



THE UNIVERSITY OF  
**SYDNEY**

**Centre for Disability Research and Policy  
Faculty of Medicine and Health**

# **Report on the Development of Alternative Formats and Support Options for the Disability Wellbeing Index (DWI)**

## **Promoting Accessibility, Safety, and Self- Reporting for Survey Respondents**

## 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 third of four reports documenting the contribution of the team at the CDRP. This report was submitted to Monash University on 25 October 2023. In this report, we describe the process undertaken by the CDRP team from July-September 2023 to develop a suite of alternative formats and support options designed to address accessibility for self-report and safety considerations for completing the DWI. The final versions of the DWI preference weighting survey and support options offered to survey respondents are also presented.

**Recommended Citation:** Hines, M., Bulkeley, K., & Llewellyn G. (2025). *Report on the Development of Alternative Formats and Support Options for the Disability Wellbeing Index (DWI): Promoting Accessibility, Safety, and Self-Reporting for Survey Respondents*. Centre for Disability Research and Policy, University of Sydney. <https://doi.org/10.25910/16sw-4e70>

## TABLE OF CONTENTS

INTRODUCTION .....	1
DEVELOPMENT OF ALTERNATE ONLINE FORMATS.....	3
DEVELOPMENT OF SUPPORT OPTIONS .....	8
CONCLUSION .....	11
APPENDIX 1: Disability Wellbeing Index Preference Weighting Survey – Standard version .....	12
APPENDIX 2: Disability Wellbeing Index Preference Weighting Survey – Easy English version .....	38
APPENDIX 3: Guidelines for Support Time with Auslan Users.....	64
APPENDIX 4: Guidelines for Dealing With Participant Distress .....	67
APPENDIX 5: Frequently Asked Questions .....	69

# INTRODUCTION

This report details the accessibility research component of the wider three-year research project, funded by the National Disability Insurance Agency and lead by Associate Professor Gang Chen, Monash University, in collaboration with researchers at the University of Sydney and Flinders University. The aim of the three-year project is to design and test a preference-based wellbeing instrument that captures factors that impact on the wellbeing of people with disability in Australia.

The component addressing accessibility, safety, and self-reporting for DWI survey respondents was conducted from July to December 2023 under the leadership of Dr Kim Bulkeley and Professor Emerita Gwynnyth Llewellyn with Senior Research Fellow, Dr Monique Hines. At the commencement of this research phase, achievements to date included:

1. Identification of items for inclusion in the Disability Wellbeing Index (DWI);
2. Incorporation of available literature and feedback from people with lived experience of disability and other stakeholders to refine DWI domains, items and descriptors, with the final version of the DWI now consisting of 14 items covering 10 life areas;
3. Consultation with representatives from Disabled People's Organisations (DPOs) and Disability Representative Organisations (DROs) to understand what technology accessible formats, support options, and safety considerations are required to facilitate DWI completion by as many NDIS participants as possible.

During the current research phase, three concurrent research foci were addressed:

1. The teams at Monash and Flinders universities developed a series of surveys for completion by NDIS participants. This series of surveys included the 14-item DWI, 14 items rating the importance of each item in the DWI, 8 discrete choice experiment (DCE) items that require respondents to identify their preferences among different hypothetical wellbeing states, a Life Satisfaction scale, and a range of demographic and disability-specific questions. This was done to establish **preference-based weightings** for items in the DWI once the survey was trialled with a large sample of NDIS participants from September to November 2023.
2. The team at the University of Sydney integrated findings from consultations with representatives from DPOs and DROs into the **development of a suite of alternative formats and support options** for supporting the completion of the above series of surveys in the NDIS trial survey.
3. The NDIS trial survey began in September 2023. An email was sent from NDIA to 1,000 NDIS participants, inviting people to complete the **DWI preference weighting survey** on 4 September, as part of a soft launch. The full launch of the survey occurred on 8 September, when approximately 40,000 NDIS participants received the invitation email from NDIA.

## Rationale for Alternative Formats and Support Options for Survey Completion

The development of alternative formats and support options was deemed of critical importance to the success of the three research foci above, given the low response rate achieved when a previous iteration of the survey was distributed to NDIS participants between October and December 2022. Specifically, from a potential response pool of over 30,000 NDIS participants aged

15 years and over, only 1,647 participants completed at least one DWI item, and only 1,140 completed all NDIS participant-related sections.

Further, of these respondents, only 16% were NDIS participants who self-reported their wellbeing and preferences, while 38% of responses were from proxy report alone (e.g., family members, friends, support workers basing their responses on their understanding of the NDIS participant), and 15% from proxy report with some contribution from the NDIS participant. It was hypothesised that provision of alternative formats and support options may not only increase the response rates in future rollouts of the DWI survey but may also reduce the rates of proxy responses.

Reliance on proxy reporting for completion of a preference weighted wellbeing index such as the DWI is extremely problematic. This is because wellbeing is subjective and therefore requires the participant to complete the survey, if possible. In addition, people with lived experience of disability and representatives of DPOs and DROs were sceptical of the accuracy of other people, that is, proxy reporting about the wellbeing of people with disabilities. The findings from Stage 2 Disability Wellbeing Index, Analysis of Qualitative Components with Adults and Young People with Disability (18<sup>th</sup> November 2022) clearly demonstrated that self-reporting was to be encouraged where at all possible, with proxy reporting only used in situations of last resort. Proxy reporting is unlikely to provide an accurate measure of another person's internal state, such as feelings about their own wellbeing<sup>1</sup>. However, people with disabilities may be assisted to report on their own wellbeing with the provision of accommodations and supports that meet the diversity of their needs, such as employing interviewer administration, visual aids, and modification of response options<sup>2</sup>.

In this report, we describe (a) the process we undertook to develop a suite of alternative formats and support options for completion of the DWI preference weighting survey, and (b) the final versions of the DWI preference weighting survey and support options offered to survey respondents.

---

<sup>1</sup> Havercamp, S. M., Barnhill, L. J., Bonardi, A., Chapman, R. A., Cobranchi, C., Fletcher, R. J., ... & Nisonger Center RRTC on Health and Function. (2022). Straight from the horse's mouth: Increasing self-report in mental health assessment in individuals with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 35(2), 471-479. DOI: 10.1111/jar.12952

<sup>2</sup> Santoro, S. L., Donelan, K., & Constantine, M. (2022). Proxy-report in individuals with intellectual disability: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, 35(5), 1088-1108. DOI: 10.1111/jar.13013

# DEVELOPMENT OF ALTERNATE ONLINE FORMATS

## 1. Standard Online Version

A hard-copy version of the DWI preference weighting survey was initially prepared by the team at Monash University and circulated across the entire team for comment prior to submission to the human research ethics committee at Monash University.

As in previous stages of the overall research project, the team at the University of Sydney sought to provide a 'disability lens' by drawing on our expertise and knowledge of key debates and tensions of concern to the disability community. We also utilised findings from consultations with representatives from disability organisations<sup>3</sup> that provided unique insights into factors that would facilitate completion. Feedback on the initial DWI preference weighting survey draft focused on:

### Increasing self-report

- Including clear descriptions of available alternative formats and support options at the introduction to the survey.
- Provision of a decision tree in the introduction to the survey that encourages potential proxy respondents to consider using these alternatives and encouraging the NDIS participant to make their own decision about preferred methods to complete the DWI, including the choice to directly complete the survey themselves.

### Safety considerations

- Inclusion of text that encourages respondents to complete the survey when in a safe environment that they are comfortable in.
- Reminders to participants that if they become tired, they can take a break at any time and later re-access the survey.
- Insertion of trigger warning statements prior to potentially distressing items, along with contact numbers to access support if they become distressed.

The Monash team incorporated these changes into the online version of the survey on the Sawtooth platform. This software was chosen due to the superiority of its display of DCE items which supported understanding of the various component within each wellbeing state.

The NDIA required a single survey weblink which would be inserted into the invitation email sent to NDIS participants. For this reason, a welcome page to the survey was prepared for this survey link. This welcome page included the opportunity for respondents to request specific survey formats and support options and provided direct links to the standard survey and Easy English version (See [Appendices 1](#) and [2](#)). This welcome page was prepared using the Qualtrics software, due to its superiority in compatibility with screen readers (see [next section](#)).

---

<sup>3</sup> *Report on interviews about technology accessibility, support and safety considerations for the NDIS Wellbeing Index.* Sydney: Centre for Disability Research and Policy, University of Sydney, report by Dr Keran Howe to Monash University Centre for Health Economics, 7<sup>th</sup> July 2023.

## 2. Screen Reader Version

### Internal review of draft survey

Initial review of the draft hard-copy version of the DWI preference weighting survey by the University of Sydney team identified several aspects that needed further investigation to ensure compatibility with screen readers. For example, previous consultations with disability organisations<sup>4</sup> indicated that the grid layout for responses to the Life Satisfaction scale and the importance of life areas was unlikely to be accessible for screen readers. Similarly, the image of a modified Cantrell's Ladder used to represent the best possible life would not be compatible to screen readers without the inclusion of alt-text providing a description of the object.

