Social Policy and Research Centre

Listening to community voices

Perspectives on consultation and engagement from people using disability services

Deborah Warr, Amber Mills and Vas Kasidis

2023

Brotherhood of St Laurence
Working for an Australia free of poverty

Let's make
change
that lasts

The Brotherhood of St. Laurence (BSL) is a social justice organisation working alongside people experiencing disadvantage to address the fundamental causes of poverty in Australia. Our mission is to pursue lasting change, to create a more compassionate and just society where everyone can thrive. Our approach is informed directly by the people experiencing disadvantage and uses evidence drawn from our research, together with insights from our programs and services, to develop practical solutions that work. For more information visit <www.bsl.org.au>.

Deborah Warr, Amber Mills and Vas Kasidis undertook this study as members of the Inclusive Communities team from 2021 to 2023 in the BSL Social Policy and Research Centre.

Published by
Brotherhood of St. Laurence
67 Brunswick Street
Fitzroy, Victoria 3065
Australia

ABN 24 603 467 024
ARBN 100 042 822
T (03) 9483 1183
www.bsl.org.au

Suggested citation: Warr, D, Mills, A & Kasidis, V 2023, *Listening to community voices: perspectives on consultation and engagement from people using disability services*, Brotherhood of St. Laurence, Fitzroy, Vic.

Contents

Summary

This small study explored the experiences of people with disability, and their partners, carers and allies, who have been involved in consultation and engagement activities as users of disability and related social services. Organisations are increasingly encouraged to consult and engage with their service users in ways that give them a voice in decision-making processes. We found that while various kinds of consultation and engagement take place, there is room for improvement in giving service users a voice in how services and programs are designed and delivered and responding to the insights that are generated.

We broadly defined 'consultation' as being asked what you think about something, and 'engagement' as taking part in an activity or decision-making processes. The widespread interest in consultation and engagement activities reflects growing recognition of the value of drawing on service users' lived experience to inform person-centred practice and develop policy and advocacy initiatives that respond to the aspirations and needs of service users.

An array of frameworks and toolkits are now available to organisations to guide consultation and engagement practices with service users. We wanted to explore service users' perspectives on their involvement in these activities. Accordingly, we conducted (separate) group discussions online with people with disability, carers of people with disability, partners and allies between June and August 2022.

We explored the significance of consultation and engagement for service users and the factors that promoted safe, respectful and effective engagement. A Community Project Officer (CPO) with disability, combining experience as a social researcher and a service user, was part of the research team.

Key insights from the study

The importance of consulting and engagement

- Participants reported they are regularly consulted for their views and experiences as service users and have been involved in activities ranging from providing feedback to membership of advisory boards and co-designing programs and services.
- There was wide agreement that activities across the continuum of consultation and engagement are important in giving service users a voice.
- Consultation and engagement can signal respect for people with disability and the value of lived experience perspectives.
- Consultation and engagement are important for understanding and meeting the diverse needs of people with disability.
- Participants wanted more engagement activities that involve co-design and co-production.
- Commitment to consultation and engagement can be factors when choosing or changing service providers.

Qualities of good consultation and engagement

- Participants wanted to feel safe and respected when involved in consultation and engagement activities.
- Safe and respectful engagement and consultation includes active listening, explaining how insights will be used, reporting back about findings and using insights to make positive changes.

Markers of poor consultation and engagement

- Service users are not given opportunities to have meaningful input or provided with contexts for consultation and engagement activities, including the aims and how information will be used. Service users then assume the consultation is largely for the benefit of other stakeholders, such as funders, rather than for improving the delivery of services and programs.
- Insensitivity to power dynamics deters service users from being involved or providing honest feedback.
- A lack of formal processes for regular consultation that offer opportunities for gaining feedback in confidential and depersonalised ways can especially disadvantage vulnerable service users concerned about the repercussions of providing negative feedback.
- Many consultation and engagement activities do not directly engage with people with disability, but rely on the perspectives of family and carers. Involving service users with disability would promote their agency and control in their lives.
- The disempowering effects of poor consultation and engagement can exacerbate other experiences of trauma.
- Poorly conceived consultation and engagement can undermine trust and confidence. Improving participation of service users may require rebuilding trust and confidence in its value while redressing concerns about its risks.

We found that while various kinds of consultation and engagement take place, there is room for improvement in giving service users a voice in how services and programs are designed and delivered and responding to the insights that are generated.

1 Contemporary interest in consultation and engagement

For some time now, interest has been growing in engaging users of social, health disability and other services to provide feedback and input, ostensibly to ensure that the services are meeting the needs of people they serve. This interest is evidenced in a proliferation of frameworks and toolkits to advise and guide governments and non-government organisations on engagement practices.

