RESEARCH

Lived Expertise and the Development of a Framework for Tracking the Social Determinants, Health, and Wellbeing of Australians with Disability

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There is increasing recognition of the value of coproduction and inclusion of people with disability in research, and a growing literature on inclusive methods, particularly involving people with intellectual disability. This article critically examines the ways leadership by, and collaboration and consultation with, people with disability informed the development of a framework to monitor Australia's progress on reducing inequalities in the social determinants of health and wellbeing for people with disability. It focuses especially on the contribution of an expert panel of advice comprising people who live with disability. Input from the expert panel resulted in changes to the language, shape, and detail of the framework and highlighted the complexity easily hidden when people's lives and experiences are measured and quantified. The article provides a practical illustration of the value of lived expertise and challenges universities and researchers to work harder to ensure people with disability shape the research agenda.

Introduction
People with disability are at risk of discrimination and disadvantage in many areas of life. In recent decades, the Australian government has made several commitments to reduce that disadvantage, including implementation of the National Disability Strategy 2010–2020 and the National Disability Insurance Scheme in 2013. Notwithstanding these positive moves, there is evidence health, social, and economic inequalities between people with and without disability are persisting and, in some aspects of life, may be increasing (Emerson et al. 2018).

The NHMRC Centre of Research Excellence in Disability and Health is a world-first research initiative that aims to build knowledge and gather the evidence needed to guide social and health policy reform for people with disability in Australia (see https://credh.org.au/). The centre's primary goals include the production of a framework and indicators to monitor health and wellbeing inequalities between people with and without disability (Fortune et al. 2019; Fortune et al. 2020). The indicators will be used initially to report national baseline data, and thereafter to track trends over time. The data reported will inform policy by identifying where action is needed and by highlighting where there is progress, regress, or no change.

One of the guiding principles for the Centre is a commitment to co-production and inclusive research. This article reflects on how these principles were realised in the development of the monitoring framework, in particular by having people with disability in positions of leadership and as members of the research team within the Centre, and by consulting with an expert panel of people with lived experience of disability. We report on the insights that emerged from the expert panel consultation process, give examples of how the input provided contributed to development of the monitoring framework and indicators, and reflect on the rich contribution of experiential disability expertise.

Co-production and Inclusive Research
Co-production is a term widely used in health and social service contexts to describe 'the involvement of citizens, clients, consumers, volunteers and/or community organisations in producing public services as well as consuming or otherwise benefiting from them' (Alford 2009: 5). It has become important in the delivery of health services in Australia and globally, challenging the prevailing (if implicit) assumption health services should be designed by experts

and delivered to passive consumers. Co-production intends to do more than obtain token representation of consumers on consultative committees, instead it looks to establish active and equal partnerships between professionals and service users in the development and delivery of services. This equality recognises the expertise of the consumer: 'the experience of consumers as they engage in a situated relationship with health professionals that is identified as the unique, significant, and potentially transformative source of information and insight' (Dunston et al. 2009: 47; also Alford 2002; Green 2016; Petukiene 2010; Ryan 2012; Staley 2015). Co-production has a deeper significance in the context of disability, where the overarching principle of 'nothing about us without us' gets to the heart of the meaning of disability, as an embodied and social reality in which paternalism and exclusion are core elements (Charlton 2000; Shakespeare 2014).

Inclusive research is a term commonly used to describe co-production in academic research, where the intent is to change the dynamic between the subjects and objects of research and move the emphasis from research on people to research with people (Nind 2014; Nind 2017). Inclusive research is an umbrella term that brings together a range of approaches sometimes labelled collaborative, participatory, or emancipatory (Johnson and Walmsley 2003: 10). There is a growing literature on inclusive research with people with intellectual disability, where the goal is to give people the opportunity to shape research that will impact upon them, thereby improving research quality, relevance, understandability, and capacity to effect real-world change. Bigby and colleagues (2014) describe three broad approaches to inclusive research: advisory, collaborative, and leading and controlling. The approach adopted will depend upon the specific context and the nature of the research, but there is growing recognition of the value of increasing involvement and control by people with intellectual disability, especially in qualitative research focused on elevating the voices and stories of research participants (Milner and Frawley 2019; Strnadová and Walmsley 2018). Key to its success is carefully designed methodology, including the provision of accessible information, appropriate resources and time frames, arranging participation as early as possible in the research process, establishing open and respectful relationships, and delivering meaningful feedback.