Most notably, the DCE items were problematic, with text displayed within an inserted image, with the two wellbeing states described side-by-side, coloured text used to highlight the differing attribute values under consideration (See [Figure 1](#)). It was unknown whether a screen reader would be able to access the text within the inserted image, and whether the coloured text was of sufficient contrast ratio for people with low vision.

**Figure 1: Example of a discrete choice experiment (DCE) item**

Which of the following two wellbeing states is better?  
(Please assume all else are equal)

Wellbeing State A	Wellbeing State B
I am satisfied with my friendships All of the time	I am satisfied with my friendships None of the time
I am satisfied with my living situation All of the time	I am satisfied with my living situation None of the time
I feel safe in my life All of the time	I feel safe in my life None of the time
I have enough money to meet my needs All of the time	I have enough money to meet my needs None of the time
<b>Wellbeing State A</b>	<b>Wellbeing State B</b>
Select	Select

Given the concerns about the accessibility of the survey on Sawtooth, and the knowledge that the Qualtrics software provided an in-built accessibility check, the Monash team opted to create a second version of the survey on the Qualtrics platform, specifically for use with screen readers. The

<sup>4</sup> Report on interviews about technology accessibility, support and safety considerations for the NDIS Wellbeing Index. Sydney: Centre for Disability Research and Policy, University of Sydney, report by Dr Keran Howe to Monash University Centre for Health Economics, 7<sup>th</sup> July 2023.

DCE items were re-formatted as plain text in a simple multiple-choice question format without use of coloured text. Similarly, questions utilising grid layout were replaced with a series of multiple-choice questions. The resultant survey passed Qualtrics' inbuilt accessibility checker, indicating that it met Web Content Accessibility Guidelines (WCAG 2.0).

### Formal expert assessment of draft survey

The University of Sydney team requested a fee-for-service audit of the Qualtrics survey from the Centre for Accessibility<sup>5</sup>. This brief audit is conducted against the thirteen World Wide Web Consortium (W3C) Web Content Accessibility Guidelines (WCAG) 2.1 standard and provides a basic overview of the accessibility of a website, highlighting the most critical accessibility issues.

Given the tight timeframes involved in the project, the results of the full heads-up audit were not available in time for the initial launch of the survey. In view of this, the University of Sydney team negotiated with the Centre for Accessibility to provide feedback in two stages, with feedback about the basic accessibility level within a relatively short timeframe prior to the launch of the survey, with details from the results of the full heads-up audit provided later, during October 2023, well after the survey launch. Findings from the full heads-up audit will be provided in the final report submitted in December 2023.

The following initial feedback was provided by the Centre of Accessibility to improve compatibility with screen readers:

- Each survey page required a unique title and heading and subheading elements structured with HTML code using heading styles.
- Appropriate list markup using HTML code needed to be added to the first page of the explanatory statement and the main survey.
- The alt text (a written description of an online image that is read aloud by screen readers) for the Monash University logo needed to be adjusted to be more descriptive.

These points were addressed by the Monash University team prior to the soft launch of the survey.

## 3. Easy English Version

### Internal review of draft survey

During an earlier stage of the overall research project, an Easy English version of the DWI was developed in collaboration with an external contractor recommended to the Monash team by NDIA. However, initial review of this version by members of the research team raised some concerns about the suitability of how certain concepts had been rendered using images, particularly the five-point response scale for the DWI. In addition, we identified a need for expert advice on how to best convey the complex concepts expressed in the DCE items and required Easy English version of other parts of the DWI preference weighting survey (i.e., explanatory statement

---

<sup>5</sup> <https://www.accessibility.org.au>

and consent form, importance ratings for DWI items, the Life Satisfaction scale, and the demographic and disability-specific questions).

### Formal expert assessment of draft survey

The University of Sydney team requested fee-for-service input into the development of the Easy English version of the survey from Victorian Advocacy League for Individuals with Disability (VALID)<sup>6</sup>. This organisation has expertise in empowering people with intellectual and cognitive disabilities, including developing accessible forms of communication such as Easy English.

During the initial consultation, VALID recommended that the explanatory statement and consent form include Easy Read English and pictures to best convey the meaning, whereas the main body of the survey, including DCE items, should use Easy English wording without pictures. It was explained that the inclusion of pictures with the DCE items would complicate rather than simplify the intended meaning of the task. Their recommendation was instead to ensure the option of accessing supports at the time of completion for those people with cognitive and intellectual disabilities who require additional assistance, such as trained facilitators who could provide support via Zoom.

The Easy English version of the survey was provided by VALID in Word document format and entered into the Sawtooth platform by the Monash team. Prior to launch, further input was sought from VALID regarding wording for a 'not applicable' response option for three DWI items (Item 1: relationships with family, Item 2: friendships, Item 3: relationships with support workers) and wording of questions for DWI importance ratings.

## 4. Voice-to-Text Users

### Internal review of draft survey

It was not known whether the versions of the DWI preference weighting survey on Sawtooth or Qualtrics were compatible for people who require voice-to-text technology to complete the survey. Initial investigation indicated that Qualtrics software offers options for respondents to video- or voice-record their response; this feature however was dependent on the purchased licence. In addition, it was not known whether either the Qualtrics or Sawtooth software could interface effectively with commonly used voice-to-text technology.

### Informal expert review of draft surveys

The tight timeframes did not permit formal testing of voice-to-text capabilities of the surveys. Consequently, the University of Sydney team approached a work colleague with disability who uses a combination of voice-to-text technology and computer mouse and asked him to informally review the online surveys and provide feedback on its accessibility.

User testing revealed that the survey on the Qualtrics platform, optimised for screen readers, was not accessible using the combination of voice-to-text and computer mouse technology. The

---

<sup>6</sup> <https://valid.org.au>

standard version of the survey on the Sawtooth platform was able to be accessed using a combination of voice recognition and a mouse, however voice-to-text technology alone was not sufficient for entering responses into free text boxes. The person conducting the informal review conceded that his lack of experience in using voice recognition alone may also have influenced this observation.

There was insufficient time prior to survey launch to seek formal advice about how to make these platforms fully accessible for voice-to-text users. This is an area that needs further attention to ensure accessibility for as many users as possible.

By way of partial solution, the link to the survey on the Sawtooth platform was added to the survey welcome page so that voice-to-text users could directly access the Sawtooth-based survey. Directions on the welcome page encouraged survey respondents who had difficulties accessing the available options to contact the researchers directly, with telephone and email details provided.

## DEVELOPMENT OF SUPPORT OPTIONS

In addition to developing alternative survey formats, a range of support options were developed to meet the diverse needs of NDIS participants. The wider team committed to providing survey respondents the opportunity to request a member of the research team support them to complete the online survey in a zoom meeting or telephone call. The aim of this support time was to provide only as much assistance as the respondent required, for example, by reading questions out aloud, providing clarification as necessary, whilst staying in the background as much as possible. To ensure this mode of survey completion flexibly accommodated diverse needs, the research team addressed the specific needs of the following subgroups of respondents:

### 1. Auslan Users

#### Internal review of draft survey

Initial plans included the development of Auslan and video-captioned videos of each page of the survey. However, it was decided that for this stage of the research, Auslan users will be supported to complete the DWI preference weighting survey via zoom meeting with a researcher and Auslan interpreter, for the following reasons:

- Zoom meetings with a researcher during this development phase would provide an opportunity for collection of additional data regarding necessary language adjustments, accessibility needs of Auslan users, response format considerations, which could inform future iterations of the DWI;
- Difficulties regarding preparation of a range of Auslan videos for the randomised wellbeing states in the DCE, which would become obsolete once the current phase of the research is completed.

#### Formal expert assessment of draft surveys

The University of Sydney team requested a fee-for-service consultation with Sweeney Interpreting<sup>7</sup> for expert advice regarding the language considerations and adjustments needed to support Auslan interpreters accurately convey the intended meanings and concepts to the survey respondents.

The following recommendations were provided by Sweeney Interpreting:

- Use the Easy English version of the survey as a default with any Auslan user who requests a Zoom meeting to support survey completion;
- Allow time prior to meeting with the survey respondent to meet with the Auslan interpreter and familiarise them with the purpose of the survey and its specific tasks, in particular the DCE;
- When explaining the DCE, ensure that the interpreter is aware that the items draw on the same life area statements that are presented in the DWI;

---

<sup>7</sup> <https://sweeneyinterpreting.com.au>

- Certain items in the DWI may require specific examples to be provided to accommodate the unique nature of Auslan, which often relies on specific examples, rather than general concepts. There is no need to be concerned that Auslan users will focus too much on a narrow context; this simply reflects how Auslan works and is a mechanism required to help Auslan users properly conceptualise the underlying concepts.
  - In particular, the items about satisfaction with living situation and feeling safe, may require interpreters to provide examples to make the extremely general concept a narrower one that the person can focus on, and then assist the person to think more generally about the concept by asking for an overall rating of their feelings for that life area.
- It might be helpful to suggest that the person takes a break once they have completed the DCE questions, in case of fatigue;
- Provide the introductory email from the NDIA in Auslan, via a video or weblink to an Auslan video. Auslan users are very unlikely to read and/or respond to emails provided only in English without a translated Auslan option. Guidance was provided by Sweeney Interpreting regarding how to highlight the video and/or weblink to the video to Auslan users by including “(Auslan video attached)” in the email subject line, including a graphic icon representing sign language in the email, or including the text “Auslan version here” with an embedded weblink in the main body of the email text.