Examples include the Victorian Government's *Client voice framework for community services*, which provides comprehensive guidelines on how to 'seek, listen and act on the client voice' (DHHS 2019, p. 3). Others include the OECD's *Guidelines for Citizen Participation Processes*, the Mental Health Commission *Engagement Framework* (developed by the Western Australian government) and the Victorian Comprehensive Cancer Centre *Consumer Engagement Toolkit*. Strategies for facilitating community and service user involvement in developing priorities, service design, formulating policy, co-designing practice guidelines and partnering for evaluation and research are also being explored and formalised in a growing body of work conducted under the banners of consumer and community involvement (CCI) and patient and public involvement (PPI).

Some frameworks focus on engagement strategies for people with disability. These include *A Guide to Community Engagement with People with Disabilities* (produced by the New Zealand government), *Engagement and consultation with people living with disability* (developed by the South Australian government) and *Walking the Talk* (commissioned by Disability Services Queensland).

Growing emphasis from governments on community and service user engagement reflects a general shift from representational to participatory models of governance (Head 2007). The principles of participatory governance assert that all stakeholders—government, business and citizens—should be actively involved in understanding social issues and the complex interaction of social, economic and environmental dynamics that shape them (Head 2007). Integrating these contrasting critical perspectives produces nuanced insights for responding to social challenges that are presented. The OECD (2022) argues that participatory governance is important in revitalising democratic processes, promoting the legitimacy, effectiveness and efficiency of services and programs, fostering inclusion in diverse societies, and upholding citizens' rights.

Participatory governance is especially significant for social groups vulnerable to their aspirations and needs being marginalised in 'business as usual' approaches. It has particular resonance for people with disability in upholding the maxim 'nothing about us without us' that insists that policy and practice should involve the direct participation of those affected by them. The community sector—civil society groups, non-government organisations (NGOs) and community-based organisations and services—that represents and advocates for people with disability, and other marginalised social groups, has a key role in promoting participatory governance for those it serves and represents.

A continuum for engagement and consultation

Many available frameworks for engagement and consultation are informed by influential schema that depict a continuum of participatory activities, ranging from passive to increasingly active methods or gathering feedback and input from service users. Key schema include Sherry Arnstein's Ladder of Participation (1969) and the 'spectrum of public participation' developed by the International Association for Public Participation (IAP2) (iap2.org.au). The IAP2 spectrum, for example, distinguishes between five categories of activities—informing, consulting, involving, collaborating and empowering—and positions them as offering expanding scope for community members and service users to exert influence and control in participatory processes.

While highly participatory activities are generally viewed as the 'gold standard', the gamut of activities offers varied possibilities for service users to provide valuable feedback and input. These activities can range from being on mailing lists to receive updates via newsletters and social media to completing surveys and involvement in advisory groups. More active modes of participation, such as involvement in co-designing and co-producing programs, policy, practice guidelines, evaluation and research and other outcomes, offer increased potential for servicer user involvement in decision-making and influencing.

While there are important social, organisational and individual benefits to be gained by engaging and consulting with community members directly affected by issues, there are also challenges. Engagement and consultation are exclusionary if they are not accessible to the diversity of group members. 'Bad faith' and tokenistic consultation that is oriented to legitimising positions and policies that have already been decided erode community trust and confidence in associated institutions. These issues underline the importance of promoting genuine and meaningful participation in ways that are transparent, inclusive and accountable (OECD 2022).

Critically, emphasis on consulting and engaging with service users recognises their lived experience as a form of expertise that contributes to deeper and more nuanced understanding of issues. Lived experience expertise complements other forms of expertise possessed by those in managerial and frontline service delivery, technical, research and evaluation, and other roles. Incorporating lived experience perspectives is important for developing effective policies, services and programs concerning people with disability (Williams et al. 2020; Beresford 2019). The aim of engagement and consultation with service users is to draw on their lived experience expertise to inform activities and initiatives conducted by organisations. This requires inclusive approaches that are sensitive to, and seek to address, potential barriers that limit or discourage service users' input.

Engaging and consulting people with disability

Facilitating capacities for people with disability to participate in genuine, purposeful consultation and engagement is also fundamental to upholding principles outlined in the United Nations Convention of the Rights of People with Disability. There remain many challenges, however, in incorporating this experiential knowledge into policy and practice (Löve et al. 2017). This research project was implemented to explore service user perspectives on consultation and engagement when these activities are increasingly common in community services. The study involved group discussions with people with disability, and their families and allies, who have participated in engagement and consultation activities conducted by varied organisations and services.

The study users the descriptor 'service users' because the term is widely used for community members accessing a range of services, while recognising that other descriptions are also used (for example, 'clients' and 'consumers'). At the same time, we acknowledge that 'service user' represents only a small part of people's identities in households and communities.