In addition to intellectual disability, there is an emerging literature on co-produced research with people with mental illness that recognises the unique insight of the insider perspective (e.g. Gillard et al. 2012; Happell et al. 2018). User control advocates in mental health research are drawing on the emancipatory logic of the disability rights movement (Beresford 2009), where disability inclusion is recognised as being about more than overcoming the divide between professionals and consumers of health services. The rejection of ableism and paternalism informs the politics of disability and invites critical questions about who has the right to shape and control an emancipatory disability research agenda (Oliver and Barnes 2012: 28–30).

Inclusion has a significance that finds an Australian parallel in Aboriginal and Torres Strait Islander leadership of and participation in research and policy concerning First Nations peoples. Drawing on the critical insights of postcolonial studies, global Indigenous scholars argue the absence of indigenous involvement in the collection and analysis of data leads to a 'statistical narrative of deficit for dispossessed indigenous peoples around the globe' (Walter and Suina 2019: 233). The Indigenous Data Sovereignty movement has emerged as a response to this dispossession (Rainie et al. 2017; Wilks et al. 2018). In Australia, there is increasing emphasis on ensuring research and policy about Aboriginal and Torres Strait Islanders is conducted with their leadership, yet similar empowerment of disability voices is still uncommon. In both cases, discrimination and marginalisation are important contributors to academic paternalism. It is true the breadth and diversity of disability poses challenges for data sovereignty. Disability is a shared experience of social disablement, and it also references a radically diverse community of people across which there is great variation in terms of types of impairments, social status, identities, and life circumstances. Yet, although it may be a challenge for disability leaders to speak for such a varied and diffuse community, their shared experience of impairment and social disablement, and their identification with the disability rights movement, provides them with a basis for taking leadership roles in disability research.

Disability inclusive research is not without the risk of tokenism, where people with disability are used 'to rubber stamp the process and not as true partners' (McLaughlin 2009: 1600). The meaningfulness of participation depends on the methodology employed and the nature and extent of involvement, where researchers recognise prevailing asymmetries and give persons with disability real power to shape the research and its outcomes (Gillard et al. 2012; Romsland, Milosavljevic & Andreassen 2019). But embracing the perspectives of people with disability and the value of contributions based on their own experiences unmasks the myth of objectivity that persists in the sciences. The risk is that such research may be unfairly dismissed in the academy and struggle to attract recognition and funding (Mellifont et al. 2019).

It is noteworthy that one of the two co-directors of the Centre of Research Excellence in Disability Health, Anne Kavanagh, lives with Multiple Sclerosis and is the mother of a child who is autistic and has intellectual disability. The other co-director, Gwynnyth Llewellyn, is a family member and lifelong academic ally of people with disability. Their commitment to bringing together scholarship and personal experience of disability is an important aspect of the Centre's vision and informs its structures and projects. This commitment is demonstrated in efforts to include researchers with lived experience of disability and to provide opportunities for them to develop their research careers. Of the authors of this paper, in addition to Llewellyn's lived experience, Shane Clifton has quadriplegia and Roger

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Stancliffe has a 40-year friendship with a man with Down syndrome. Paul Williamson, who joined the list of authors as a representative of the expert panel, lives with neurological and physical disability.

Disability experience is not given the prominence in research institutions that it warrants. While writing this article, the authors realised the disability experience of Centre for Research Excellence in Disability and Health scholars is not currently profiled in any substantive way; it is not described in the biographies of chief investigators on the Centre's website, and few researchers include it on their university profiles. Disclosure of disability is a complex issue and should not be forced, especially because prejudice persists in the academy as elsewhere (Mellifont et al. 2019; Miller and Dika 2018; Shigaki et al. 2012; Titchkosky 2008). But one way forward for scholars and organisations looking to challenge the status quo and emphasise the importance and value of inclusive research is to elevate their own lived experience — 'you cannot be what you cannot see.'

