

Report on interviews about Technology Accessibility, Support and Safety Considerations for the NDIS Disability Wellbeing Index

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Abstract

The Centre for Disability Research and Policy (CDRP), University of Sydney, was contracted to contribute to a three-year research project, 2022-2024, funded by the National Disability Insurance Agency (NDIA) and lead by Associate Professor Gang Chen, Monash University. The overarching aim of this research project was to design and test a preference-based wellbeing instrument that captures factors impacting on the wellbeing of people with disability in Australia, now known as the Disability Wellbeing Index (DWI). The role of the team based at the CDRP was to facilitate people with disabilities being involved in each stage of the research, including accessibility, safe environment, and self-reporting considerations for survey respondents.

This is the second of four reports documenting the contribution of the team at the CDRP. This report was submitted to Monash University on 7 July 2023. It describes the results of a consultations conducted with representatives from Disabled People's Organisations (DPOs) and Disability Representative Organisations (DROs) to understand the accessible formats, support options, and safety considerations required to facilitate completion of the DWI. Dr Keran Howe, on behalf of CDRP, consulted with 16 representatives from eight Disabled People's Organisations (DPOs) and Disability Representative Organisations (DROs) during April-June 2023. Results from this study confirmed that people with disability strongly recommended self-reporting of wellbeing where at all possible, with proxy completion being the option of last resort. Findings informed the development of a suite of alternative formats and support options that met a range of respondent support needs and communication preferences and further detailed safety considerations needing to be addressed, such as the potential for certain items to be triggering and cause distress.

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INTRODUCTION

This report was commissioned by Dr Kim Bulkeley and Professor Emerita Gwynnyth Llewellyn, Centre for Disability Research and Policy, University of Sydney as part of a broader three-year research program, funded by the National Disability Insurance Agency, on the development of a Disability Wellbeing Index for the NDIS, and under the leadership of Associate Professor Gang Chen, Monash University.

The first stage of the DWI program of research was undertaken in 2021-2022 and focused on identifying items for inclusion in the DWI, and using feedback from stakeholders, people with lived experience of disability, and literature to refine index domains, items, and descriptors. In the second stage of DWI development, a number of projects were undertaken. The project which is the subject of this report, undertaken between April and June 2023, specifically focused on technology accessible formats for the DWI online survey, the nature of support needed, and safety considerations for implementation for a diversity of respondent needs.

In this project, interviews were conducted with representatives from organisations primarily DPOs and DROs on what technology accessibility or other supports are required to permit as many as possible people with disability to use the Disability Wellbeing Index and what will ensure they feel safe and confident when completing the Index. The interviews explored:

- Alternative versions for online survey as well as alternatives to an online survey.
- The variety of assistance respondents may require or desire to complete the DWI.
- Whether proxy completion is appropriate for a wellbeing index when self-reporting is deemed not possible.
- The requirements for respondents to feel confident and safe when completing the DWI.

THE PROCESS

Interview questions were devised to explore the functional requirements for accessibility, support structures, and safety when completing the DWI. See Appendix 1: Interview Questions.

Written informed consent was gained from participants to undertake and record the interviews. Interviewees were briefed on the confidentiality of their responses and assured that their organisation would be deidentified in any report to the NDIA.

The interviews were undertaken online via videoconferencing, utilising captioning and Auslan interpreters where required. The interviews were recorded and a summary of the key points from each interview was provided to each respondent. Participants were invited to add or amend any comments in the summary.

THE ORGANISATIONS

Eight impairment-specific organisations were represented. Seven provided advocacy services and one provided information services. Three were registered as NDIS service providers, two of which also provided advocacy services.

Sixteen interviewees from these eight organisations participated in this project, thirteen of whom identified as having a disability. Another two were employed in an advocacy service and one was employed in a disability-specific service. The disabled interviewees had a range of impairments similar to NDIS participants: low vision and blindness, deafness, neurodiversity, and physical, intellectual and psycho-social disability. One organisation was specifically for young people with disability, who may have more familiarity with technology and multiple device usage.

LIMITATIONS OF THE RESEARCH

The interviewee representing a Deaf advocacy organisation noted that their organisation is not yet in contact with certain groups of deaf people - people in group homes who use Auslan, or people who are quite language deprived, or have disabilities that impact their ability to communicate fluently. They requested their answers need to be understood within the context that the DWI respondent is fluent in Auslan or is not severely language deprived.