2 Method for group discussions

The research was conducted by members of the Inclusive Communities (IC) team in the Social Policy and Research Centre (SPARC) at the Brotherhood St. Laurence. The research team comprised two researchers and a Community Project Officer (CPO). The CPO position was specially designed to bring lived experience expertise into the project team. The CPO combined this lived experience with experience in conducting disability-related research. All members of the team were involved in co-designing the research, obtaining ethics approval, co-facilitating a series of online discussion groups, analysing the data and co-presenting the findings at a conference. The CPO advised on terminology and other aspects of the method to promote accessibility of the concepts we explored and minimise risks of perpetuating ableist attitudes and assumptions (Bogart and Dunn 2019).

Focus groups were used because they blend two ways of talking about issues: when focus groups are conducted with people who share similar experiences, interaction typically shifts between speaking to 'outsider' researchers and 'insider' others. This can enhance the sense of safety for participants in research and generates a mix of interactional styles that offer nuanced insights (Warr et al. 2005).

People with disability, partners or other family members and allies participated in group discussions that were conducted between June and August 2022. Most discussions were online (due to ongoing COVID-related concerns) in groups of no more than three participants. One online and one in-person interview were conducted in response to participants' preferences. Separate discussions were held for people with disability and parents, partners/family and allies.

Participants were recruited via social media and newsletters of organisations such as local councils and Carers Victoria. Despite information posted on BSL communication channels, only three participants using BSL services were recruited.

To cater for participants' communication needs, live captioning was used in all the online sessions, and participants were also encouraged to use the chat function available on the online platform if they wished. The structure of the discussion sessions and, in some instances, the questions were shared ahead of time. Consent to participate was obtained via an online survey, where a small amount of demographic information was also collected from participants.

Guided online discussions were conducted with two to three participants with some visual material to encourage discussion shared on screen. This included working definitions of 'consultation' (being asked what you think about something) and 'engagement' (participation in, taking part, or being involved in an activity or decision-making). A typology of consultation/ engagement activities, ranging from passive (such as fact sheets or websites) to active (opportunities for co-design and citizen-led initiatives) was also shared to guide participants to reflect on their experiences of providing feedback and input. This scaffolding for the discussions provided some structure to support participants in considering issues of interest.

Discussions explored the following questions:

- How important is it to have a say about program and service use?
- What is the suitability of different communication activities?
- What does safe and respectful engagement look like?

Discussions were audio-recorded and then converted to text to generate a transcript; the transcripts were reviewed and the research team identified and coded themes. When reporting findings from the discussions, quotes are used to illustrate issues and these are attributed to the relevant focus group. This is because the group discussion itself is considered the unit of analysis and individual comments are made in the context of interactions with others that influence what is shared or left unsaid. Even with careful facilitation, conversations are influenced by participants' preferences on what they wish to share with the group, the extent of agreement and disagreement over issues, and the practical limitations of turn-taking, which mean people may be unable to say everything they might wish to (Warr 2005).

In this study, 20 participants took part in 12 online and one in-person sessions. The participants identified themselves across four categories (Table 1), and multiple counts were possible.

Table 1 Study participants

People	Count
Person with disability	9
Parent	10
Partner	2
Ally	4

Participants were mostly female, mostly aged over 45 years, predominantly English speaking and were living in metropolitan Melbourne.

Limitations

This study's small sample of participants limits the generalisability of the findings presented here. The sample is likely to represent individuals who are interested in consultation and engagement consultation, and the method—particularly the online discussions—is likely to have excluded potential participants who weren't comfortable with this format. A few potential participants raised this concern; we offered to conduct a one-on-one interview and one person took up this option. Online recruiting strategies and discussions were convenient for some participants with disability; however, they also likely impacted the ability of many others to hear about the study and to share their experiences. The overrepresentation of women may reflect the significance of gender constructs, where women are more likely to be carers and/or more likely to participant in consultation and engagement activities.

When focus groups are conducted with people who share similar experiences, interaction typically shifts between speaking to 'outsider' researchers and 'insider' others. This can enhance the sense of safety for participants in research and generates a mix of interactional styles that offer nuanced insights.

3 What participants told us

Participants described being involved in a broad range of consultation and engagement activities conducted by organisations delivering services to people with disability. These included large and small community-based organisations, local government services, commercial entities, informal community projects and independent contractors.

Across the discussions, four broad themes emerged. First, participants affirmed the value of lived experience perspectives for delivering effective and empowering services and programs for people with disability. This potential was a strong motivating factor for being involved in consultation and engagement activities.

Two themes show how consultation and engagement can be irrelevant, frustrating, disempowering and even harmful for service users. There were concerns with how these activities are frequently decontextualised, with little explanation of why they are being conducted or how information will be used. This was described by one participant as not knowing 'the rules of engagement'. Another theme related to the implications of power dynamics that are explicit and implicit in consultation and engagement activities.

A fourth theme refers to the qualities and processes that enhance the potential for consultation and engagement to be meaningful, useful, safe and respectful to people with disability.

These themes are explored in turn.