The Expert Panel and the Development of the Monitoring Framework

To develop the monitoring framework and indicators, the Centre for Research Excellence in Disability and Health established a team of researchers with quantitative, qualitative, and lived disability research expertise. To gain the insight of the diverse disability community, wider consultation was needed. Feedback was sought from the centre's Partner Advisory Group (an advisory board constituted by membership from government and non-government organisations, statutory bodies, and disabled people's organisations that have detailed knowledge of the disability and health sectors) on a proposed process of inclusive research involving two rounds of consultation with an expert panel of people with disability, the first to obtain feedback on the draft framework structure and relevant domains, and the second to seek input on potential indicators for each domain.

Approval for the expert panel consultation process was granted by the University of Sydney Human Research Ethics Committee (Project no. 2018/884). All participants gave written informed consent indicating research findings may be published and presented orally but they would not be identified in any publication without their agreement. The focus of the input provided by the expert panel was on the development of the framework. The views and reflections of panellists on the efficacy of the consultative process were not sought and are not reflected in this article, except for Paul Williamson, who was a member of the expert panel and is a co-author of this article.

In constituting the expert panel, the intention was to recruit people with lived experience of disability. Precisely what should count as lived experience required careful consideration. In constituting the expert panel, one issue was whether to include family members of people with disability, given that disability advocates generally insist on the distinction between disability experience and disability allies. This issue was subsequently raised by the expert panel itself, in the context of discussing the 'gatekeeping' role often assumed by disability allies. Paternalism is an enduring problem for the disability community, and people in the neurodiversity movement have been especially vocal about parental control and bias (Kirkham 2017). It was decided, in addition to people with disability themselves, the expert panel should include family members of people with profound or complex disability who are dependent upon others to communicate their interests and concerns, in order that this important section of the disability community could be represented.

The intention was to convene an expert panel with broad representation, including people with different disability experiences, from varied geographic locations and from key population groups, such as Aboriginal and Torres Strait Islander people. Seventeen participants joined the expert panel, including people with physical, neurological, and/or sensory disability (10 people), intellectual disability (4), and parents of people with profound disability (3). Members lived in six Australian jurisdictions; two members lived in non-metropolitan areas.

Two rounds of consultation were held. In each round, participants met in small groups of between two and six people via online videoconferencing; one participant who could not attend a scheduled videoconference was interviewed one-on-one by phone. Before the first round of consultation, participants were sent background information about the project, including an initial draft monitoring framework and a list of questions. Before the second round of consultation, a revised version of the framework and a list of potential indicators were circulated. For each round of consultation, participants were invited to send written feedback by email prior to the group discussions. Functional accommodations and pre-meeting training on the use of the videoconferencing platform were offered to all participants; however, most had their own adaptations in place and had little difficulty participating in the online conversation. Online discussions were facilitated by two members of the research team and went for approximately 90 minutes. The group discussions and one-on-one interview were audio recorded, with permission of the participants, and transcribed.

For participants with intellectual disability, an easy-read version of the background information was prepared, including pictures, symbols, and charts alongside simplified text to describe the framework. Staff members of the New South Wales Council for Intellectual Disability used this to facilitate discussion of the framework in a face-to-face meeting with four expert panel participants and two members of the research team. This meeting was not recorded, but detailed notes were taken and a summary report produced by the facilitator.

Established thematic analysis techniques were used to analyse the input provided (Ritchie et al. 2013). Transcripts and the written responses provided by some participants were reviewed to extract points of input, which were individually numbered and categorised according to the domain of the draft framework to which they related. Two

additional categories were created for input not related to a specific domain: 'Overall comments on the framework' and
'Comments concerning data for reporting against indicators'. The research team then reviewed points of input within
each category and decided what changes should be made to the framework and indicators in response; these decisions
were documented category by category.