Based on this feedback, a checklist was created for use by members of the research team providing support to complete the survey with Auslan users, summarising the above points (See [Appendix 3](#)). In addition, Sweeney Interpreting was commissioned to prepare an Auslan video interpretation of the NDIA invitation email.

This video was not able to be prepared in time for the programming of the NDIA invitation email. As a result, it was not included in the emails sent out to NDIS participants during the soft and full launches. As a workaround, the Auslan video was included on the survey welcome page prior to the soft launch of the survey. It was also negotiated with NDIA that the Auslan video and/or weblink be included in reminder emails to NDIA participants.

## 2. Provision of Safe, Supportive Environments

Previous stages of the research identified important safety considerations for the person with disability when they complete the DWI, including (i) ensuring the safety of the context within which the person with a disability completes the DWI, and (ii) managing the potential for certain items in the DWI to be triggering and cause distress to survey respondents. The members of the research team providing support via Zoom or telephone calls therefore need to be prepared to deal with respondent distress.

Since the research team included members with diverse experience, guidelines for dealing with participant distress were required. The team at the University of Sydney prepared a set of guidelines on dealing with respondent distress to members of the research team requiring additional guidance in this area, and to ensure consistency across the team (See [Appendix 4](#)). Key principles included highlighting the role of the researcher in offering support at the time as well as connecting the person with external sources of ongoing support. These were circulated across the team in preparation for requests from respondents for support to complete the survey.

Aside from provision of safe environment for completion of the DWI, previous consultation with DPOs and DROs<sup>8</sup> indicated that some survey respondents, including those with intellectual disability and cognitive impairments, may benefit by being able to complete the DWI with a researcher via Zoom or telephone within a supportive environment where they can ask questions to clarify the meaning of survey questions. In preparation, a set of anticipated Frequently Asked Questions was prepared for use by members of the team providing support to respondents (See [Appendix 5](#)). A record of additional questions asked and comments made by survey respondents was also created and shared across the research team so that the list of questions could be updated or refined over time as support sessions were conducted.

### 3. Allocation of Requests

Despite the large potential response pool, it was difficult to anticipate how many survey respondents would request support to complete the DWI preference weighting survey. However, it was expected that the greatest numbers of requests for support may come from people with intellectual disability, given the proportion of NDIS participants for whom intellectual disability is their stated primary or secondary diagnosis.

It was agreed that requests from respondents requesting support to understand the meaning of questions would first be allocated to the Flinders team, given their experience in survey completion with people with mild cognitive difficulties. If the quantity of requests received exceeded capacity of the Flinders team, additional requests would be forwarded to the Sydney team to handle. In addition, the Sydney team confirmed the availability of VALID to support people with intellectual disability and higher support needs to complete the survey on a fee-for-service basis. All other requests for support would be allocated to the Sydney team.

---

<sup>8</sup> *Report on interviews about technology accessibility, support and safety considerations for the NDIS Wellbeing Index.* Sydney: Centre for Disability Research and Policy, University of Sydney, report by Dr Keran Howe to Monash University Centre for Health Economics, 7<sup>th</sup> July 2023.

## CONCLUSION

It is our hope that the alternative formats and support options described in this report will be effective in facilitating self-completion of the DWI preference weighting survey by people with disabilities. Beyond this immediate aim, it is also our intention to draw on learnings from this research component to develop a framework that strengthens the capacity of organisations and agencies to provide accessible information and communications with people with disabilities. This framework must (a) be responsive to the diverse and specific communication needs and preferences of people with disabilities, and (b) uphold the dignity and autonomy of people with disabilities, putting them in a position of agency and capacity regarding decisions that affect their own lives.

To date, we have developed a suite of alternative formats and support options of the DWI preference weighting survey: a standard online version, an online Easy English version, hard copy versions of both the standard and Easy English versions, an online version compatible with screen readers, and an online version optimised for voice-to-text technology users. In addition, support via Zoom or telephone was offered to enable flexible accommodation of diverse respondent needs, such as for Auslan users, those requiring support to understand survey questions, and those requiring provision of a safe environment for survey completion.

These formats were designed to reflect the diversity of communication requirements of people with disability, ensure their informed choice and direct participation, and decrease the rate of proxy completion. It is evident that best practice in accessible communication requires considerable commitment from all stakeholders. We have seen that an investment of time and funds is needed to contract the technical and lived experience experts in accessible communication, and to ensure that the needs of specific groups are appropriately catered for.

## APPENDIX 1: Disability Wellbeing Index Preference Weighting Survey – Standard version

Q1. Who is completing this survey? Please choose one. (tick one box)

- I am an NDIS participant and I am completing this survey without support from another person. **[GO TO Q2]**
- I am an NDIS participant and I am completing this survey with support from another person. **[GO TO Q2]**
- I am supporting an NDIS participant to complete this survey. **[GO TO Q2]**

*Note: If you are supporting an NDIS participant to do the survey, the answers you tell us need to be what the NDIS participant would say.*

- I am completing this survey on behalf of an NDIS participant.

*Note: If you are supporting an NDIS participant to do the survey, the answers you tell us need to be what the NDIS participant would say.*

Q1A. What is your relationship to the NDIS participant? Please choose the best answer. (tick one box)

- I am the mother or father of the participant.
- I am the brother or sister of the participant.
- I am a child of the participant.
- I am another family member of the participant.
- I am a friend of the participant.
- I am a support worker of the participant.
- I am someone else.

Q1B. What is your sex? (tick one box)

- Male
- Female
- Another term (please specify) \_\_\_\_\_
- Prefer not to say

If you feel any difficulty while answering the questions, please reach out to us. You can send an email to [dwi@monash.edu](mailto:dwi@monash.edu) or contact Dr Gang Chen at 0425 811 029 or Dr Gozde Aydin at 03 9903 4363.

Q2. What was your age last birthday? \_\_\_\_\_ (years)

Q3. What is your sex? (tick one box)

- Male
- Female
- Another term (please specify)
- Prefer not to say

Q4. Which state or territory do you currently live in? (tick one box)

- Australian Capital Territory (ACT)
- New South Wales (NSW)
- Northern Territory (NT)
- Queensland (Qld)
- South Australia (SA)
- Tasmania (Tas)
- Victoria (Vic)
- Western Australia (WA)

Q5. In everyday life, do you have difficulty participating in any of the following, related to a long-term health condition or impairment? (tick one box)

**Daily activities**, such as:

- washing, dressing
- walking, handling, or lifting objects
- speaking, using communication devices

- Yes
- No

**Activities of independent living**, such as:

- shopping, cooking, caring for others
- making decisions, handling stress
- learning, solving problems
- relationships with people (tick one box)

- Yes

No

**Activities of work, education and community living, such as:**

- Social and community life
- Work, education, or training (tick one box)

Yes

No

Q6. The categories below are disability groups based on underlying health conditions and on impairments, activity limitations and participation restrictions.

Which of the following best describes your disabilities?

(Please tick the box next to any that apply – you can tick more than one box)

- Sensory** (e.g., sight, hearing, speech)
- Intellectual** (e.g., difficulty learning or understanding)
- Physical** (e.g., breathing difficulties, chronic or recurrent pain, blackouts or seizures, incomplete use of limbs)
- Psychosocial** (e.g., nervous or emotional conditions, social or behavioural difficulties)
- Head injury, stroke or acquired brain injury**
- Autism**
- Other (please specify)** \_\_\_\_\_

## Section A – Subjective Wellbeing

The following questions mention safety.

If you become distressed at any time, you could call Lifeline’s 13 11 14 and speak to a trained Crisis Supporter over the phone, any time of the day or night.

For Internet relay users, you could be connected to the National Relay Service (NRS) by the NRS Chat Call link (<https://nrschat.nrsconnect.gov.au/nrs/internetrelay>), then ask for 13 11 14.

### A1. Disability Wellbeing Index (DWI)

The following statements ask how you feel about your own life as it is now. There are no right or wrong answers. Please choose the option that comes closest to how you feel now.

I am satisfied with the way I get along with my family. (tick one box)

- All of the time
- Most of the time
- Some of the time
- A little bit of the time
- None of the time
- Not applicable

I am satisfied with my friendships. (tick one box)

- All of the time
- Most of the time
- Some of the time
- A little bit of the time
- None of the time
- Not applicable

I am satisfied with the way I get along with people who support me.

(for example, support workers, allied health, counsellors) (tick one box)

- All of the time
- Most of the time
- Some of the time
- A little bit of the time
- None of the time

Not applicable

I am satisfied with my personal care.

(for example, eating, bathing, dressing, toileting, with or without the help of others) (tick one box)

All of the time

Most of the time

Some of the time

A little bit of the time

None of the time

I am satisfied with my day-to-day activities.