Asking for people's opinions and input is important

Participants strongly endorsed the importance of consulting and engaging with service users because 'people with disabilities and all their carers are experts' (Session 7). Their insights can be applied to improve the quality and effectiveness of services; and seeking their opinions signals that service providers care about the people they serve. There was wide agreement that, with the market model of NDIS, good consultation and engagement can keep people attached to services; otherwise 'they just move on somewhere else' (Session 3). In circumstances where people have less choice of providers, consultation and feedback remains important for understanding the 'different struggles that we do have that may not be apparent' (Session 8).

Some participants were aware of, and welcomed, growing acknowledgment of lived experience expertise and that this informed current interest in seeking feedback on. As one participant explained, 'In the past it's been about "this is what you need to do" … and I like the idea of … getting a voice … and being heard' (Session 11). Many participants described being routinely asked to provide feedback to services via surveys and informal conversations. There was strong agreement that this feedback is useful for understanding 'where things work and where things don't work' (Session 13). Regular consultation and engagement are critical; otherwise 'you can just be receiving care or support that is not relevant or beneficial to what is needed' (Session 9).

Participants were familiar with activities spanning the continuum of consultation and engagement. They perceived potential value in both consultation and engagement and understood that these activities varied in the time, effort and commitment required from service users and organisations. Consultation is important for checking in because 'You can always improve, you can always learn ... [when] you get some feedback from actual participants' (Session 3). Involving service users and community members in co-produced and citizen-led activities was also identified as important:

> ***I would love to see more advisory groups ... include people with disabilities because I think they bring so much to the advisory group.***
>
> ***(Session 13)***

At the same time, participants understood that these efforts should focus on initiatives where there is feasible potential to contribute to co-designing programs and services or exert influence.

Consultation and engagement show organisations care

In addition to insights from consultation and engagement informing continual improvement, participants described specific benefits of signalling that organisations care about them:

> ***I think it's really great if organisations [ask] 'What did you think of this? What could we have improved? Is there anything you would have added or taken away?'. I feel that that's really valuable for the organisation, but also for us to know that our opinion is valid, [that] they're interested in our opinion, and interested in making things better for us as well.***
>
> ***(Session 11)***

Importantly, participants are also appreciative when their feedback is taken on board:

> ***I really like it when somebody listens to the way that I like to communicate ... my voice message says to send me a text or email me [but] a lot of the times people will just leave me a voice message ... I really value it when people use my preferred form of communication which I've just started to express and not feel ashamed of it.***
>
> ***(Session 8)***

Sharing the insights from consultation and engagement activities offers service users opportunities to 'learn from each other as well as share ideas' (Session 11) and 'promotes willingness to participate in feedback' and 'builds confidence to give feedback' (Session 1).

Asking service users what they think also humanises people with disability and supports person-centred care. One participant emphasised how providing feedback on care supported 'seeing [my dad] as a person in his own right' (Session 7). This idea was expressed in another way by a participant explaining how they struggled not to feel that:

> ***... if you have a disability, you're less a person or something than [other] people ... you're starting off below the other person ... one person is above or feeling superior to another [This makes it important] to have a say, to explain your experience so that people can understand it but also to have a sense of ... that I actually matter as a person as well.***
>
> ***(Session 11)***

These insights underline the practical value of gathering lived experience perspectives for delivering appropriate and quality services, and its specific significance for people with disability in recognising and respecting their autonomy.

Consultation is important for checking in because 'You can always improve, you can always learn ... [when] you get some feedback from actual participants'.

Summary points

- Opportunities for genuine, constructive and respectful consultation and engagement are important to participants.
- Consulting and engaging with service users signals care and respect for service users and their lived experience expertise.
- Participants would welcome more opportunities for service users to be involved in processes of co-design and co-production.
- Ensuring service users have access to the findings shows that organisations take consultation and engagement seriously and builds confidence to participate in such activities going forward.

Not knowing the rules of engagement

While some organisations are making positive efforts, many participants expressed the view that opportunities to provide feedback or share their experiences as service users are not as frequent or genuine as they should be and that 'most services … are not interested in your opinion' (Session 1). This conveys an attitude of 'This is the service we provide, love it or lump it' (Session 1). Participants experienced some kinds of consultation and engagement as tokenistic and seemingly conducted to fulfil contractual or other obligations: 'In all honesty … [it] felt like they were ticking the boxes [more] than really going to follow through with all of it, but I still liked the idea that they did it' (Session 11).

These issues highlight how the parameters of engagement and consultation are generally formulated beyond the line of sight of service users. This includes whether it is conducted or not, as well as the aims, timing and scope of activities, what happens with the findings and who has access to them. This was described as not knowing the 'rules of engagement' (Session 11); and another participant described consultation and engagement as 'some sort of secret society where we have to guess what's behind the box' (Session 9).

