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# The critical role of lived experience reporting guidelines to improve research with young disabled people

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## ABSTRACT

Social and public health research has been transformed by the acknowledgment that it should involve the very people it will affect, and lived experience input from disabled people is increasingly common. Although this indicates engagement with disabled people in research is getting better, the reporting of their involvement is not. In this paper, we focus on the intersection of youth and disability, a population that is underrepresented in both disability research and its supporting resources. We argue there is an urgent need for research to clearly document the involvement of young disabled people so we can properly understand the impact of their lived experience. We propose essential reporting criteria that will facilitate research quality by fostering accountability and reproducibility. Without clear reporting guidelines, lived experience input from young disabled people will remain undocumented and its impact overlooked.

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codesign; coproduction;  
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## Introduction

The disability activist's motto of "Nothing About Us Without Us" has had significant epistemological and methodological impacts on disability research. Although the involvement of disabled people in disability research is improving, the reporting of that involvement is not. This paper focuses on research that involves young disabled people, who are often overlooked in both youth research (due to disability) and disability research (due to age). We draw upon our experiences from the Research Alliance for Youth disability and mental health (RAY) project to argue that the reporting of lived experience needs to be transparent, specific, and sufficiently detailed.

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This is a current issue because the prevalence of disability in young people aged 15–24 is rising, likely due to increased awareness of disability and increased prevalence of some long-term health conditions (ABS 2024; Kelsey & Kendall 2024). Thus, research that engages with this population is likely to increase. We can also expect increased lived experience input because co-design and related terms are current buzzwords within research circles and funding bodies. Hence, it is critical to ensure that lived experience input from young disabled people is meaningful and benefits the research, the researchers, and the disabled community. Clear reporting is one way to achieve this.

### ***The intersection of youth and disability***

Whilst all disabled people face barriers to being involved in research, young disabled people face distinct barriers as both participants and researchers (Rios et al. 2016). Adult caregivers may gatekeep young people's access to participating in and conducting research (Pincham, Harrison, and Collin 2020), and their involvement is more likely to be filtered through an adult proxy, such as a parent. There are additional layers of power imbalance due to age and experience, so young people are often not recognised as credible knowledge holders. This impacts whether and how their contributions are documented.

The criteria we propose for reporting lived experience input from young disabled people could apply to research with disabled people of any age. However, we are arguing for their importance with young disabled people specifically. Firstly, because they have different needs deserving of a focused approach. Secondly, there is an absence of resources to support engaging this population in research. In contrast, resources are more readily available for involving disabled people in research (Nind and Vinha 2013; RDI Network (Research for Development Impact Network) 2020) and for engaging with young people generally (Giordano et al. 2020; O'Kane and Levy 2022). Similarly, although research with disabled people and research with young people are not difficult to find individually, research that directly involves young disabled people is scarce. Of the research that does include them, lived experience input and its impact are often unclearly documented (Liddiard et al. 2019; Oliver, Kothari, and Mays 2019). Research may state that young people offered reflections or critical insights, but without further explanation. This may reflect the lack of supporting resources and guidelines or be a consequence of it. Hence, this paper argues for clearer documentation of lived experience input from young disabled people specifically. It reveals a critical need for resources, but especially reporting guidelines, to enable the consistent and meaningful inclusion of young disabled people in research.

## Documenting disability inclusion

We propose that any study engaging young disabled people should document the following criteria and call upon researchers to: define and justify their chosen approach to disability inclusion; clearly describe the research activities young disabled people were involved in; state the supports given and comment on accessibility; and finally, mention if and how young people were compensated. Transparency and specificity in these areas will allow readers to surmise whether research was inclusive or inaccessible, tokenistic or meaningful.