In the time available we were not able to include any organisation representing people who are deaf-blind. Consideration needs to be given to technology accessibility, support and safety for people who are Deaf-blind, for whom a multimodal approach is most likely to be required.

THE FINDINGS

Participants indicated that there are significant challenges attached to implementing the DWI as an online survey and that there is no one technological or support and safety approach that will work for all DWI respondents.

The preferred approach in summary

Analysis of interviewee's responses suggested the need for the following approach to accommodate the needs of all people with disabilities when completing the DWI:

1. The DWI in default mode (i.e., the standard version) should be an online self-report survey for all NDIS participants with a clear preamble that explains to the participant what is required and permits each participant to make a decision about their preferred method to complete the DWI.

2. A request to complete the DWI should be sent to NDIS participants with:
 - a list of the alternative response options available.
 - assurance that completing the DWI is not compulsory and if the person is an NDIS participant, that completion or non-completion will in no way effect their plan.
 - contact details of a person to call, email, or text if they wish to discuss a DWI alternative response option.
3. The contact person should be ready to discuss available response options with participants seeking advice about DWI alternative formats and be available to support individuals to complete the DWI if needed. Alternative formats could include, for example, trained DWI interviewers available via Zoom or telephone, e-Braille, and other formats.
4. The contact person should provide an opportunity for participants to talk about their preferred support person and refer the participant to a DPO or other relevant supports, if the standard format is not accessible to them. Several organisations reported supporting people with disabilities with form completion, however organisations would need to be approached by the NDIA to discuss terms of their involvement in supporting people to complete the DWI for this option to be implemented. It is estimated that the proportion of respondents requiring alternative response options (including organisations to support completion) would reflect the proportion of NDIS participants who have difficulties with using the internet, for whatever reason such as access or technology or communication challenges or for psychological support in completing the DWI.
5. Proxy completion is strongly discouraged. Exploration of alternative ways of gaining information on the observed behaviour of participants who are unable to complete the DWI should be explored further.
6. Training of NDIA personnel is required to ensure that there is an understanding of the anxiety participants may feel about the DWI and the need to create a sense of trust and confidence in order to facilitate completion.
7. Advice needs to be provided to respondents and support persons along with the DWI about debriefing supports for respondents who may become distressed when completing the DWI. Debriefing support could be made available from an external agency such as Lifeline or Beyond Blue.
8. Further advice is needed on the accessibility requirements of people who are deaf-blind.

The sections below are arranged by the challenge identified, followed by approaches suggested by interviewees to address these challenges. Direct quotes are included in italics.

1. TECHNOLOGY

Interviewees were asked about what types of technology would enable their members to complete an online survey. Although there were clear differences according to the nature of impairment, what was most notable was the commonality of advice provided and the type of considerations raised, as demonstrated by the following themes.

Flexibility of DWI Formats

Any index that targets a community with diverse functional needs will involve significant complexity. As NDIS participants have different functional requirements and preferences, customised methods for access to the DWI will be necessary.

Among interviewees there was consensus that the DWI needs to be available in a range of formats to ensure accessibility for all people with disability and by the Deaf community. A flexible approach that provides an opportunity for participants to specify their preference and that allows for choice of formats will be most likely to elicit a positive response from participants to a request to complete the DWI.

1.1 Access challenges across all disabilities

Attitudes to completing the DWI

- Interviewees indicated that many people with disability experience survey fatigue and resist completing surveys. Some interviewees said they had difficulty in encouraging their members to complete online surveys, regardless of whether they had the functional capability to do so.

When someone has a lot of medical and allied professional people and all of the government departments that they have to provide their data to, people over time find quite a resistance to sharing.

Access to an online survey

Interviewees identified a range of barriers that could hinder participants' access to an online survey:

- It was reported that some NDIS participants do not have access to a computer, do not use email, cannot afford a computer or internet connection, or have poor internet reception.
- Online surveys can be too cognitively difficult for some people to complete. For example, some people may not understand what a particular question means.
- In terms of the survey design, it was noted that what is most accessible for some groups is not accessible for others. For example, free text was recommended for some groups, while others recommended yes/no response options.