(for example, shopping, cooking, cleaning, attending personal appointments, with or without the help of others) (tick one box)

All of the time

Most of the time

Some of the time

A little bit of the time

None of the time

I do things in my life that are important to me. (tick one box)

All of the time

Most of the time

Some of the time

A little bit of the time

None of the time

I am satisfied with my living situation. (tick one box)

All of the time

Most of the time

Some of the time

A little bit of the time

None of the time

I am satisfied with my physical health. (tick one box)

- All of the time
- Most of the time
- Some of the time
- A little bit of the time
- None of the time

I am satisfied with my mental health. (tick one box)

- All of the time
- Most of the time
- Some of the time
- A little bit of the time
- None of the time

Lifeline is a crisis support service. They can help if you or someone you know is having a mental health crisis. You can speak to a trained Crisis Supporter any time of the day or night. You can call 13 11 44 or text 0477 13 11 14 or chat online.

Internet relay users can use the National Relay Service link and then ask for 13 11 14.

I learn new things as much as I want to. (tick one box)

- All of the time
- Most of the time
- Some of the time
- A little bit of the time
- None of the time

I am satisfied with how people treat me. (tick one box)

- All of the time
- Most of the time
- Some of the time
- A little bit of the time
- None of the time

I feel safe in my life. (tick one box)

- All of the time
- Most of the time
- Some of the time
- A little bit of the time
- None of the time

\*If you are in danger, call 000.

1800RESPECT (1800 737 732) is a free counselling service for people impacted by sexual assault, domestic or family violence and abuse.

National relay users can contact 1800 RESPECT through the National Relay Service on 1800 555 677 and give the number 1800 737 732.

The National Disability Abuse and Neglect Hotline (the Hotline) 1800 880 052 is for reporting abuse or neglect of people with disability.

Beyond Blue is an Australian mental health and wellbeing support organisation.  
[www.beyondblue.org.au](http://www.beyondblue.org.au)

I have enough money to meet my needs. (tick one box)

- All of the time
- Most of the time
- Some of the time
- A little bit of the time
- None of the time

\*The National Debt Hotline help people with money problems. You can call them on 1800 007 007 or chat with them on their website.

I am satisfied with my work situation. (tick one box)

(not working, doing paid or unpaid work)

- All of the time
- Most of the time
- Some of the time
- A little bit of the time

None of the time

A2. How easy or difficult was it to complete the Disability Wellbeing Index? (tick one box)

Very easy

Easy

Neither easy nor difficult

Difficult

Very difficult

A3. If you have **any comments on the Disability Wellbeing Index**, please let us know below.

---

## Section B – Relative Importance of Wellbeing States

We are going to ask you to choose between different wellbeing states. We would like you to tell us which one you would prefer.

**Each imaginary state of wellbeing will be described using 4 randomly selected life aspects from the wellbeing questionnaire you have just completed.**

**Each life aspect will be described using one of the five levels:** ‘All of the time’, ‘Most of the time’, ‘Some of the time’, ‘A little bit of the time’, or ‘None of the time’.

Except for what has been presented, please assume that all else is the same between the two hypothetical wellbeing states.

Here is an **example** of a choice question.

In this example, the respondent thought Wellbeing State A is better and clicked the “Select” button under Wellbeing State A.

Which of the following two wellbeing states is better?  
(Please assume all else are equal)

Wellbeing State A	Wellbeing State B
<p>I am satisfied with my friendships Most of the time</p> <p>I do things in my life that are important to me Some of the time</p> <p>I learn new things as much as I want to A little bit of the time</p> <p>I have enough money to meet my needs All of the time</p> <p><b>Wellbeing State A</b></p> <p><input checked="" type="button" value="✓"/></p>	<p>I am satisfied with my friendships Some of the time</p> <p>I do things in my life that are important to me None of the time</p> <p>I learn new things as much as I want to Most of the time</p> <p>I have enough money to meet my needs Some of the time</p> <p><b>Wellbeing State B</b></p> <p><input type="button" value="Select"/></p>

**B1. Let's start with a warm-up question:**

**Which of the following two wellbeing states is better? Please tick one box below:**

(please assume all else are equal)

Wellbeing State A	Wellbeing State B
I am satisfied with my <b>friendships</b> All of the time	I am satisfied with my <b>friendships</b> None of the time
I am satisfied with my <b>living situation</b> All of the time	I am satisfied with my <b>living situation</b> None of the time
I <b>feel safe in my life</b> All of the time	I <b>feel safe in my life</b> None of the time
I have <b>enough money to meet my needs</b> All of the time	I have <b>enough money to meet my needs</b> None of the time
Wellbeing State A <input type="checkbox"/>	Wellbeing State B <input type="checkbox"/>

Now for the following 8 questions, please tell us which hypothetical wellbeing state you prefer.

This is not a test so there are no right or wrong answers.

**TASK 1. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am satisfied with the way I get along with <b>my family</b> <b>A little bit of the time</b>
I am satisfied with <b>my friendships</b> <b>None of the time</b>
I am satisfied with the way I get along with <b>people who support me</b> <b>Some of the time</b>
I do <b>things in my life that are important to me</b> <b>Some of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am satisfied with the way I get along with <b>my family</b> <b>Some of the time</b>
I am satisfied with <b>my friendships</b> <b>Most of the time</b>
I am satisfied with the way I get along with <b>people who support me</b> <b>None of the time</b>
I do <b>things in my life that are important to me</b> <b>A little bit of the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 2. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am satisfied with <b>my day-to-day activities</b> <b>Most of the time</b>
I <b>learn new things</b> as much as I want to <b>Some of the time</b>
I have <b>enough money to meet my needs</b> <b>All the time</b>
I am satisfied with <b>my work situation</b> (not working, doing paid or unpaid work) <b>None of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am satisfied with <b>my day-to-day activities</b> <b>All the time</b>
I <b>learn new things</b> as much as I want to <b>Most of the time</b>
I have <b>enough money to meet my needs</b> <b>Most of the time</b>
I am satisfied with <b>my work situation</b> (not working, doing paid or unpaid work) <b>Most of the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 3. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am satisfied with <b>my friendships</b> <b>None of the time</b>
I am satisfied with <b>my living situation</b> <b>Most of the time</b>
I am satisfied with <b>my physical health</b> <b>Some of the time</b>
I am satisfied with <b>how people treat me</b> <b>Most of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am satisfied with <b>my friendships</b> <b>All the time</b>
I am satisfied with <b>my living situation</b> <b>All the time</b>
I am satisfied with <b>my physical health</b> <b>A little bit of the time</b>
I am satisfied with <b>how people treat me</b> <b>All the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 4. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am satisfied with the way I get along with <b>people who support me</b> <b>A little bit of the time</b>
I am satisfied with <b>my living situation</b> <b>Most of the time</b>
I <b>feel safe in my life</b> <b>All the time</b>
I am satisfied with <b>my work situation</b> (not working, doing paid or unpaid work) <b>Some of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am satisfied with the way I get along with <b>people who support me</b> <b>None of the time</b>
I am satisfied with <b>my living situation</b> <b>None of the time</b>
I <b>feel safe in my life</b> <b>None of the time</b>
I am satisfied with <b>my work situation</b> (not working, doing paid or unpaid work) <b>Most of the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 5. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am satisfied with <b>my personal care</b> <b>All the time</b>
I <b>learn new things</b> as much as I want to <b>A little bit of the time</b>
I am satisfied with <b>how people treat me</b> <b>A little bit of the time</b>
I <b>feel safe in my life</b> <b>Most of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am satisfied with <b>my personal care</b> <b>None of the time</b>
I <b>learn new things</b> as much as I want to <b>All the time</b>
I am satisfied with <b>how people treat me</b> <b>Some of the time</b>
I <b>feel safe in my life</b> <b>A little bit of the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 6. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am satisfied with <b>my friendships</b> <b>A little bit of the time</b>
I do <b>things in my life that are important to me</b> <b>Some of the time</b>
I am satisfied with <b>my mental health</b> <b>All the time</b>
I <b>feel safe in my life</b> <b>Most of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am satisfied with <b>my friendships</b> <b>Some of the time</b>
I do <b>things in my life that are important to me</b> <b>All the time</b>
I am satisfied with <b>my mental health</b> <b>A little bit of the time</b>
I <b>feel safe in my life</b> <b>None of the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 7. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am satisfied with the way I get along with <b>people who support me</b> <b>None of the time</b>
I am satisfied with <b>my physical health</b> <b>Most of the time</b>
I am satisfied with <b>my mental health</b> <b>A little bit of the time</b>
I am satisfied with <b>my work situation</b> (not working, doing paid or unpaid work) <b>A little bit of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am satisfied with the way I get along with <b>people who support me</b> <b>Most of the time</b>
I am satisfied with <b>my physical health</b> <b>A little bit of the time</b>
I am satisfied with <b>my mental health</b> <b>Some of the time</b>
I am satisfied with <b>my work situation</b> (not working, doing paid or unpaid work) <b>All the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 8. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am satisfied with <b>my personal care</b> <b>A little bit of the time</b>
I am satisfied with <b>how people treat me</b> <b>Most of the time</b>
I have <b>enough money to meet my needs</b> <b>Most of the time</b>
I am satisfied with <b>my work situation</b> (not working, doing paid or unpaid work) <b>A little bit of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am satisfied with <b>my personal care</b> <b>None of the time</b>
I am satisfied with <b>how people treat me</b> <b>A little bit of the time</b>
I have <b>enough money to meet my needs</b> <b>Some of the time</b>
I am satisfied with <b>my work situation</b> (not working, doing paid or unpaid work) <b>None of the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**B10. How easy or difficult was it to complete the choice tasks? (tick one box)**

- Very easy
- Easy
- Neither easy nor difficult
- Difficult
- Very difficult

**B11. Which of these statements best describes your thoughts about the choice tasks? (tick one box)**

- I completely understand what I was supposed to do.
- I think I understood what I was asked to do.
- I did not understand what I was asked to do.