The following section describes what was learned from the expert panel consultation and discusses its relevance for
conducting inclusive research.

Results and Discussion
Expert panel process, small group discussion, and complexity
The expert panel small group discussions were an effective means of receiving feedback and insight from people with
lived experience of disability, especially concerning the nuances, complexity, and intersectionality of disability. The
expert panel input informed substantial modification and refinement of the framework and indicators (further detail
about development of the monitoring framework and indicators, and a full summary of input provided by the expert
panel of advice, can be found in a technical report available upon request from the first author).

In conducting the discussion groups, facilitators had to let go of their expectations about how the discussion
should proceed. The original intention had been to work through pre-planned questions and to review the framework
domain by domain. However, discussion quickly expanded beyond the original agenda, as panellists explored domain
topics of interest and concern to them and identified the interconnections between domains. Facilitators used their
intuition and experience to balance the need to allow discussion to flow naturally while also refocusing panellists
on the details of the framework. The fluid, nonlinear, and creative conversations that transpired allowed participants
to explore topics in their own way and reduced the potential for facilitators' expectations to determine content and
outcomes (Kamberelis and Dimitriadis 2014). In some instances, discussion facilitators at first felt was tangential
to the monitoring framework provided rich insight, including important considerations for the presentation and
interpretation of indicator data.

In presenting the input provided by the expert panel of advice, below, we do not distinguish the voice of participants
with intellectual disability, deliberately treating their contribution the same as that of other participants. Discussion
in the facilitated focus group proceeded in much the same way as it did for the other groups. The facilitators from
the NSW Council of Intellectual Disability used the easy read document to explain important concepts, and invited
discussion. Panellists asked for clarification, expressed their opinions clearly, and pursued related, and sometimes
tangential, topics—and facilitators allowed scope for creative conversation, while regularly steering discussion back
to a focus on the framework. Panellists identified many of the same issues and concerns as those raised in the other
discussion groups, as well as some unique items, such as the importance of including bullying in the framework. They
also discussed the presentation of data, reflecting on the value of adding pictures, symbols, and clear explanatory
text to charts and data tables. They provided feedback on forms of presentation that were easier (and harder) to
understand.

Discussion in the various groups focused on different issues and had different emphases, depending upon the
individual interests and concerns of participants. However, expert panel members did not restrict their focus to those
matters that affected them personally, recognising the importance of the framework for all people with disability. In
some cases (not many) inconsistent positions were expressed in different groups, revealing the nuance and complexity
of topics in relation to the experience of disability. For example, the draft framework included the domains *Health
behaviours*, covering topics such as 'physical activity', 'smoking', 'alcohol consumption', and 'diet', and *Personal biomedical
factors*, which included 'BMI/Obesity'. Facilitators had speculated about whether the expert panel would identify 'fat
shaming' as a disability rights issue and raise concerns around indicators in these domains (Aphramor 2009). A variety
of views were put forward in different discussion groups. Some participants argued obesity and health behaviours are
important to measure to provide evidence on health-related inequities experienced by people with disability. Other
participants raised concerns about the paternalistic monitoring of behaviour, noting people with disability

> are heavily monitored and our behaviour is compared to the behaviour of the perceived model citizen, a white,
> middle-class, rational, able-bodied man, … who has a low BMI, a glass of sherry once a year, doesn't smoke, and a
> diet reflective of the Mediterranean or something. … It's like, you have to behave like this or it's a problem.

Some participants noted the term behaviour 'is often used in a negative way around people with intellectual disability.'
Taking all these views into account, the research team decided to change the domain heading *Health behaviours* to
Lifestyle factors, but to retain this domain and *Personal biomedical factors* in the framework. In this and other cases, the
research team used their judgement to decide between alternatives.