When we attempt to understand the involvement of young disabled people in research, we quickly encounter a major difficulty: the variable – sometimes impenetrable – terminology. When working in a research capacity, young disabled people may be called service user researchers, research survivors, consumer researchers, lived experience researchers, participant-researchers, peer researchers or co-researchers (Aubrecht et al. 2021; Mellifont 2023; Nind 2017). The research process also has many different names, including co-design, co-production and participatory research. The abundant terminology ultimately complicates meaningful engagement rather than supporting it.

Ideally, we need unifying terminology in this area. At a minimum, however, researchers must explain and justify their terms and approach. For example, Knowles et al. (2022) engaged young people with lived experience of self-harm and suicide to prioritise interventions and outcomes for a future Cochrane review. They explain their approach is co-design and not co-production since young people were involved in decisions *about* the review and its design, not the review itself (Knowles et al. 2022). This type of explanation allows the reader to understand the researchers' position on the debated terminology and consider it within wider disability studies discourse.

It is paramount that researchers then detail the research activities young disabled people were involved in. This enables readers to assess the quality of disability inclusion, and credibility of the findings. For example, Liddiard et al. (2019) list ten ways that six disabled young people co-led inquiry and Nicholson et al. (2024) use a table to show how the choices of their co-researchers changed workshop activities. Aubrecht et al. (2021), who studied the experiences of disabled adults in long-term care, included three young disabled women (all long-term care residents) as co-researchers. They are transparent about what activities the co-researchers were or were not involved in, and why. For example, co-researchers were unable to present at a national conference since funding was limited, requiring all researchers to self-fund travel expenses (Aubrecht et al. 2021). They recognise the exclusion of their colleagues from an in-person experience as a limitation of their study.

Details about accessibility and flexibility are important to understand how the participation of young disabled people was enabled and supported. Publishing these details gives other researchers the opportunity to consider accessibility in their own approaches. Liddiard et al. (2019) argued that virtual research environments are “critical” to disability research with young people, enabling more accessible participation and communication (11). Nicholson et al. (2024) allowed for support people, and emphasised that accessibility ultimately relies on the preferences and choices of young disabled people. In contrast to these examples, authors may state they created an inclusive environment without explaining how they fostered inclusivity or supported accessibility needs.

Finally, researchers must report whether young people were remunerated and how. It is essential that young disabled people are paid for their time and experiential expertise, and researchers need to be transparent about the type of compensation. Justifying the choice of compensation may be more important than the choice itself, which depends on many factors, including workplace policies, budgets, and young people’s preferences. For example, peer researchers on a project by MacKinnon et al. (2021) were paid an hourly rate consistent with that for all research assistants, set by the standards of the University of Toronto. Regarding gift cards and other incentives, some argue these devalue lived experience expertise (Mellifont 2023), whilst others recognise that wages can impact welfare payments and gift cards circumvent this issue (MacKinnon et al. 2021).

### ***What reporting guidelines could achieve***

Without adequate reporting, we cannot truly understand the impact of lived experience. We also cannot judge the reliability of a study’s findings nor interpret them appropriately. We need consistent reporting so that studies can be collectively examined *via* scoping or systematic reviews, to then evaluate the best ways of involving young disabled people in research. We will be able to identify what types of research do not include lived experience and develop new approaches to address these gaps. Requiring the documentation of essential components will establish accountability in young people’s disability research and enable us to better judge the quality of lived experience involvement. It will also increase the reproducibility of studies that involve young disabled people, which is important for scientific integrity. As a disability research community, we need to learn together what works and what doesn’t. Guidelines that facilitate consistent reporting will help us achieve this.

### **Conclusion**

To produce truly inclusive research that is conducted *with* and *by* young disabled people, instead of *on* and *for* them, we need clear reporting guidelines

that promote transparency and specificity. Without these, we cannot truly understand the impact of lived experience, nor can we evaluate its effectiveness. We have argued for essential details about the chosen approach, research activities, accessibility, and remuneration. These features provide the feedback necessary to reflect upon current research and conduct future research. This is key to understanding the true involvement of young disabled people in research and the impact of their lived experience.

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