- The time taken to complete online surveys can be exhausting for some participants and use of technologies such as Eyegaze and headpieces are fatiguing.
- Software changes occur frequently and influence accessibility; software updates can even render previously accessible software inaccessible.

Suggested solutions offered by organisations

“It is important to plan for universal accessibility from the beginning rather than trying to retrofit.”

There was a unanimous view amongst interviewees that people should be allowed to respond in the manner that best suits their communication style through providing a range of flexible formats available from the outset. Interviewees made the following recommendations regarding language and context, online survey design and format, and alternatives to online survey formats.

Language and Context

“Keep it simple, if it is complicated for the user they will give up.”

- Provide context so the meaning of questions is clear.
- Use clear language set out in short sentences.
- Provide tip sheets to explain key concepts. For example, who is family? What does ‘family’ mean?
- Provide both Plain English and Easy English formats. Some people may be offended if they are only offered Easy English versions.
- Ensure consistency in the style of questions throughout the survey.

Online survey design and format

- Use trained staff to assist respondents to set-up and talk with people via Zoom discussion about their preferred response option.
- Use software compatible with smartphones, smartwatches, tablets, and different screen sizes.
- Use a larger font size and ensure adequate spacing between questions to facilitate readability.
- Allow plenty of time for completion of the survey, for example, it was suggested to assume that a person with cognitive impairment may take much longer than people with other impairments who might complete the survey within 15 minutes.
- Design the survey so that it is broken up into sections, with only two or three questions per page, and ensure that survey responses can be saved, and the remainder of the survey completed later. The principle that needs to be applied is that information needs to be in manageable chunks for people likely to be overwhelmed by a lot of questions at once.
- Have a free text box to allow participants to provide additional comments and expand on their response or thoughts.
- Provide participants with access to a tablet or other suitable technology to address barriers related to cost and accessibility of technology.

- Update the DWI online format in line with changes in web accessibility techniques and standards.
- Regularly test software used to produce DWI with users to maintain currency of accessible methods for the DWI.
- Use software that adapts to new technology and can be used across different hardware.

“The introduction of Otter was a complete game changer. When Otter.ai, a live captioning tool, was introduced the demand for live captioning in our community went down.”

Alternatives to online survey format

Interviewees made the following suggestions regarding options that could be provided to participants, aside from an online survey, to support their completion of the DWI.

- Provide participants with the option to call the NDIS and request an alternative format.
- Provide a hard copy sent by post.
- Completion of the DWI via telephone interview.
- Provision of a support person who is available to clarify the meaning of a question.

1.2 Challenges for people with physical disability

Interviewees identified that people with physical disability may have limited hand function and experience fatigue induced by assistive technology devices, which may affect their ability to complete the online survey.

Suggested solutions offered by organisations

- Create a digital version of the DWI that allows for answers to be selected on a phone or computer screen.
- Ensure software is compatible with:
 - Augmented and Alternative Communication (AAC) systems and devices.
 - Eyegaze technology.
 - Speech generating devices.
 - Adaptive switch controls.

1.3 Challenges for people with intellectual disability

Interviewees reported that accessible survey technology for people with intellectual disability has not yet been developed.

- Some respondents may be confused about whether a question relates to a specific timeframe. For example, does a question refer to my feelings in the last week or in the last year? Even then, a respondent might reference feelings from previous years if they are particularly strong.
- Voice-to-text software might not function if the person is talking quickly or has more complex communication challenges.
- Surveys can be overwhelming or strenuous for some respondents, particularly if complex in its design or content.
- Scales can be particularly difficult to understand. For example:
 - Some people might tick all the boxes.

- phrases like “some of the time” and negative options like “disagree” may be difficult for some respondents to understand.

Suggested solutions offered by organisations

- A more appropriate response scale is to include “Yes/no/sometimes/don’t know” response options, with each option being paired with an image to support comprehension of each.
- Use easy read guidelines and icons that relate to the text and to indicate actions.
- Break down questions into simple, specific statements without too many steps. It was suggested there should be no more than three choices in any multiple choice questions.
- Clearly specify time frames when designing questions.
- Talk-to-text applications are appropriate for yes/no and short answer responses.
- Text-to-speech applications that visually track along each word and read digital text aloud may be helpful for people with dyslexia or other cognitive disabilities. Text-to-speech can be accessed via a button visible on the survey page.