Participants noted that they are seldom offered opportunities to influence consultation and engagement activities. One participant emphasised that it would be helpful to 'explain (the) rules … like the stuff that's not flexible at all, but [also] the stuff that is flexible … be able to give me some choices with some of those things' (Session 11). Another participant explained: [they] 'never asked you how well they're doing [delivering a program] they just ask us questions and then they say, "Yeah, thanks very much. Goodbye"' (Session 4). Participants reflected that in their experience, consultations focus on the impacts of programs and services, rather than how they are meeting needs or roll out phases where there are timely opportunities to identify and address emerging issues.

Participants reported that they are rarely told what happens to information they provide:

> ***There can be like this clinical push every six months; we're going to send out this survey, we're sort of robotically pumping it out there. Everybody fills it in and it's very uncaring and [you] don't really see any changes from the results [and] you don't know what other people's results are because you're never shown.***
>
> ***(Session 1)***

Participants reflected that in their experience, consultations focus on the impacts of programs and services, rather than how they are meeting needs or roll out phases where there are timely opportunities to identify and address emerging issues.

Hearing about the results of consultation and engagement activities is also important because it contextualises one's own experiences in relation to those of other service users. Hearing the views of other services users provides an 'overall view of how other people felt as well' and shows that 'they're not alone ... [it] validates their concerns' (Session 1).

Participants explained how consultation and engagement can be insincere. Bad faith engagement conveys disdain towards services users that reinforces perceptions of worthlessness that can be generally experienced by people with disability. This leaves people feeling upset and discourages future participation. Participants were also concerned that consultation and engagement is tokenistic if positive views (or respondents) are cherry-picked:

> ***I've seen it ... in disability organisations ... they get really choosy about who they pick [for giving feedback] ... and they'll be like, you're a consumer and you agree with me and you make my job easier.***
>
> ***(Session 11)***

Engagement and consultation also risks being perceived as tokenistic when there is an absence of support from senior staff: 'Who are we going to put questions to, if there's no true representation of decision makers?' (Session 6).

Summary points

- Service users frequently have little influence over, or understanding of, contexts in which consultation and engagement activities are conducted. This includes aims, focus and what happens with findings and other results.
- Despite growing emphasis on engaging with service users, many organisations either do not offer opportunities for them to provide feedback or input, or their engagement activities are perceived as tokenistic.
- Hearing about findings from consultation and engagement is important to service users because they can validate individual concerns and identify shared issues.

Power dynamics in consultation and engagement

Discussions with participants showed their concerns with power dynamics that inevitably infuse consultation and engagement activities. These dynamics range from organisational power to determine whether consultation and engagement is conducted and to set the 'rules of engagement', to the ways in which power is embedded in the micro-processes of activities. Participants' accounts suggested how formal, well-designed processes can offer service users safe, confidential and depersonalised processes for identifying and addressing issues.

A lack of formal processes for consulting and engagement with service users means that individuals are left to provide feedback in informal ways, including raising issues with individual staff members, or through complaints processes that present them with some risks. Participants described how power dynamics surfaced in interactions where they gave negative feedback and service providers responded with defensiveness, hostility or rejection. For instance, one participant described being told that they were 'too sensitive' when they provided negative feedback in a face-to-face setting. Other participants were reluctant to provide negative feedback because they didn't want to be labelled as 'difficult' (Session 6). Others explained, 'It puts you in an awkward position because you're bringing problems' (Session 3). Some described being accused of 'taking advantage of their disability' (Session 10) or 'treated like problem cases, vexatious complainants, [a] bad smell that won't go away' (Session 6).

These situations left people feeling silenced and even unsafe and issues are personalised when negative feedback is dismissed as 'complaining'. Service users may opt to put up with unsatisfactory situations because raising issues leaves them feeling uncomfortable, they will be perceived as troublemakers, that it will make 'things worse' (Session 8), or they are denied services. One participant explained:

> ***I've found services that if you give them any feedback that's negative, you know, everybody's taking it very, very personally … it puts you in an awkward position because you're bringing problems … even the tone of how they speak to you becomes different … you're spoken down to [and it] can get pretty horrible and that's not good … I've changed services because of it.***
>
> ***(Session 1)***

Encountering these situations, some participants had exercised market choice and changed service providers because they were dissatisfied with a lack of formal consultation processes and felt unsafe when providing feedback that they believed was warranted. In these ways, the market model for NDIS services facilitates some recalibration of power for some people and suggests that conducting respectful and genuine consultation and engagement can be good for business.

Not all service users, however, are able to flex market preferences. Those who are reluctant to speak up because they lack confidence or are concerned about the repercussions can be left feeling powerless, frustrated, afraid and occasionally angry (Session 13). These responses can exacerbate other experiences of trauma. For example, one participant had lodged a formal complaint after a staff member challenged whether they needed the level of support they had requested: '[It] never got anywhere [and] it still sits in my head, and it just lives with me every day … it never goes away' (Session 6). Despite the perceived risks, participants explained that sometimes you 'only get action when kick[ing] up a fuss' (Session 9).