Group discussion often highlighted the inter-connectedness of and interactions between topics represented in
different framework domains and the complexity added by considering how particular social determinants of health
interact with different lived experiences of disability. In some instances, this led to questioning whether certain indicators
could provide a basis for meaningful comparison between people with and without disability. For example, the domain
Food environment included potential indicators in relation to access to healthy and affordable food. Members of the

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expert panel commented 'this domain does not make a lot of sense from a disability perspective. … Food outlets might exist [nearby], but people with certain types of disability need support to access them.' The point is not that the food environment, as generally conceptualised in a mainstream public health context, is irrelevant to people with disability, but rather that other, disability-related factors may determine whether a person with disability can benefit from a healthy food environment to the same extent as someone without disability. Whether a person with disability can access healthy food may be affected not only by the types of food outlets available in their neighbourhood, but also by the accessibility of those outlets, the availability of support for both purchasing and preparing food, and appropriate kitchen modifications to enable them to cook at home.

Framework structure and content

The expert panel provided input into the structure and content of the framework. There was general agreement the draft framework, which was presented initially as an unstructured list of 18 domains, needed a more user-friendly structure. In response, it was restructured, grouping domains under three broad elements (Health, Social determinants of health, and Service systems) and making other changes at the domain level. One participant suggested the framework should mirror the structure of the United Nations Convention on the Rights of Persons with Disabilities, a foundational international instrument widely used by advocacy organisations and government in a disability policy context. The Convention had been drawn upon in the initial development of the draft monitoring framework, but this comment prompted the research team to revisit the Convention, mapping the framework domains to the Articles of the Convention to identify possible gaps. As a result, a new domain, *Family and relationships*, was added (to capture Article 23 'Respect for home and the family') and it was agreed all indicator data would be disaggregated by gender (to capture Article 6 'Women with disabilities'); in addition, it was decided a subset of indicators should be identified as of particular relevance for monitoring performance in relation to Australia's obligations under the CRPD.

The expert panel provided substantive input on topics and indicators within domains, including the following examples:

a. Participants observed 'there is greater stigma around having a mental health issue than other types of disability,' and asked of the framework, 'Where does mental health fit in? Particularly the mental health of people with disabilities, which can be so negatively affected by systemic barriers they face.' This led to inclusion of mental health indicators in the *Self-rated health and wellbeing* and *Morbidity* domains.
b. Participants highlighted the importance of the domain *Information and communications environment*, given 'online interactions are important for people with disability,' and suggested the inclusion of indicators relating to social media use and the presence of appropriate support to access available technologies.
c. In the domain *Income and material resources*, the expert panel questioned the appropriateness of household-level income measures, noting 'Living in a household with reasonable income and asset levels can disguise the fact that individuals themselves may have very little,' and 'economic abuse' can be a barrier to financial freedom. In response, the research team included indicators of both household income and personal income in this domain, recognising both are relevant factors in understanding people's level of material wellbeing.
d. Participants noted the negative effects of bullying and various forms of abuse on mental health. In response, indicators on experience of bullying or harassment, partner violence, physical violence, sexual violence, emotional abuse, and financial abuse were included in the domain *Justice and safety*.

Language usage and disability representation

The expert panel provided insightful perspectives on the choice of language used to speak about disability and highlighted the need to ensure the monitoring framework and indicators did not reinforce negative attitudes toward disability. For example, participants questioned use of the term 'working-age adults'. This term was used in the background information distributed to the expert panel to delineate the focus population of the framework (Australians with disability aged 15 to 64 years) and was also used on the Centre for Research Excellence in Disability and Health website and in other publications of the Centre. Although this term is commonly used in statistical and policy contexts, the point was made it can tend to imply engaging in work is central in determining people's worth as human beings. As one participant put it:

> if you talk about someone of working age, what are you assuming about what's ordinary or "the norm"? Sure, there's lots of issues around employment opportunities for people with disabilities, but at the same time, why we matter isn't just tied to our ability to be in paid employment.