1.4 Challenges related to screen readers

- Screen reader programs are diverse; a program that works for some people may not work for others.
- Even when testing has proven that a particular screen reader is useful for an individual, it can become inaccessible if the back end of the software changes.
- Web compatibility guidelines can facilitate a technically accessible survey but if access to the survey is still overly burdensome, people will not be motivated to complete it.
- Tables and check boxes may not be compatible with screen readers. For example, respondents may not be able to select check boxes.
- Problems will arise when surveys require a mouse to be used, for example, slider scale questions.

Suggested solutions offered by organisations

- Identify and use the few formats that are accessible for screen readers.
- Make a web-based form with HTML.
- Work with a range of common browsers such as Google or Safari.
- Scales are appropriate for screen readers if the DWI is internet based and uses simple questions.
- Free text is generally most accessible and more easily completed by people using screen readers.
- Highlight required fields showing ‘required’ in text or with an asterisk.
- Use text-based responses that can be entered using a keyboard rather than requiring a response that uses a graphic which can be confusing for people with cognitive impairment.
- Use software compatible with:
 - JAWS, NVDA, Windows screen readers.
 - Screen magnification and voiceover on Apple OS.
 - Voice-to-text applications.
 - a Braille display.

1.5 Challenges for people with low vision

- Italics and all caps text can be difficult to read for people who use the shapes of words to read.
- People with low vision may not be able to see coloured text (or specific colour text) and therefore may not know that a certain field is required.

Suggested solutions offered by organisations

- Primarily use a design that is compatible with screen magnifiers.
- Ensure good contrast ratio for text and background colours.
- Adapt colour and font size to enhance readability for people with low vision, for example, white on black, black on white.
- Use an alternative to colour to signify a required field.

1.6 Challenges for Deaf people

Deaf language is different to English and has a different culture. For deaf people cultural norms are an important consideration.

- A Deaf person may not want to use English text.
- The meaning of a question in English is not always understood by a Deaf person.
- MS Teams, WebEx and forms other than Zoom are not appropriate.
- An avatar, now sometimes used for signing, is definitely not a suitable option at this point.

Suggested solutions offered by organisations

- Enable conversation via in-person or Zoom interactions to allow the person an opportunity to ask questions.
- For an online survey, provide both Auslan and a simplified version of Auslan, like Plain English, so that each person is able to respond in their native language, Auslan.

For example, with Auslan I would sign "what's your experience with the Government services" but a plain version of Auslan would be "what's your experiences? Have you had positive or negative experiences with government services; for example, Medicare, Centrelink".

- Use a Deaf interpreter who is more likely to adjust to the appropriate language level, rather than a hearing Auslan interpreter for Deaf people who are not as proficient in Auslan.
- Use software such as SurveyMonkey and Qualtrics that offer video capacity which allows for answering by signing in Auslan.
- Employ Deaf workers to support both the development of surveys and to be available to answer questions when a respondent receives a request to complete the DWI.

2. SUPPORT

2.1 Types of support required

Interviewees were asked about whether their members required support and in what situations they may require support. There were a variety of perspectives regarding what kinds of support and assistance might be required. For example, in addition to requiring assistance with accessing an online survey, people may require communication supports, or assistance with understanding the survey questions or for emotional support following a past trauma.

All interviewees emphasised self-determination and stated that their organisation is generally prepared to help members complete surveys. However, one organisation noted they do not have the resources to assist everyone who will require assistance and another service provider noted they offer support on a fee-for-service basis.

Challenges with providing support

“Someone with a disability that prevents them doing an online survey or has less access to technology will require support or telephone assistance to fill in the survey.”

“I wouldn’t use an unknown person to assist completing a survey. Every day I could have a stranger do my personal care, which is very personal, you feel vulnerable. It’s the same for completing personal information.”

- People with disability are concerned about privacy and confidentiality when they require personal support. The intrusive nature of some supports can be a significant issue for some.
- Not all participants will want to use their family or support worker to help them complete the DWI:
 - Young adults living at home may have different views to their parents and may not want to be honest with a parent.
 - Someone experiencing family violence will not want to rely on their partner to support them in completing the survey.
 - If the question relates to their views of their support person, it will be hard to answer honestly and comfortably.
 - People may not want to be assisted by someone from the same small town due to a lack of privacy.
- The Deaf community is so small that finding a neutral person may be difficult.