Other discussions highlighted issues of power when the methods for consultations and engagement are not accessible to people with disability, and implicitly rely on carers and family members responding on behalf of others. Participants with disability and carers expressed concern that there is frequently little or no effort to engage people directly, 'The problem [is] that surveys are sent to me' (Session 3). They are concerned that this undermines the agency of people with disability.

Summary points

- Organisational commitment to genuine consultation and engagement with service users can be a factor in choosing service providers.
- Effective consultation and engagement requires sensitivity to power dynamics in relationships between service provides and service users. This is particularly important for vulnerable service users who lack confidence in expressing preferences and capacities to exercise choice.
- Lack of or tokenistic consultation and engagement can contribute to service users feeling silenced, unsafe, confused, hurt, angry and marginalised.
- Inclusive methods are important to involve people with disability directly in consultation and engagement activities.

Safe and respectful consultation and engagement

There was agreement across groups that consultation and engagement should be safe and respectful while using inclusive approaches that, as much as possible, engage directly with service users with disability. Participants noted this is key to empowering and promoting their agency and control. They also noted the importance of applying communication practices such as active listening strategies and using preferred communication techniques. Also important were consulting and engaging across phases of activities, asking if programs and services are meeting user needs and keeping them informed 'when there are changes' (Session 9).

Participants stressed using methods and approaches suited to the varied communicative needs of people with disability. Although some people will have 'trouble expressing ... things' (Session 5), it remains important to explore ways of including people in consultation activities. As one participant noted:

> ***When we know accommodations are available, it feels like a safer setting to be in and that the people that are running [things] are being respectful of us.***
>
> ***(Session 11)***

The focus of activities should range from 'asking if there was anything that we needed support with' (Session 11) to inviting users to be involved in co-designing and co-producing services and programs.

Participants also had ideas for supporting service users to provide thoughtful input. For example, background information can set the scene, and scaffolding strategies can guide and support people to reflect and deliberate on central issues. This material should be mindful of participants' needs, such as being 'preferably in easy read ... so that it's easy to understand ... because my capacity to process things and retain things varies' (Session 11). Participants pointed to the way we used diagrams and explanations of consultation and engagement activities for the group discussions in this study—'having that little bit of walking through' (Session 10)—as a good example of how this can be done. Information on what to expect when participating in consultation and engagement activities can also be useful in 'lower[ing] our anxiety, we know what to anticipate ... it's easier to focus' (Session 11).

Other strategies for promoting useful, safe and respectful consultation and engagement could include developing agreed 'rules of engagement'. These could be used to lay out issues that are open to negotiation and change, accommodate different communication needs and commit to reporting findings. These rules may also extend to managing interpersonal dynamics, such as having only one person speaking at a time and emphasising respectful listening. This was summarised by one participant as 'listening to understand and understanding that there are multiple truths in any situation' (Session 10). Participants in one discussion observed that recreational services oriented to individual interests are very good at engaging with service users, although it's not clear why this might be the case (Session 2).

Digital tools and interfaces were viewed as enabling novel and interactive approaches to consultation and engagement. In response to restrictions on face-to-face contact related to COVID 'suddenly all this technology is available' (Session 11). Although online formats will not suit everyone, they were welcomed by those who otherwise faced many barriers attending face-to-face activities because of mobility and transport challenges, demands at home or social anxiety.

Participants also shared some ideas for enhancing the safety of consultation and engagement, to avoid risks of giving negative feedback and to ensure that those who gave or received feedback should feel safe and supported. This includes recognising that being honest about how one is feeling takes effort and courage. On the other hand, receiving negative feedback can be experienced as unpleasant and unwarranted, and may elicit defensive reactions. One participant described a useful technique they learned from yoga that they referred to as a 'sacred pause'. It encourages taking time for reflection before responding when something is expressed that is critical or unexpected:

> ***Feelings are happening. We've communicated as much as we can, let's just take a minute ... it's taken really gently and respectfully and with the desire to learn from each other.***
>
> ***(Session 10)***

Summary points

- Participants emphasised the importance of feeling respected and safe when involved in consultation and engagement activities.
- Communication strategies that support people to express and receive feedback are helpful in conducting safe, genuine and useful consultation and engagement activities.
- Strategies that prepare and support service users and staff to deliberate on issues of interest can be helpful in encouraging people to give and receive constructive and thoughtful feedback.

4 Reflection on the findings

What did we learn?

Participants insisted that consulting and engaging with service users with disability, carers and allies are critical because their lived experience offers invaluable insights for developing and delivering responsive, high quality and effective services. It also signals that organisations care about them. They are regularly asked to provide feedback on services they use; the approaches for consultation and engagement span information-sharing activities, surveys and advisory board memberships, although there are fewer opportunities for involvement in co-design and co-production.