Before completing this section, we want to know how various aspects of your life contribute to your overall wellbeing.

Please rate the importance of the following 14 life aspects.

Getting along with my family (tick one box)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

My friendships (tick one box)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

Getting along with people who support me (tick one box)

(for example, support workers, allied health, counsellors)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

My personal care (tick one box)

(for example, eating, bathing, dressing, toileting, with or without the help of others)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

My day-to-day activities (tick one box)

(for example, shopping, cooking, cleaning, attending personal appointments, with or without the help of others)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

Doing things in my life that are important to me (tick one box)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

My living situation (tick one box)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

My physical health (tick one box)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

My mental health (tick one box)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

Learning new things as much as I want to (tick one box)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

How people treat me (tick one box)

- Extremely important
- Very important
- Moderately important
- Slightly important

- Not important

Feeling safe in my life (tick one box)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

Having enough money to meet my needs (tick one box)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

My work situation (tick one box)

(not working, doing paid or unpaid work)

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not important

## Section C – Information About Your Disabilities

C1. Have you had your disability since birth or before you were 5 years old? (tick one box)

- Yes **[GO TO C3]**
- No
- Unsure **[GO TO C3]**

C2. How long have you had a disability?

- Less than 5 years

- 6-10 years
- More than 10 years
- Unsure

C3. Is there someone in your household that provides care or support for you?

- Yes
- No

C4. How many hours of active daily support do you receive from paid or informal supporters?

(e.g., help and supervision to complete daily tasks like personal care, getting ready, cooking, eating, and drinking, cleaning, and doing chores)

- None
- 1 to 5 hours each day
- 6 to 11 hours each day
- 12 to 23 hours each day
- 24 hours each day
- Don't know

C5. Do you currently receive a Disability Support Pension (DSP)?

- Yes
- No but I used to
- No, I have never received a Disability Support Pension

C6. Are you currently an NDIS participant? (tick one box)

- Yes
- No, but I used to be
- No, I have never been an NDIS participant

## Section D – Personal Background

D1. Are you of Aboriginal origin, or Torres Strait Islander origin or both?

- No
- Aboriginal
- Torres Strait Islander
- Both Aboriginal and Torres Strait Islander

Prefer not to say

D2. Do you speak a language other than English at home?

No, English only

Yes

Prefer not to say

D3. What is your home postcode? \_\_\_\_\_

D4. Which of these best describes your current marital status? (tick one box)

Married/De facto

Widowed

Single (never married)

Divorced/Separated

Prefer not to answer

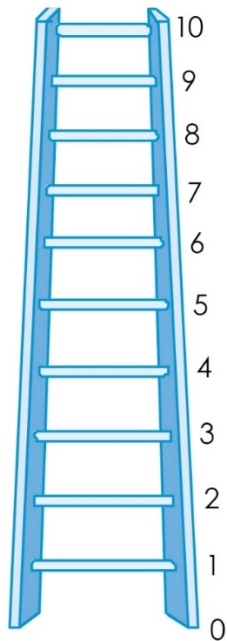
D5. Satisfaction With Life Scale

Below are five statements that you may agree or disagree with. Indicate your agreement with each item by tapping the appropriate box, from strongly agree, to strongly disagree. Please be open and honest in your response.

	Strongly agree	Agree	Slightly agree	Neither agree nor disagree	Slightly disagree	Disagree	Strongly disagree
<b>In most ways my life is close to my ideal</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>The conditions of my life are excellent</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>I am satisfied with my life</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>So far, I have gotten the important things I want in life</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>If I could live my life over, I would change almost nothing</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D6. Now, imagine a ladder with steps numbered from 0 at the bottom to 10 at the top.

Best Possible Life



Worst Possible Life

Suppose we say that the top of the ladder represents the best possible life for you and the bottom of the ladder represents the worst possible life for you.

On which step of the ladder do you feel you stand at this time? \_\_\_\_\_

D7. In general, would you say your physical health is:

- Excellent
- Very good
- Good
- Fair
- Poor

D8. In general, would you say your mental health is:

- Excellent
- Very good
- Good
- Fair
- Poor

D9. What is the highest level of education you have completed?

- Never attended school
- Year 8 or below
- Year 9 or equivalent
- Year 10 or equivalent
- Year 11 or equivalent
- Year 12 or equivalent
- Trade Certificate I-IV
- Diploma or Advanced Diploma
- Graduate Certificate or Graduate Diploma
- Bachelor degree
- Postgraduate degree (e.g., Masters, PhD)
- Other, please specify \_\_\_\_\_
- Prefer not to say

D10. What is your current employment status?

- Full-time employed
- Part-time employed
- Unemployed
- Retired/Pensioner
- Home duties/home carer
- Student
- Laid off due to the COVID-19 (coronavirus) situation
- Other, please specify \_\_\_\_\_
- Prefer not to answer

D11. This is the end of the survey. If you have any comments on the survey, please let us know:

---

**Thank you very much for taking the time to complete this survey!**

## APPENDIX 2: Disability Wellbeing Index Preference Weighting Survey – Easy English version

Q1. Who is doing this survey? Please choose one.

- I am an NDIS participant (also known the participant) and I am doing this survey by myself. **[GO TO Q2]**
- I am an NDIS participant and I am doing this survey with support. **[GO TO Q2]**
- I am doing this survey with an NDIS participant. **[GO TO Q2]**

*If you are supporting an NDIS participant to do the survey, the answers you tell us need to be what the NDIS participant would say.*

- I am doing this survey for an NDIS participant. **[GO TO Q1A]**

*If you are supporting an NDIS participant to do the survey, the answers you tell us need to be what the NDIS participant would say.*

Q1A. How do you know the NDIS participant? Please choose the best answer.

- I am the mother or father of the participant.
- I am the brother or sister of the participant.
- I am a child of the participant.
- I am a family member of the participant.
- I am a friend of the participant.
- I am a support worker of the participant.
- I am someone else.

Q1B. What is your gender?

- Female
- Male
- My gender is \_\_\_\_\_
- I do not want to say

If you have any difficulty while answering the questions, please contact us. You can send an email to [dwi@monash.edu](mailto:dwi@monash.edu) or contact Dr Gang Chen at 0425 811 029 or Dr Gozde Aydin at 03 9903 4363.

Q2. How old are you? \_\_\_\_\_ (years)

Q3. What is your sex?

- Male
- Female
- My gender is \_\_\_\_\_
- I do not want to say

Q4. Where in Australia do you live?

- Australian Capital Territory (ACT)
- New South Wales (NSW)
- Northern Territory (NT)
- Queensland (Qld)
- South Australia (SA)
- Tasmania (Tas)
- Victoria (Vic)
- Western Australia (WA)

Q5. Is it hard for you to do any of these things because of a health problem you have had or will have for a long time or a disability:

### **Daily Living Activities**

These are things you do every day, like:

- washing, dressing
- walking,
- holding or lifting things
- speaking or using communication devices

- Yes
- No

### **Activities of independent living**

These are things you do for yourself, like:

- shopping, cooking
- care for others
- make decisions, deal with stress
- learn things, fix problems
- have relationships with people

- Yes
- No

### Activities of work, school and being in the community

These are things like:

- Going out with friends or family
- Work, school, or training

- Yes
- No

Q6. Can you tell us about your disability?

Please tick the boxes that tells us about your disability, you can tick more than one box.

- Sensory** like not being able to see or hear well
- Intellectual** like it being hard to learn or do everyday things
- Physical** like it being hard to breathe, always being in a lot of pain, falling over, having seizures, or not being able to use one or more of your arms or legs
- Psychosocial** like being worried or sad all the time, it being hard to make friends or needing support with your behaviour
- Head injury, stroke or acquired brain injury (ABI)**
- Autism**
- Other (please tell us)**

## Section A – Subjective Wellbeing

These questions are about feeling safe.

If the questions make you feel worried or sad, you can call Lifeline to talk to someone. You can call any time. Phone: 13 11 14

National Relay Service (NRS): Chat Call link (<https://nrschat.nrscall.gov.au/nrs/internetrelay>), then ask for 13 11 14

### A1. Disability Wellbeing Index (DWI)

Tell us how you feel about your life now. There are no right or wrong answers.