Suggested solutions offered by organisations

“As an advocacy service we provide a telephone number to let people know our organisation will assist them with the registration over the phone if preferred.”

“We have a common experience with others, and this is important for people to feel comfortable talking to us. It would be good to have someone who is a peer providing support. This is really important.”

- NDIS staff should wait until participants are alone before asking them if they want support to complete the DWI. This way, participants are free to make their own decision about who they choose without feeling coerced or pressured into identifying a particular support person.
- A support person could be a peer, support worker, carer, service provider, partner or a specific person from the NDIS, provided that the participant feels a sense of trust and confidentiality in their relationship.
- Provide guidelines on the provision of support that emphasise the least restrictive and self-determining approach.
- For a Deaf person, offer the use of a Deaf interpreter as a support person.

2.2 Using supported decision-making

Supported decision-making supported (SDM) is the process of assisting a person to make a decision. It is underpinned by the principle of least restrictive support where decisions are directed by a person’s own will, preferences and rights. Interviewees were asked in what situations SDM might be required and in what way SDM should be employed.

There were a range of reasons cited for respondents requiring SDM to assist them in making a decision about their wellbeing. Interviewees observed that everyone has a different support person and there are multiple support roles that may need to be utilised.

Challenges

“A lot of young people require assistance in decision-making. However, it’s often assumed that someone else should actually make the decision ...Capacity should be assumed and all information that will assist the person to make the decision themselves should be provided.”

“I don’t know if assistance in completing with someone else is accurate. We tried this and found people weren’t giving truthful answers whether out of embarrassment or wanting to appear better than they were. Survey answers were at odds with what was observed. Particularly regarding mental health, personal care, relationships.”

- Family and support workers do not always understand the principle of least restrictive intervention, that is, the difference between mediating the information and influencing the answer.

- The person offering SDM assistance may have a conflict of interest. For example, questions may relate to the service they provide.
- The individual may not be able to choose the person that they actually wish to assist them with SDM.

Suggested solutions offered by organisations

“Create an accessible and independence-promoting tool to minimise the level of support required.”

“Our members have built a level of trust with us that they can use their voice and there is only a minimum intervention to assist them understand the questions or how to use the software.”

- Ensure that each participant has the opportunity to nominate who they choose to assist their decision-making.
- Provide guidelines on the role of SDM support to ensure the least restrictive approach is undertaken in all cases.
- Create a list of organisations qualified to provide SDM and skilled in assisting their members in decision-making.
- Ensure the SDM provider has an understanding of the respondent’s individual needs. Consider using an advocacy service for this purpose.
- Create a response option for those who prefer alternative forms of communication, for example, using picture cards.

2.3 Use of a proxy

“Rather than relying on proxy NDIA should go to any other means possible to ascertain a self-report because another person can’t anticipate someone’s internal life.”

“Thinking about proxy measures versus self-report, the findings for people who experience intellectual disability are often different to those who don’t, to what extent is this because the index is not capturing their experience?”

The use of proxy responses for wellbeing surveys was seen as very problematic. In general, interviewees were emphatic that proxy report is not a suitable method for a wellbeing index because a person cannot really know what is going on inside another person and is not likely to accurately answer for them. Outcomes reported by proxy may be systematically different from those obtained directly from people with disability.

Disability advocates gave clear, unambiguous answers that proxy reporting should not be used. Representatives from two service providers suggested there may be situations, for example, when someone has a significant impairment, that a proxy report needs to be employed as the only available option. One provider suggested this required further exploration with organisations that are familiar with proxy reporting.

Interviewees unanimously recommended that if proxy completion of the DWI is employed, the data must be analysed and stored separately from data that is provided directly by NDIS participants.

Challenges

“Where a person has more power, it adds another layer of power if they are completing it on behalf of the participant.”

- In the autistic community, there are significant differences between outcomes reported by proxy and when self-reported.
- A DWI may not have the capacity to capture a participant’s experience by proxy.
- In some situations, a family member may not have the best interests of the person at heart, which will influence the outcomes reported by them.
- It is not appropriate for parents to be asking a young person about sensitive personal information.