Participants reflected on the opportunities, potential, limits and challenges of different approaches for consultation and engagement. They understood that consultation and engagement can be used to gather varied kinds of feedback and input and that strategies of co-production and consumer or citizen-led initiatives are appropriate where there is real potential to exert influence. Further, consultation and engagement are tokenistic when they are not taken seriously by decision-makers in organisations.

For some participants, respectful consultation and engagement with service users was a factor in choosing service providers. They also perceived that some organisations with which they had contact did not appear to be interested in gathering services users' perspectives. Their experiences of poor consultation and engagement left them feeling frustrated, angry, upset and disempowered. The group discussions identified the following key issues:

- Consultation and engagement is too often oriented to organisational needs, with strong emphasis on identifying impacts and outcomes. While these are important to appraise and measure, participants suggested that the process should also focus on the ways programs and services are developed and delivered. These insights could enable timely adjustments to benefit service users.
- Participants wanted to hear more about the findings gleaned from consultation and engagement. In addition to generating insights on whether programs and services are meeting the needs of service users, sharing findings can be helpful for validating and identifying common concerns among service users.
- Participants would welcome expanding opportunities to be involved in processes of co-design and co-production with organisations and service providers.
- Minimal efforts are made to ensure that consultation and engagement activities are accessible to, or directly engage with, people with disability. This leaves service users either unable to contribute or relying on carers, partners and allies to speak on their behalf.
- Consultation and engagement practices that are not safe or respectful of service users discourage participation. This can also undermine self-confidence, provoke anxiety about the repercussions of giving negative feedback and foster low expectations that it will lead to change. Increasing participation in consultation and engagement activities requires acknowledging and addressing these perceptions and barriers.
- Poor consultation and engagement risks aggravating other experiences of worthlessness and trauma that affect people with disability.

Crucially, issues raised by participants in the study corroborate key insights from the Victorian Government's *Client voice framework for community services*. These include service users reporting 'negative experiences when having a say', that 'they haven't felt listened to', 'disappointment in engagement processes' and not 'see[ing] any evidence that what they say is used to make changes' (DHHS 2019, p. 5). The framework also notes that within organisations efforts to consult and engage with the experiences of service users can be 'uncoordinated, ad hoc and inconsistent' (p. 5).

It was encouraging to hear participants' experiences of good consultation and engagement, although the examples they shared referred largely to recreational and community-led initiatives. We received positive feedback for having a research team that included lived experience expertise. Participants commented that this contributed to perceptions of safety and stimulated open and thoughtful reflections on the issues. We acknowledge that we were unable to engage with some kinds of lived experiences of people with disability because of the additional support and resources this requires.

Implications for service users having a voice

There is growing consensus that service users should have a 'voice' in decision-making processes related to designing, developing, delivering and evaluating social, health and other human services, programs, policies and research and evaluation. The *Client voice framework for community services* defines 'voice' as capacities for service users to express opinions and contributions across all their interactions with a service, ranging from contact with case workers and service delivery personnel to complaints processes, service reviews and policy consultations. Service users' perspectives are critical for promoting quality and safety, coordination across services, meaningful social outcomes and accountability in community services (DHHS 2019, p. 5). Consultation and engagement activities are vehicles for facilitating service users' voices and they should address individual, organisational and systems-level processes. Strategies for incorporating lived experience expertise across these levels will vary but should remain grounded in respect for these perspectives.

Promoting services users' voices requires changing current ways of working. Special efforts must be made to foster and integrate the voices of service users vulnerable to experiences of marginalisation. For service users with disability, this is a key plank in upholding the Convention of the Rights of People with Disability, where point (o) of the preamble proclaims that:

> ***… people with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programs, including those directly concerning them.***
>
> ***(United Nations Office of the High Commissioner for Human Rights 2006)***

Bringing service users' voices into decision-making processes has critical personal and political significance in promoting participatory democracy where people with disability are 'directly involved in the political process, rather than being represented by others' (Beresford 2019, p. 4).

We received positive feedback for having a research team that included lived experience expertise. Participants commented that this contributed to perceptions of safety and stimulated open and thoughtful reflections on the issues.

There are plentiful examples of frameworks, strategies and toolkits available to guide consultation and engagement activities that seek to give voice to service users, clients and citizens. Critically, having a voice requires listening and responding to insights gathered through consultation and engagement activities.

There remain challenges, however, in realising these ambitions. They include inadequate resourcing, tendencies towards tokenism and co-option, and competing interests and power among governmental, organisational, community and other stakeholders (Beresford 2019). Some stakeholders still need persuading of the value of giving service users a voice, believing they already have a sound, or even superior, understanding of people's situations or holding concerns that service users will make unrealistic demands (see also DHHS 2019, p. 5).