I am happy with the way I get along with my family.

- Always
- Most of the time
- Sometimes
- A little bit
- Never
- The things in this question are not part of my life

I am happy with my friendships.

- Always
- Most of the time
- Sometimes
- A little bit
- Never
- The things in this question are not part of my life

I am happy with the way I get along with people who support me. These could be people like support workers, doctors, Occupational Therapists, counsellors.

- Always
- Most of the time
- Sometimes
- A little bit
- Never
- The things in this question are not part of my life

I am happy with my personal care, like eating, showering, dressing, or going to the toilet. This could be with or without other people helping me.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

I am happy with the things I do, like shopping, cooking, cleaning, or going to appointments. This could be with or without other people helping me.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

I do things in my life that are important to me.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

I am happy with where I live and who I live with.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

Physical health is about how healthy my body is.

I am happy with my physical health.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

Mental health is about what you think and how you feel, like happy or sad.

I am happy with my mental health.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

If the questions make you feel worried, you can call Lifeline and speak to someone.

You can call any time.

Phone: 13 11 14

Text: 0477 13 11 14

On the computer use the National Relay Service link:

(<https://nrschat.nrsconnect.gov.au/nrs/internetrelay>) and then ask for 13 11 14

I learn new things as much as I want to.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

I am happy with how people talk to and treat me.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

I feel safe in my life.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

If you do not feel safe or if you are in danger call 000

You can also call:

1800RESPECT - 1800 737 732 to talk to someone if you have been abused or have seen it happen to someone else.

You can use the National Relay Service on 1800 555 677 and give the number 1800 737 732.

The National Disability Abuse and Neglect Hotline to tell someone a person with a disability is being abused or neglected. Phone: 1800 880 052.

Beyond Blue if you need support with your mental health and wellbeing. Phone: 1300 224 636

[www.beyondblue.org.au](http://www.beyondblue.org.au)

I have enough money to pay for things I need.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

The National Debt Hotline can help people who have problems with money.

Phone: 1800 007 007

Website: (add in web address)

I am happy with what I do for work.

This could be not working, doing work you get paid for, or doing work that you are not paid for, like volunteering.

- Always
- Most of the time
- Sometimes
- A little bit
- Never

A2. How easy or hard was it to do this survey?

- Very easy
- Easy
- Not easy or hard
- Hard
- Very hard

A3. If there is anything you want to say about **the Disability Wellbeing Index**, please tell us here:

---

## Section B – Relative Importance of Wellbeing States

We are going to show you some examples of wellbeing. We are calling these Wellbeing States. We want you to tell us which one you would choose.

**The survey you just did had questions about different parts of your life.**

**We call these different parts life areas.**

**Each of the life areas have a value but are not all the same. Value means how important something is.**

Values for each life areas:

- Always
- Most of the time
- Sometimes
- A little bit
- Never

Each wellbeing state will be from 4 life areas. They have been picked by chance.

For each question, please tell us which state you think is best.

Here is an example of questions we will ask you.

When you choose the Wellbeing State that you think is better, tick the box at the bottom.

In this example the person thinks Wellbeing State A is better.

Wellbeing State A	Wellbeing State B
<p>I am happy with my <b>friendships</b> <b>Most of the time</b></p> <p>I <b>do things in my life that are important to me</b> <b>Sometimes</b></p> <p>I <b>learn new things</b> as much as I want to <b>A little bit</b></p> <p>I have <b>enough money to pay for things I need</b> <b>Always</b></p> <p style="text-align: center;"><b>Wellbeing State A</b> <input checked="" type="checkbox"/></p>	<p>I am happy with my <b>friendships</b> <b>Sometimes</b></p> <p>I <b>do things in my life that are important to me</b> <b>Never</b></p> <p>I <b>learn new things</b> as much as I want to <b>Most of the time</b></p> <p>I have <b>enough money to pay for things I need</b> <b>Sometimes</b></p> <p style="text-align: center;"><b>Wellbeing State B</b> <input type="checkbox"/></p>

**B1. Let's try this question:**

**Which of the following two wellbeing states is better? Please tick one box below:**

(please assume all else are equal)

Wellbeing State A	Wellbeing State B
I am happy with my <b>friendships</b> <b>Always</b>	I am happy with my <b>friendships</b> <b>Never</b>
I am happy with <b>where I live and who I live with</b> <b>Always</b>	I am happy with <b>where I live and who I live with</b> <b>Never</b>
I <b>feel safe in my life</b> <b>Always</b>	I <b>feel safe in my life</b> <b>Never</b>
I have <b>enough money to pay for things I need</b> <b>Always</b>	I have <b>enough money to pay for things I need</b> <b>Never</b>
Wellbeing State A <input type="checkbox"/>	Wellbeing State B <input type="checkbox"/>

For the next 8 questions, please choose the wellbeing state you think is better.

There are no right or wrong answers.

**TASK 1. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am happy with the way I get along with <b>my family</b> <b>A little bit</b>
I am happy with <b>my friendships</b> <b>Never</b>
I am happy with the way I get along <b>with people who support me</b> <b>Sometimes</b>
I do <b>things in my life that are important to me</b> <b>Sometimes</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am happy with the way I get along with <b>my family</b> <b>Sometimes</b>
I am happy with <b>my friendships</b> <b>Most of the time</b>
I am happy with the way I get along <b>with people who support me</b> <b>Never</b>
I do <b>things in my life that are important to me</b> <b>A little bit</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 2. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am happy with <b>the things I do during the day</b> (for example, shopping, cooking, cleaning, or going to appointments) <b>Most of the time</b>
I <b>learn new things</b> as much as I want to <b>Sometimes</b>
I have <b>enough money to pay for things I need</b> <b>Always</b>
I am happy with <b>what I do for work</b> (This could be not working, doing work you get paid for, or doing work that you are not paid for) <b>Never</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am happy with <b>the things I do during the day</b> (for example, shopping, cooking, cleaning, or going to appointments) <b>All the time</b>
I <b>learn new things</b> as much as I want to <b>Most of the time</b>
I have <b>enough money to pay for things I need</b> <b>Most of the time</b>
I am happy with <b>what I do for work</b> (This could be not working, doing work you get paid for, or doing work that you are not paid for) <b>Most of the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 3. Which of the following two wellbeing states is better? Please tick one box below:**

Wellbeing State A
I am happy with <b>my friendships</b> <b>Never</b>
I am happy with <b>where I live and who I live with</b> <b>Most of the time</b>
I am happy with <b>my physical health</b> (how healthy my body is) <b>Sometimes</b>
I am happy with <b>how people talk to and treat me</b> <b>Most of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

Wellbeing State B
I am happy with <b>my friendships</b> <b>All the time</b>
I am happy with <b>where I live and who I live with</b> <b>All the time</b>
I am happy with <b>my physical health</b> (how healthy my body is) <b>A little bit</b>
I am happy with <b>how people talk to and treat me</b> <b>All the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 4. Which of the following two wellbeing states is better? Please tick one box below:**

Wellbeing State A
I am happy with the way I get along <b>with people who support me</b> <b>A little bit</b>
I am happy with <b>where I live and who I live with</b> <b>Most of the time</b>
I <b>feel safe in my life</b> <b>Always</b>
I am happy with <b>what I do for work</b> (This could be not working, doing work you get paid for, or doing work that you are not paid for) <b>Sometimes</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

Wellbeing State B
I am happy with the way I get along <b>with people who support me</b> <b>Never</b>
I am happy with <b>where I live and who I live with</b> <b>Never</b>
I <b>feel safe in my life</b> <b>Never</b>
I am happy with <b>what I do for work</b> (This could be not working, doing work you get paid for, or doing work that you are not paid for) <b>Most of the time</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 5. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am happy with <b>my personal care</b> (for example, eating, showering, dressing, or going to the toilet) <b>Always</b>
I <b>learn new things</b> as much as I want to <b>A little bit</b>
I am happy with <b>how people talk to and treat me</b> <b>A little bit</b>
I <b>feel safe in my life</b> <b>Most of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am happy with <b>my personal care</b> (for example, eating, showering, dressing, or going to the toilet) <b>Never</b>
I <b>learn new things</b> as much as I want to <b>Always</b>
I am happy with <b>how people talk to and treat me</b> <b>Sometimes</b>
I <b>feel safe in my life</b> <b>A little bit</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 6. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am happy with <b>my friendships</b> <b>A little bit</b>
I do <b>things in my life that are important to me</b> <b>Sometimes</b>
I am happy with <b>my mental health</b> (what I think and how I feel, like happy or sad) <b>Always</b>
I <b>feel safe in my life</b> <b>Most of the time</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am happy with <b>my friendships</b> <b>Sometimes</b>
I do <b>things in my life that are important to me</b> <b>Always</b>
I am happy with <b>my mental health</b> (what I think and how I feel, like happy or sad) <b>A little bit</b>
I <b>feel safe in my life</b> <b>Never</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 7. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am happy with the way I get along <b>with people who support me</b> <b>Never</b>
I am happy with <b>my physical health</b> (how healthy my body is) <b>Most of the time</b>
I am happy with <b>my mental health</b> (what I think and how I feel, like happy or sad) <b>A little bit</b>
I am happy with <b>what I do for work</b> (This could be not working, doing work you get paid for, or doing work that you are not paid for) <b>A little bit</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am happy with the way I get along <b>with people who support me</b> <b>Most of the time</b>
I am happy with <b>my physical health</b> (how healthy my body is) <b>A little bit</b>
I am happy with <b>my mental health</b> (what I think and how I feel, like happy or sad) <b>Sometimes</b>
I am happy with <b>what I do for work</b> (This could be not working, doing work you get paid for, or doing work that you are not paid for) <b>Always</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**TASK 8. Which of the following two wellbeing states is better? Please tick one box below:**