Suggested solutions offered by organisations

- Seek further advice on the use of proxy reporting from relevant advocacy organisations representing people with severe intellectual and communication disabilities.
- For instances where a proxy is the only alternative after all other options have been examined, develop and provide specific instructions for proxies to help them understand their role in accurately representing the experience of the participant.
- Explore ways to assess if proxy use influences responses. Compare findings between proxy- and self-reported responses, including any similarities and differences in the trend of responses.
- Ensure that the proxy acts in the best interests of the participant, knows them well, and is unbiased.
- Family members might be suitable if they have the person’s best interests at heart. Siblings can at times have a different and better understanding of a person’s abilities or skills than their parents.
- Explore the effectiveness of using a separate instrument based on measuring observed behaviour rather than proxy reports of a person’s sense of wellbeing.
- Be clear about who is providing the information gained from the DWI, what their role is, and on what basis the observation is made.

3. SAFETY

This section explores what conditions are needed for a participant to feel safe and confident to complete the DWI. It includes what information the NDIS should provide to a participant who is considering completing the DWI.

Again, the responses were consistent across different disability groups and organisations. The importance of trust was strongly emphasised by all interviewees. Interviewees stated that there needs to be a culture that builds trust in people with disability with regard to choice, cyber-safety, and psychological safety through a comprehensive explanation of all

aspects of the Disability Wellbeing Index. Trust was seen as even more important than providing the DWI in appropriate and alternative response options.

3.1 Trust Challenges

People with disability experience a high level of discrimination, which has resulted in a level of distrust of services and agencies. Some interviewees were of the view that the NDIS is not a trusted organisation.

“The NDIA must promote itself as a trusted organisation in order to successfully implement the Disability Wellbeing Index.”

“I didn’t think the Independent Assessment Information workshops were genuine consultation because they allowed no time for Q and A and were impersonal with consultants wearing suits reinforcing the power dynamic”.

“Understand the disconnect people feel with the NDIA – there is a lot of anxiety in the community about the NDIS with regard to finance, family and psycho-social health. People may not feel they can be honest.”

Suggested solutions offered by organisations

Clarity in explanation and transparency were seen as central to trust-building and engagement of participants in completing the DWI. In order to engender trust and to feel safe, participants will require preparation for the DWI. They will require information that provides an understanding of the purpose of the DWI, what to expect in completing the instrument, how to care for themselves throughout the process, and how it will be stored and used.

- Use respectful, clear language and avoid jargon words such as “survey” or “index”.
- Choose the language appropriate for each disability.
- Choose gender-inclusive language to ensure there are options to select the gender identity that is most relevant to each person.

“If we don't have those options available for people, it may make them feel psychologically unsafe or unsafe in providing their data.”

- Establish an NDIS contact person who can clarify any confusion a participant may have.
- Information should include a clear explanation of:
 - The rationale of the DWI, in order to assist participants to understand the meaning of the DWI.
 - The benefits for the participant.
 - The accessibility features that are available.
 - The number of sections and questions in the instrument.
 - The expected time required for completion.
 - The nature of the information being asked.
 - Advice that participants should complete the survey when they are feeling relaxed.
 - The types of supports that are available if a person becomes distressed.

- Details on how the information will be stored and when it will be discarded.
- Who will have access to the respondent's material.
- How the NDIA will share the findings with respondents.

3.2 Challenges re Psychological distress

The potential of the DWI to be a trigger for distress was raised as a significant concern.

"It causes me a great deal of anxiety having to answer questions, for example, for Centrelink or about my housing. It's a fear based on the reality of the system and the level of power you don't have in that situation. I think it would be the same for the NDIS DWI."

"Young people have a lot of anxiety about getting it wrong with negative consequences."

- Respondents will be making very personal self-disclosure, which means there is a need to consider the psychological safety of both respondents and staff receiving the data. Even if the answers are not open ended, completing the DWI could be distressing for some respondents.
- An online survey can be difficult because the person does not know if there is someone offscreen who is able to see their responses. For example, when on Zoom, participants may be unsure about who else is present outside the vision of the screen. This could arouse feelings of pressure to give positive responses, even if that is not in line with their true feelings.
- For people who have an acquired disability, reflection about their wellbeing may raise painful memories of trauma. People with degenerative conditions could feel traumatised when reflecting on their anticipated wellbeing in the future.
- People often do not want to talk about their wellbeing immediately after acquiring a disability or soon after discharge from hospital.
- People who have grown up in controlled environments, such as in institutions, are often compliant and have trouble reporting that they are not happy. Giving "no" or "I don't like" responses can actually be very difficult for some people.