At the same time there are well-evidenced discussions of how good consultation and engagement can overcome these perceptions and doubts to foster deliberative processes and blend varied expertise and perspectives to build 'inclusive, provisional, and yet actionable, consensus' (Lehoux et al. 2009, p. 2007; see also Boivin et al. 2014). It does require commitment and developing new skills: 'business as usual' approaches are not amenable for working collaboratively with service users and communities (Williams et al. 2020). Organisations need to cultivate a preparedness for innovative ways of working. Meeting these challenges is critical for social justice organisations providing services and support for people with disability and other people experiencing marginalisation because they are also their advocates in political arenas and public discourse.

Critically, having a voice requires listening and responding to insights gathered through consultation and engagement activities.

References

Arnstein, S 1969, 'A ladder of citizen participation', *Journal of the American Institute of Planners*, vol. 35, no. 4, pp. 216–24, doi: 10.1080/01944366908977225.

Beresford, P 2019, 'Public participation in health and social care: exploring the co-production of knowledge', *Frontiers in Sociology*, vol. 3, no. 41, pp. 1–12, doi: 10.3389/fsoc.2018.00041.

Bogart, K, & Dunn, D 2019, 'Ableism special issue introduction', *Journal of Social Issues*, vol. 75, no. 3, pp. 650–664, doi: 10.1111/josi.12354.

Boivin, A, Lehoux, P, Burgers, J & Grol, R 2014, 'What are the key ingredients for effective public involvement in health care improvement and policy decisions? A randomized trial process evaluation', *Milbank Quarterly*, vol. 92, no. 2, pp. 319–350, doi: 10.1111/1468-0009.12060.

Department of Health and Human Services (DHHS), *Client voice framework for community services, DHHS, Melbourne*. Viewed 31 May 2023.

Government of South Australia n.d., *Engagement and consultation with people living with disability*. Viewed 31 May 2023.

Government of Western Australia, *Working together: mental health and alcohol and other drug engagement framework 2018–25*. Viewed 31 May 2023.

Head, B 2007, 'Community engagement: participation on whose terms?', *Australian Journal of Political Science*, vol. 42, no. 3, pp. 441–454, doi: 1080/103611407441-45401513570.

Lehoux, P, Daudelin, G, Demers-Payette, O & Boivin, A 2009, 'Fostering deliberations about health innovation: what do we want to know from publics?', *Social Science & Medicine*, vol. 68, no. 11, pp. 2002–2009, doi: 10.1016/j.socscimed.2009.03.017.

Löve, L, Traustadóttir, R, Quinn, G & Rice, J 2017, 'The inclusion of the lived experience of disability in policymaking', *Laws*, vol. 6, no. 33, pp. 1–16, doi: 10.3390/laws6040033.

Ministry of Health 2017. *A guide to community engagement with people with disabilities,* 2nd edn, Ministry of Health, Wellington, NZ. Viewed 31 May 2023.

OECD 2022, *OECD guidelines for citizen participation processes*, OECD Public Governance Reviews, OECD Publishing, Paris, doi: 101787/f765caf6-en.

Oliver, K, Kothari, A & Mays, N 2019, 'The dark side of coproduction: do the costs outweigh the benefits for health research?', *Health Research Policy and Systems*, vol. 17, no, 33, pp. 1–10, doi: 10.1186/s12961-019-0432-3.

Robinson, S, & Dyke, J 2004, *Walking the talk*, Disability Services Queensland. Viewed 31 May 2023.

United Nations Office of the High Commissioner for Human Rights 2006, *Convention on the Rights of Persons with Disabilities*. Viewed 1 August 2023.

Victorian Comprehensive Cancer Centre, *Consumer engagement—model and cases studies*. Viewed 31 May 2023.

Warr, D 2005, '"It was fun ... but we don't usually talk about these things": analysing social interaction in focus groups', *Qualitative Inquiry*, vol. 11, no. 2, pp. 200–225, doi: 10.1177/1077800404273412.

Warr, D, Mann, R & Tacticos, T 2011, 'Using peer-interviewing methods to explore place-based disadvantage: dissolving the distance between suits and civilians', *International Journal of Social Research Methodology*, vol. 14, no. 5, pp. 337–352, doi: 1080/13645579.2010.

Williams, O, Sarre, S, Constantina, P, Knowles S, Robert, G, Beresford, P, Rose, D, Carr, S, Kaur, M & Palmer, V 2020, 'Lost in the shadows: reflections of the dark side of co-production', *Health Research Policy and Systems*, vol. 18, no. 43, pp. 1–10, doi: 10.1186/s12961-020-00558-0.

Listening to community voices

Perspectives on consultation and engagement from people using disability services

Deborah Warr, Amber Mills and Vas Kasidis
2023

Acknowledgement of Country

The Brotherhood of St. Laurence acknowledges the Traditional Custodians of the land and waterways on which our organisation operates. We pay our respects to Aboriginal and Torres Strait Islander Elders past, present and emerging.

Brotherhood of St Laurence
Working for an Australia free of poverty