<b>Wellbeing State A</b>
I am happy with <b>my personal care</b> (for example, eating, showering, dressing, or going to the toilet) <b>A little bit</b>
I am happy with <b>how people talk to and treat me</b> <b>Most of the time</b>
I have <b>enough money to pay for things I need</b> <b>Most of the time</b>
I am happy with <b>what I do for work</b> (This could be not working, doing work you get paid for, or doing work that you are not paid for) <b>A little bit</b>
<b>Wellbeing State A</b> <input type="checkbox"/>

<b>Wellbeing State B</b>
I am happy with <b>my personal care</b> (for example, eating, showering, dressing, or going to the toilet) <b>Never</b>
I am happy with <b>how people talk to and treat me</b> <b>A little bit</b>
I have <b>enough money to pay for things I need</b> <b>Sometimes</b>
I am happy with <b>what I do for work</b> (This could be not working, doing work you get paid for, or doing work that you are not paid for) <b>Never</b>
<b>Wellbeing State B</b> <input type="checkbox"/>

**B10. How easy or hard was it to answer the questions?**

- Very easy
- Easy
- Not easy or hard
- Hard
- Very hard

**B11. What do you think about the questions?**

- I know what I was doing.
- I think I know what I was doing.
- I did not know what I was doing.

**We want to know what other things help you to feel good about yourself and your life.**

We want to know how important things are to you. Please choose one answer for each of these questions.

Getting along with my family.

- The most important
- Very important
- Important
- A little bit important
- Not important

My friendships.

- The most important
- Very important
- Important
- A little bit important
- Not important

Getting along with people who support me.

These could be people like support workers, doctors, Occupational Therapists, counsellors.

- The most important
- Very important
- Important
- A little bit important
- Not important

My personal care.

This could be things like, eating, showering, dressing, or going to the toilet. This could be with or without other people helping me.

- The most important
- Very important
- Important
- A little bit important
- Not important

The things I do during the day.

These could be things like shopping, cooking, cleaning, or going to appointments. This could be with or without other people helping me.

- The most important
- Very important
- Important
- A little bit important
- Not important

Doing things in my life that are important to me.

- The most important
- Very important
- Important
- A little bit important
- Not important

Where I live and who I live with.

- The most important
- Very important
- Important
- A little bit important
- Not important

My physical health – how healthy my body is.

- The most important
- Very important
- Important
- A little bit important
- Not important

My mental health - what I think and how I feel, like happy or sad.

- The most important
- Very important
- Important
- A little bit important
- Not important

Learning new things as much as I want to.

- The most important
- Very important
- Important
- A little bit important
- Not important

How people talk to and treat me.

- The most important
- Very important
- Important
- A little bit important
- Not important

Feeling safe in my life.

- The most important
- Very important
- Important
- A little bit important
- Not important

Having enough money to pay for the things I need.

- The most important
- Very important
- Important
- A little bit important

- Not important

What I do for work.

This could be working or not working, doing paid or unpaid work.

- The most important
- Very important
- Important
- A little bit important
- Not important

## Section C – Information About Your Disabilities

C1. Did you have a disability when you were born or before you were 5 years old?

- Yes **[GO TO C3]**
- No
- I do not know **[GO TO C3]**

C2. How long have you had a disability?

- Less than 5 years
- 6-10 years
- More than 10 years
- I do not know

C3. Do you get care and support from someone you live with?

- Yes
- No

C4. Active daily support is help to do things every day like personal care, getting dressed, cooking, eating, drinking and cleaning

How many hours of active daily support do you get from support workers or other people?

- None
- 1 to 5 hours each day
- 6 to 11 hours each day
- 12 to 23 hours each day
- 24 hours each day

I do not know

C5. Do you get the Disability Support Pension (DSP)?

- Yes
- No but I used to
- No, I have never got the Disability Support Pension

C6. Are you currently an NDIS participant? (tick one box)

- Yes
- No, but I used to be
- No, I have never been an NDIS participant

## Section D – Your Background

D1. Are you Aboriginal or Torres Strait Islander or both?

- No
- Aboriginal
- Torres Strait Islander
- Both Aboriginal and Torres Strait Islander
- I do not want to say

D2. Do you speak a language other than English at home?

- No, English only
- Yes
- I do not want to say

D3. What is the postcode where you live? \_\_\_\_\_

D4. Are you

- Married or living with your partner
- Widowed (my partner died)
- Single (never married)
- Divorced/Separated
- I do not want to say

D5. How Happy are You With Your Life Scale

In the box below we have written 5 things that you might agree or disagree with.

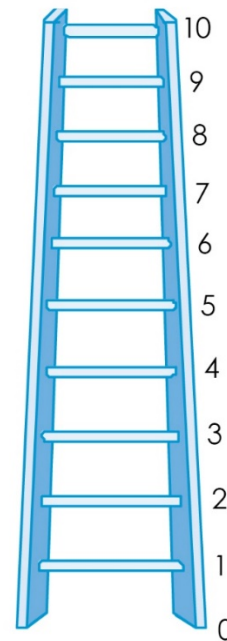
Tell us how much you agree or disagree by clicking on your answer.

	Agree a lot	Agree	Agree a little bit	Do not agree or disagree	Disagree a little	Disagree	Disagree a lot
<b>My life is the best it could be</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>My life is really good</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>I am happy with my life</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>I have the important things I want in life</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>If I could live my life again, I would not change anything</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D6. Look at the picture of a ladder.

If 10 is the best life you could have and 0 is the worst life you could have, which number on the ladder are you? \_\_\_\_\_

Best Possible Life



Worst Possible Life

D7. Physical health is how healthy your body is.

Is your physical health:

- Excellent
- Very good
- Good
- Okay
- Not very good

D8 Mental health is about what you think and how you feel, like happy or sad.

Is your mental health:

- Excellent
- Very good
- Good
- Okay
- Not very good

D9. When did you stop going to school?

- I didn't go to school
- Before year 8
- Year 8
- Year 9
- Year 10
- Year 11
- Year 12
- Trade Certificate I-IV
- Diploma or Advanced Diploma
- Graduate Certificate or Graduate Diploma
- Bachelor degree
- Postgraduate degree (e.g., Masters, PhD)
- Other, please tell us \_\_\_\_\_
- I do not want to say

D10. What kind of work do you do?

- Full-time
- Part-time
- I don't work
- Retired/Pensioner
- I look after my home
- I go to school
- I lost my job because of COVID-19 (coronavirus)
- Other, please tell us \_\_\_\_\_
- I do not want to say

**Thank you very much for doing this survey!**

D11. This is the end of the survey.

If you want to say anything about the survey, please tell us:

---

## APPENDIX 3: Guidelines for Support Time with Auslan Users

### Checklist for support time to complete DWI survey

To meet the diverse needs of NDIS participants, survey respondents can request a member of the research team support them to complete the online survey in a zoom meeting or telephone call. Whilst some Auslan users will be comfortable completing the standard version of the survey in English, others may prefer to complete the survey using Auslan. The aim of this support time is to give the person an opportunity to understand and respond to survey items using Auslan. Both the person using Auslan as well as the interpreter may also require clarification of the meanings of certain items.

It is recommended to use the **Easy English version** during support time with Auslan users. Make sure to arrange time with the interpreter prior to the support time with the survey respondent, to ensure they understand the purpose of the survey and are familiarised with the specific tasks, particularly the DCE.

There will likely be a need to adjust the way certain survey items are delivered to accommodate the unique nature of Auslan. Auslan often relies on specific examples, rather than general concepts. Interpreters generally provide examples to make an extremely general concept a narrower one that the person can focus on, and then assist the person to think more generally about the concept by asking for an overall rating of their feelings for that life area. There is no need to be concerned that Auslan users will focus too much on a narrow context; this simply reflects how Auslan works and is a mechanism required to help Auslan users properly conceptualise the underlying concepts.

- For example, for the item “I am satisfied with my living situation”, an interpreter may want to add, “For example, I am content with where I live, I like who I live with. Overall, how satisfied are you with your living situation?”
- For the item “I feel safe in my life”, the interpreter may want to add, “For example, I feel safe when I am out in the community by myself, I feel safe when I am at home. Overall, how safe do you feel in your life?”

