far inclusive methods had travelled down a road intended to change the power relationships that underwrite knowledge production' (Milner et al. 2020, p. 127). These examples of inclusive research in health, rehabilitation, and assistive technology can be described as partial. Despite our best efforts, there are many factors which limit the full realization of co-produced and inclusive work. Based on the above learnings we suggest a progressive model is needed, but must go hand in hand with research governance and practice that builds, rather than inadvertently blocks, inclusion for all.

Arnstein's (1969) ladder of citizen participation provides a useful approach (Callaway et al. 2020). Originally it presented a hierarchy of citizen participation from non-participation through to tokenism and ending with the ideal of citizen control. In the last decade, however, the ladder concept has been applied to consumer participation, broadly moving through rungs of 'doing to' (coercing, educating); 'doing for' (informing, consulting, engaging); 'doing with' (co-designing, co-producing) and arriving at 'doing for themselves' (co-delivery, co-ownership) (New Economics Foundation 2012; People with Disabilities Western Australia 2020).

We draw on this co-design and co-production thinking to propose a revised ladder of participation suitable for inclusive research (see Figure 3). Our proposed classification of research roles recognizes that all researchers may hold roles as a research subject; a research consultant; a research collaborator; a research colleague or a director of research who contributes to or is in charge of the mechanisms of research production.

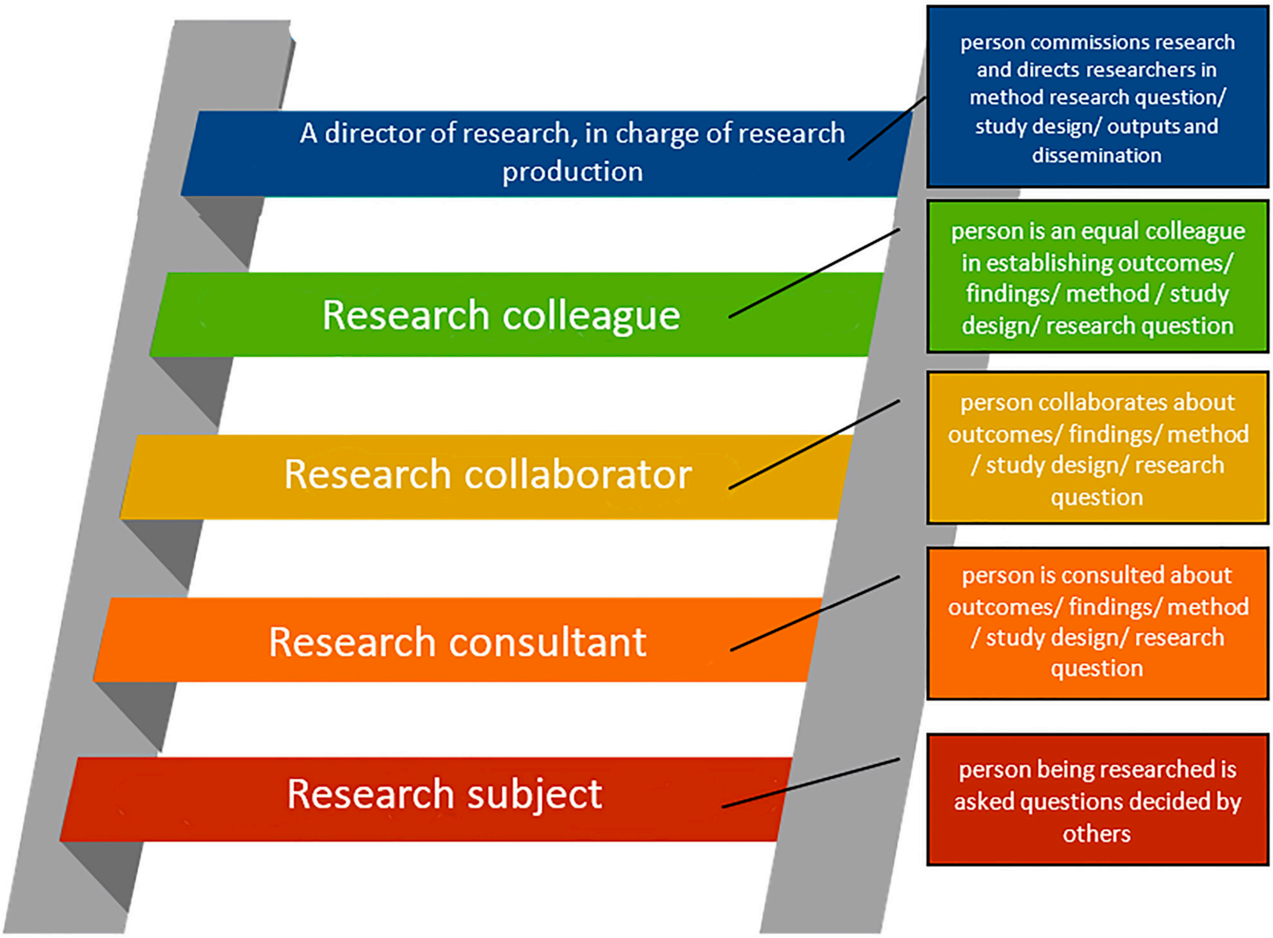

Figure 3. Ladder of research inclusion.

Such a ladder will, at a minimum, alert those involved with research as to its potential emancipatory opportunities and enable claims of 'inclusive and co-designed' research to be interrogated. To accept the premise that people with lived experience can, and should, engage across all aspects of research production will require a changed ontological positioning on the part of academic researchers and lived experience experts like us who have been acculturated into roles predetermined by 'the academy'.

To enact the ladder and deliver on inclusion will require a range of conversations and strategies. A shift towards intersectionality (Gressgård 2008) is a key epistemological tool. Discourse amongst intellectual disability thinkers (Jones et al. 2020; O'Brien 2020) explores whether participants in research will assume differentiated roles based on what they bring, or whether group collaboration will play out, knowing the right people are in the room and each will do according to their capability. Strategies such as engaging in a strengths-based dialogue about what each person brings to the research endeavor may serve to bring rehabilitation researchers on this journey. And attention to the ways in which this inclusive view might be adopted by stakeholders holding power in research environments, for example research funders and ethics boards, would be a further step on the road toward inclusion (Gaventa 2006).

5. Conclusions

In our introduction, we asked how our knowing and doing is influenced, and we framed our answer from the position of practitioner and consumer researchers. But really, our knowledge, our skills, and our position on the trajectory of learning how to do research are all intersecting qualities. These are poorly articulated by the binary of 'researcher', and person with disability or the 'researched'. We know that our knowledge is likely to be partial as our positioning which, by definition, does not encompass the positions of all others. Exploring the practice of inclusive research across the areas of assistive technology policy; digital health access; and the co-design of housing and support, demonstrates a lag in the inclusive credentials of thinking about inclusion in rehabilitation research. Explicit strategies, such as the ladder of inclusive research participation, may enable the implicit role (and power) entrenchment in health and medical research to be illuminated, discussed and redressed.

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Note

[1] R.B. chooses to describe herself with these words.

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