Panellists concerns were later raised at a full meeting of the Centre for Research Excellence in Disability and Health that brought together researchers from several universities throughout Australia. Some researchers argued 'working age' is merely a useful descriptive category, with no implications for the value of people not in paid employment. Researchers did not reach agreement on how to proceed, so the matter was referred to the Centre's Partner Advisory Group, who agreed with the advice of the expert panel. Thus, it was decided the term 'working age' will not be used in presenting

the monitoring framework or reporting indicator data. This example highlights academics are not always aware of the extent to which terminology commonly used in a research context can inadvertently communicate ableist and derogatory assumptions. It also raises the bigger issue of how, as a society, we value (and reward) the contributions of people both with and without disability who do not participate in the labour market.

The expert panel raised other concerns about language used in the documents presented to them. One member noted 'people with disability' is preferred over 'people with disabilities' in the Australian disability sector, 'because we're social model focused. Saying "disabilities" focuses on diagnoses and impairment, and we don't do that."

Another concern raised was the danger the monitoring framework, rather than highlighting inequity, could cement the negative assumption people with disability are inherently unhealthy. The expert panel examined the concept of health for people with disability, identifying the need to distinguish 'between health problems that are related to a person's disability and health problems that are not related to disability.' This can be complex because 'People with certain disability types are at higher risk of particular health problems.' Reporting data on health indicators might give the impression people with disability are unhealthy by virtue of their impairments (Bickenbach 2013), which would feed stereotypical presumptions about the 'awfulness' of disability and exacerbate shame and marginalisation. The expert panel affirmed it is possible for a person with disability to be healthy notwithstanding their particular impairment (Putnam et al. 2003; Faull et al. 2004; Nazli 2012). A person with disability may or may not have health deficits associated with their impairment. Importantly, a person with disability can experience ill-health in the same way as a person without disability, for example, by catching the latest influenza circulating in the community. It was agreed indicators should be selected carefully to focus on inequalities in health outcomes related to differential exposure to social determinants (e.g., differences in cancer incidence associated with variation in exposure to risk factors or access to preventive health services); indicators likely to be affected by disability-related health conditions should not be included.

Data source limitations

The expert panel highlighted some limitations of Australian national data sources related to the complexity of disability in interaction with the methods used to collect data.

Baseline data for the indicators in the monitoring framework will be drawn from key Australian national data sources in which it is possible to identify people with and without disability (e.g., Australian Bureau of Statistics surveys, the Household Income and Labour Dynamics Survey (Fortune et al. 2019; (Fortune et al. 2020)). Participants raised concerns about the comprehensiveness, accuracy, and interpretation of the data to be reported. Negative experiences fed into their apprehensions. One participant cited National Disability Insurance Scheme surveys that claim high levels of participant satisfaction: 'they report 93% satisfaction rate, which is just rubbish' (see De Luca 2018). Another observed 'measures of "satisfaction with" are problematic because satisfaction is related to expectations. If you have come to have low expectations through your life circumstances this will affect how you respond to questions about satisfaction.' Similarly, another participant noted self-report data based on questions such as, '"compared to others I know …," would be skewed if someone is living in a segregated setting like a group home.' Some expert panel members thus argued all indicators that reference satisfaction should be excluded, preferring more objective measures. For example, the indicator 'satisfaction with your health' should be rejected in favour of indicators of health conditions, such as 'cardiac disease prevalence.'

The concern about self-reported data is at least in part supported by psychological studies on the disability paradox and hedonic adaptation. This research suggests, notwithstanding the seemingly obvious impact of disability on quality of life, most people with serious disabilities adapt and report having a good life (Albrecht and Devlieger 1999; Frederick and Loewenstein 1999). An implication of this conclusion may be that objective rather than subjective measures of wellbeing are likely to be more effective as indicators of inequity. Yet, it is problematic to purport to prioritise the choice, control, and perspective of people with disability, while denying the importance of the judgements people make about the quality of their own lives (Clifton 2018: 95–100). If paternalism is the primary problem of disability, then excluding self-judgements from indicators of health may feed into negative assumptions about disability. Perhaps there is a distinction to be made between life satisfaction (a measure of personal wellbeing, see (Emerson et al. 2020)) and measures of satisfaction with aspects of life in common with others, such as housing, service provision, and so forth. The latter are more problematic, as they are more likely to be affected by limited expectations. You cannot tell someone they should not feel satisfied with their life, in the same way that you can say they ought not be satisfied with the quality of service they are receiving (although this still risks paternalism). In response to these issues, the research team removed some measures of satisfaction from the indicator set but retained several self-reported subjective measures of health and wellbeing alongside objective indicators.