"Both the Disability Wellbeing Index and the World Health Organisation Disability Assessment Schedule are blunt instruments to complete For someone living with permanent decline of functional capacity this will be distressing, for example, talking about employment and other aspects of life."

"Access problems are endless so someone approaching this might feel they are pouring from an empty cup. This means people might need to have access to emotional support after completing the Index."

Suggested solutions offered by organisations

“Make sure that they know that they can stop at any time. You know, people can be filling in a wellbeing survey and feel psychologically unsafe.”

- Ensure that participants are able to save their progress in completing the instrument and come back to it later.
- Ensure that support persons have training in mental health first aid.
- Provide information about debriefing support if someone becomes distressed.
- Ensure that respondents are able to choose to complete the DWI in an environment that they are comfortable in.
- Make sure that respondents are able to make decisions freely and are not subject another person’s influence.
- When completing the DWI in person with another person, use a private space so that the respondent feels comfortable sharing information.

3.3 Challenges regarding the possible impact on a participant’s plan

Deidentification of responses and the importance of maintaining separation of the DWI responses from a person’s plan was a strong theme throughout the interviews. The view was also expressed that many participants are interested in improving the NDIS and many will want to contribute if their responses are deidentified.

- There is a fear that a participant’s responses could influence the outcome of a participant’s plan. For example, people may be concerned that scoring highly on the DWI could result in a perception from NDIS that less support is needed.

“Some of the Disability Wellbeing Index questions might tap into sensitive concerns, for example, mental health. It gets to the core of wellbeing, so it needs to be strongly disconnected from the individual’s planning.”

“People will worry that it might be shared with a service provider and that will affect their service or that they might get a staff member in trouble.”

Suggested solutions offered by organisations

- Ensure information provided by respondents is deidentified. Promote the fact that the data gathered will be used systemically and will not put a participant’s plan at risk.

3.4 Challenges regarding perceived insecurity of data

- All interviewees raised the issue of data breaches and the heightened sensitivity about cyber-safety. With data breaching proving to be rife, many people feel increasingly unsafe about providing personal information.
- People with vision impairment experience security problems with website tracking via screen readers. One interviewee stated they often receive a notification when using their screen reader that asks, “Are you using a screen reader, can we take your data?”

“It actually makes a lot of people using screen readers feel unsafe and feel they're being tracked, or their information is being misused.”

Suggested solutions offered by organisations

- Establish a phone system that allows the participant to call back to verify the authenticity of requests to complete the DWI.
- Supply an option for anonymous DWI completion, where the respondent is able to register and is then provided with a code that they can use to complete the DWI rather than using their name or NDIS number.
- Allow participants to access the DWI via a safe and secure link from a trusted source such as the NDIS portal.

3.5 Challenges regarding choice

- Concerns that the DWI will be mandatory for NDIS participants was raised. All interviewees reported the need for participants to know that completion is not a condition of their NDIS participant status and that they can choose not to complete the DWI without repercussion.

Suggested solutions offered by organisations

- Advise participants they have a choice about completing the DWI to engender trust in the NDIS and the DWI process.

3.6 Specific challenges for Deaf People

“I might not feel safe to share my information with a specific Auslan interpreter present. This has happened so there is a lot of fear. A lot of Deaf people have a short list of who is their appropriate interpreter.”

Suggested solutions offered by organisations

- Ensure that a Deaf person has the opportunity to specify who will act as their interpreter when dealing with very sensitive topics.
- Plan well in advance to ensure the appropriate interpreter is organised and available.

4. CONCLUSION

The research team from the University of Sydney and Monash University thank the organisations who so willingly shared their time, and their perspectives on the challenges of on-line surveys, and supporting people with disability to fill in forms. Their experiences with supporting people with disability are invaluable to understanding technology accessibility, support and safety considerations for people with disability being asked to complete an on-line DWI survey.