Expert panellists also highlighted concerns data sources may exclude people with certain types of disability. As one panellist observed, 'I don't know whether the indicators would capture all people, rather than just people who are capable of self-reporting.' Two issues give rise to this concern. First, some data sources may not capture data at all for people who are not able to respond to survey questions, including people with profound disability. Second, there is the potential for misrepresentation where a person relies on a proxy respondent to speak on their behalf. As one participant observed,

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> We call it gatekeeping. Where people's ideas and choices are monitored and controlled by others, a family mem-
> ber, support worker or an organisation. I think that needs to be identified and drawn out and spoken about.
> People are being made invisible. Not through their own choice.

As a separate but related issue, expert panel members were also concerned whether some indicators included in the
framework could meaningfully represent the circumstances and perspectives of people with profound disability:

> So much of this [framework] is very difficult to relate to someone like [my daughter], who has no capacity to
> self-rate anything. It can only be through myself and others that share life with her, interpreting her behaviour
> and trying to describe that.

Finally, vulnerable people are sometimes affected by health inequalities invisible to the data, such as when others deny,
neglect, or overlook a health condition requiring attention. As one participant lamented, 'We're very conscious of the
people who are dying because when behaviour is demonstrated but it's not acknowledged and communicated, we're
seeing people get very sick and die.' It is difficult to capture experiences not acknowledged and recorded, whether
through malintent or lack of knowledge.

These various limitations present a challenge for the project, not only because people with complex disability are
likely to experience high levels of disadvantage, but also because invisibility is not easy to solve. As existing Australian
national data sources will be used to report indicator data, in the short term it will be important to acknowledge people
with complex disability may be missing or misrepresented when reporting on results. In the longer term, efforts are
needed to ensure people with complex disability are represented in national data sources so social, economic, and
health inequities experienced by this group of people can be measured and addressed. Likewise, data advocacy is
needed to collect data for indicators meaningful to people with disability that are not currently available. That the
expert panel highlighted the importance of including indicators on topics not included in the initial draft framework
and for which data are not currently available (e.g., bullying) demonstrates the value of including people with disability
when conducting research of this type. The Centre for Research Excellence in Disability and Health intends to use
the monitoring framework as a basis for working with governments and agencies responsible for data collection and
reporting to address the data limitations identified through this work (Fortune et al. 2019).

Data interpretation and presentation

The expert panel was concerned about the danger of indicators reinforcing negative conceptions of disability and
encouraged the research team, where possible, to frame indicators positively. For example, a participant suggested
rather than focusing on exclusion, indicators of inclusion should be sought to capture 'the fundamental experience
of belonging, connection to community and being valued.' This reflected a broader interest of the expert panel, that
'in presenting data we want to highlight inequalities, but not paint a negative picture of people with disabilities,
that is, avoid projecting an "ableist" perspective.' This concern is related to issues of language usage and disability
representation, outlined above, but also points to the risk that indicator data showing people with disability as worse
off than people without disability could be used to disparage rather than to highlight systemic injustice. There is no
straightforward way to present measures of inequality positively, because 'flipping' indicators (e.g., from the percentage
of people who report their health as poor to the percentage who report their health as good) does not change the fact
of inequality. It is possible, however, to write about the monitoring framework and describe indicators so inequality and
injustice are the focus.