There are two stand-out findings from these experiences. The first is that reasonable accommodations to the technological offering of an on-line survey will need to be implemented to ensure as many people with disability as possible will be able to provide their own perspective on their wellbeing. The second is the consensus among the organisations that proxy completion is not acceptable. All organisations strongly supported the adaptations needed to ensure each person with disability could complete the DWI according to their own perspective, not presented or mediated by a third party.

APPENDIX 1: INTERVIEW QUESTIONS FOR THE TECHNOLOGY ACCESSIBILITY PROJECT ABOUT THE DISABILITY WELLBEING INDEX

Preamble:

Thanks for making the time. We are seeking your expertise and your experience to guide the NDIS in developing the DWI over the next twelve to 18 months prior to implementation.

This interview focuses on what you consider is required to provide an accessible method for people your organisation represents to be able to use the Disability Wellbeing Index and what is important for them to feel safe and confident completing the Disability Wellbeing Index. I will be asking about:

- alternative versions for online survey as well as alternatives to online survey.
- What assistance your members/clients may require. Self-reporting is the primary goal, but if this is not possible or desired then collaboratively and if with assistance then if not by proxy (based on the CRPD).
- What is a safe environment for completion – what might trigger distress or mean that the person completing the DWI is afraid to give honest answers for fear of repercussion from their support person or service provider for example and what is the right environment for undertaking the Disability Wellbeing Index.

This process is a follow up from the testing of the content of the Disability Wellbeing Index with DPOs, DROs people with disability and staff at NDIA. We are **not** seeking feedback on the content of the DWI itself but specifically on accessible formats, support needed and safety considerations.

The information you provide will be reported to the NDIA, the report will be confidential, and your organisation will be deidentified.

The interview is being recorded so that we have full details rather than relying on notes taken or memory. Is that okay?

I will be taking notes as I go so I might have my head down, is that ok?

Would you like a to see the summary of the interview?

Do you have any questions before we start?

Questions

1. Nature of the relationship to people with disability

- a) Are you a registered NDIS provider?
- b) What services do you provide?

2. Accessibility

- a) In your experience what are the best ways you have found to do online consultations/surveys with your members?
- b) Are there any other formats you have found to be effective for member interaction?
- c) What are the types of online formats or methods that are most important for a Disability Wellbeing Index to be accessible to your members/clients?
- d) What software technology should be available to ensure accessibility of a Disability Wellbeing Index?
- e) Are you aware of new hardware technology that might be coming online in the future that the NDIS should consider for online surveys?
- f) With regard to electronic tools how do you think a DWI could maintain its relevance with changing accessibility options?
- g) Do you have guidelines for your staff or for other organisations to encourage Information being accessible to your members/clients?

3. Supports

- a) Are you aware of any of your members requiring assistance in completing online surveys or interviews?
- b) In your experience **who** do you think have been the most effective people to provide support in completing confidential surveys or interviews such as a wellbeing index?
- c) Are there situations where you think “a neutral person” for example a person not known is the most effective support person?
- d) In what situations do you employ or recommend supported decision-making? What guidelines/training do you provide to your staff on supported decision-making?
- e) Do you have guidelines to uphold members/clients’ rights to autonomous decision-making or supported decision making.
- f) Does your organisation assist members to complete surveys/interviews?

Proxy completion

The NDIA will provide for the DWI being completed by proxies when appropriate:

- a) Do you think there are situations/conditions where a proxy is an appropriate alternative to the person completing their own DWI?
- b) What are these conditions?
- c) Who do you think in your experience have been **effective proxies**?
- d) Are there guidelines your organisation provides on proxies being consulted or surveyed on behalf of your members/clients?
- e) Are there any guidelines or instructions to proxies the NDIS should specify for completion of the Disability Wellbeing Index?

4. Safety

- a) What in your experience are **the important considerations** to encourage your members/clients to feel safe in completing a wellbeing index?
- b) What sort of **environments** should be available to participants to complete their Disability Wellbeing Index?
- c) What do you think are the **most effective ways** to ensure safety in implementing a wellbeing index which is entirely about the participant's preferences and values about their own wellbeing?
- d) Is there any guidance the NDIS should provide to its participants about completing the DWI to assist them to feel safe and confident?
- e) Have you developed a guideline or protocol to raise awareness of safety in completing on-line surveys or other formats which are about their wellbeing in working with your members/clients?