With respect to inequalities, participants also highlighted the need to recognise 'intersectional compounding factors
like race and gender.' The research team agreed indicator data should be disaggregated, where possible, to highlight
the intersectionality of disadvantage (National Disability Research and Development Agenda 2011). It is unrealistic
and unsatisfactory to treat people with disability as a homogeneous group when seeking to understand or address
disadvantage.

Reflections of the Research Team

Reflecting on the experience of facilitating the panel after its completion, the research team identified aspects of the
process that worked well and some limitations. Providing a draft framework for the expert panel to respond to, rather
than starting with a blank slate, worked well in practice. This might be a controversial conclusion, given inclusive
research ideally involves people with disability from the beginning of the research journey. In this case, however, people
with disability were on the research team and the Partner Advisory Group, so there was input from disability perspectives
from the outset. Starting the expert panel consultation process with a draft framework meant panellists were able to
bring their expertise to bear to discuss the strengths and weaknesses of the draft framework and to identify gaps. With
a draft in place, it was nonetheless possible to make space for a less rigidly structured discussion. Allowing free-flowing
and seemingly tangential conversation encouraged panellist participation and led to surprising and important insight.
A benefit of the group discussion format was that particular points of input would often spark other panellists to
contribute reflections and comments, thus fostering a deeper exploration of issues around a given topic.

We also noted the following limitations:

i)   Although the expert panel was diverse, membership was not fully representative of all people with disability. Despite our best efforts, we were unable to secure representation of some key perspectives, in particular Aboriginal and Torres Strait Islander people with disability, people with disability from culturally and linguistically diverse backgrounds, and those living in rural and remote areas. In addition, some impairment types were not represented (e.g., hearing impairment, psychosocial impairment).

ii)   The group discussion sessions went for a maximum of 90 minutes each, which did not allow sufficient time to discuss all of the domains in detail. The challenge of running consultative projects is weighing the time needed against the busy schedules of potential participants. Whether additional time would have generated more knowledge is uncertain.

iii) As the researchers had the final say in what went into the framework, their views could over-ride those of the expert panel; however, our strong intent was to ensure expert panel input would shape the framework in meaningful ways, and we believe this was achieved.

iv) While group discussion stimulated creative conversation, those participants who were more vocal than others tended to steer the discussion towards certain topics and may have influenced the views of other members. It is difficult to assess what effect this had on the final content of the framework; we note that other, more structured, approaches, such as the Delphi method, might be more effective in ensuring everyone's input has equal influence.

Conclusion

The value of the expert panel's contribution to the development of the monitoring framework cannot be overstated. Those involved were committed to the project and generously provided their input, engaging with complex concepts over the two rounds of consultation. Their input resulted in fundamental changes to the language, shape, and detail of the framework and will continue to influence the way data are reported and interpreted. Inclusion did not mean every suggestion the expert panel made was adopted, but their experience was treated as expertise and taken seriously. They brought a fresh and unique lens to engagement with the framework and indicators. They unmasked the complexity too easily lost when the lived reality of disability is measured and quantified. They added depth and nuance, helped order priorities, and identified gaps and data limitations (Fortune et al. 2020). If it is true we can only improve what we can measure, it is equally true our commitment to the health and wellbeing of Australians with disability will depend upon tracking inequalities in the social determinants of health and wellbeing experienced by people with disability, and improving the quality and inclusivity of data.

The expert panel consultation process was central in realising the Centre for Research Excellence in Disability and Health's aim to conduct research including people with disability. The panel advised a team that has leaders with disability and values collaboration between academics and people with disability. Even so, there is more to be done. The parallels between disability and indigenous politics are instructive, and the Indigenous Data Sovereignty movement provides a model clearly relevant in a disability context. While the diversity of the disability community poses challenges for an equivalent data sovereignty approach, the principle of 'nothing about us without us' dictates people with disability should have greater control over data and research that concerns them. Universities have a key role to play in providing opportunities for and supporting the next generation of academics with disability, empowering them to take lead roles in research that impacts on their wellbeing and that of their peers, and recognising the value of expertise that comes with lived experience.

Competing Interests
The authors have no competing interests to declare.

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