<b>WHEN ARRANGING SUPPORT TIME TO COMPLETE SURVEY</b>	
Email/text the person to identify if they have a preferred interpreter, and ask for their contact details if possible. Ask them to let you know when they are available for a zoom interview to complete the survey, providing several convenient times if possible.	
Once you have received the person’s reply, contact their preferred Auslan interpreter and make a booking for Auslan interpreting. If the person does not suggest any particular interpreter, contact one of the following interpreters:  <b>Deaf Connect</b> <a href="mailto:interpreting@deafconnect.org.au">interpreting@deafconnect.org.au</a> , cc: <a href="mailto:info@deafaustralia.org.au">info@deafaustralia.org.au</a> Or book online at: <a href="https://bookings.deafconnect.org.au/#/authenticate/logout">https://bookings.deafconnect.org.au/#/authenticate/logout</a> <b>Sweeney Interpreting</b> 0427 755 753 <a href="mailto:bookings@sweeneyinterpreting.com.au">bookings@sweeneyinterpreting.com.au</a>	
Ensure that the interpreter is booked in for 10-15 min prior to the support time. This allows time to speak individually with the interpreter and prepare them for the survey.	

Send zoom invite to the participant and Auslan interpreter.	
---	--

<b>BEFORE SUPPORT TIME TO COMPLETE SURVEY</b>	
<p>Have on hand the National Crisis Numbers handout. This includes national helplines and crisis numbers for each state. In particular, note:</p> <ul style="list-style-type: none"> <li>• Lifeline (131114)</li> <li>• Beyond Blue 24/7 line (1300 224 636)</li> </ul> <p>Make sure you have on hand the person’s phone number or email address.</p>	
<p>During 1:1 time with the Auslan interpreter, help familiarize them with the survey:</p> <ul style="list-style-type: none"> <li>• Using the share screen function in zoom, display the PDF file that displays the various screenshots of the survey.</li> <li>• As you move through the document, explain the overall purpose of the survey, including the purpose of the DWI as well as the DCE items.</li> <li>• Let the interpreter know that there may be times where we need to adjust the way items are interpreted so that we can accurately convey the intended meanings. Encourage them to let you know if at any time through the survey they notice this.</li> <li>• When explaining the DCE items, point out that they use the same life area statements that have just been presented in the previous section. However, in this section, they are presented differently and require the respondent to choose which set of conditions they prefer. Highlight that an example choice question is given, followed by a “warm-up” question and a set of 8 items.</li> <li>• Let the interpreter know that we will watch out for any signs of fatigue or distress in the respondent, and that we will suggest the person takes a break if necessary. Encourage the interpreter to let you know if they see any signs that the respondent might need a break. It might be helpful to suggest that the person takes a break once they have completed the DCE questions.</li> </ul>	

<b>DURING SUPPORT TIME TO COMPLETE SURVEY</b>	
<p>Explain to the person that you are there only to support them to complete the survey. Tell the participant:</p> <p><i>“If you feel you need to stop and take a break at any time, just let me know. As you go through the survey, if there is a question you don’t understand, let me know. I will explain it. If there is a question you don’t want to answer, please just move on to the next question.”</i></p> <p>Use the share screen function in zoom so that the interpreter and survey respondent can see the survey, as well as the other participants attending the zoom meeting.</p>	
<p>Be alert for signs of fatigue. It might be helpful to suggest that the person takes a break once they have completed the DCE questions.</p>	
<p>Be alert for signs of discomfort and follow the distress protocol:</p> <ul style="list-style-type: none"> <li>• If the person appears to become uncomfortable, ask: <i>“Are you OK? Would you like to take a short break now?”</i></li> </ul>	

<ul style="list-style-type: none"> <li>• Wait for response. If they remain upset and don't respond, a useful approach is to say: <i>"I am happy to wait a few minutes if that would help."</i></li> <li>• If the person is still distressed and there is no change for the better, a helpful approach is to say: <i>"Would you like to move on to the next question?"</i> If yes, continue onto the next question.</li> <li>• If the person does not want to, or is unable to continue to the next question, say: <i>"I think perhaps it might be best to stop the survey, and that's fine with me."</i></li> <li>• If the person begins to display marked distress or continues to be distressed as above and seemingly unlikely to continue, then: <ul style="list-style-type: none"> <li>a. Ensure they have appropriate strategies in place to deal with the distress. For example, ask: <i>"Is there someone you can talk to now?"</i></li> <li>b. If you feel concerned that the person is still not really listening or is too distressed, ask them: <i>"Would you like me to call someone for you, perhaps a friend, or family member of support workers?"</i></li> <li>c. Provide the person with the numbers for Lifeline or Beyond Blue if necessary.</li> <li>d. Reassure the person that it is OK to finish the session. Let them know you will check in with them later. Say: <i>"It's fine to finish now. I would like to call in around 30 minutes however, just to check you are OK."</i></li> </ul> </li> </ul> <p>Let the person know that you will check in with them later at a time that suits them.</p>	
--	--

<b>AFTER SUPPORT TIME</b>	
<p>If arranged during the support time, contact the person as agreed.</p> <p>Ask them how they are feeling and whether their distress has resolved. Say: <i>"How are you going? I am just checking in. Are you OK?"</i></p> <p>If there is a clear unmet need for support, encourage the person to contact a counselling service, such as Lifeline or Beyond Blue. Provide these numbers again, if necessary.</p> <p>If the person wishes to continue the survey, offer to complete it with them at a mutually convenient time.</p>	

## APPENDIX 4: Guidelines for Dealing With Participant Distress

### Checklist for support time to complete DWI survey

To meet the diverse needs of NDIS participants, survey respondents can request a member of the research team support them to complete the online survey in a zoom meeting or telephone call. The aim of this support time is to provide only as much assistance as the respondent requires, for example, by reading questions out aloud, providing clarification as necessary, whilst staying in the background as much as possible.

We know that certain items may be triggering for some people. Some may also become fatigued by the length of the survey. By providing support time with a researcher, we aim to minimise any potential negative impact of the research on the respondent. If a respondent does become distressed, our role is to offer support at the time as well as connect the person with external sources of ongoing support. This means the researcher needs to watch out for signs of fatigue or distress in the respondent throughout the support time and respond sensitively by offering helpful suggestions to manage this.

<b>BEFORE SUPPORT TIME TO COMPLETE SURVEY</b>	
<p>Have on hand the National Crisis Numbers handout. This includes national helplines and crisis numbers for each state. In particular, note:</p> <ul style="list-style-type: none"> <li>• Lifeline (1311114)</li> <li>• Beyond Blue 24/7 line (1300 224 636)</li> </ul> <p>Make sure you have on hand the person's phone number or email address.</p>	

<b>DURING SUPPORT TIME TO COMPLETE SURVEY</b>	
<p>Explain to the person that you are there only to support them to complete the survey.</p> <p>Tell the participant:  <i>"If you feel you need to stop and take a break at any time, just let me know. As you go through the survey, if there is a question you don't understand, let me know. I will explain it. If there is a question you don't want to answer, please just move on to the next question."</i></p>	
<p>Be alert for signs of fatigue. It might be helpful to suggest that the person takes a break once they have completed the DCE questions.</p>	
<p>Be alert for signs of discomfort and follow the distress protocol:</p> <ul style="list-style-type: none"> <li>• If the person appears to become uncomfortable, ask:  <i>"Are you OK? Would you like to take a short break now?"</i></li> <li>• Wait for response. If they remain upset and don't respond, a useful approach is to say: <i>"I am happy to wait a few minutes if that would help."</i></li> </ul>	

<ul style="list-style-type: none"> <li>• If the person is still distressed and there is no change for the better, a helpful approach is to say: <i>“Would you like to move on to the next question?”</i> If yes, continue onto the next question.</li> <li>• If the person does not want to, or is unable to continue to the next question, say: <i>“I think perhaps it might be best to stop the survey, and that’s fine with me.”</i></li> <li>• If the person begins to display marked distress or continues to be distressed as above and seemingly unlikely to continue then: <ul style="list-style-type: none"> <li>e. Ensure they have appropriate strategies in place to deal with the distress. For example, ask <i>“Is there someone you can talk to now?”</i></li> <li>f. If you feel concerned that the person is still not really listening or is too distressed, ask them: <i>“Would you like me to call someone for you, perhaps a friend, or family member of support workers?”</i></li> <li>g. Provide the person with the numbers for Lifeline or Beyond Blue if necessary;</li> <li>h. Reassure the person that it is OK to finish the session. Let them know you will check in with them later. Say: <i>“It’s fine to finish now. I would like to call in around 30 minutes however, just to check you are OK.”</i></li> <li>i. Let the person know that you will check in with them later at a time that suits them.</li> </ul> </li> </ul>	
--	--

<b>AFTER SUPPORT TIME</b>	
<p>If arranged during the support time, contact the person as agreed.</p> <p>Ask them how they are feeling and whether their distress has resolved. Say: <i>“How are you going? I am just checking in. Are you OK?”</i></p> <p>If there is a clear unmet need for support, encourage the person to contact a counselling service, such as Lifeline or Beyond Blue. Provide these numbers again, if necessary.</p> <p>If the person wishes to continue the survey, offer to complete it with them at a mutually convenient time.</p>	

## APPENDIX 5: Frequently Asked Questions

<b>QUESTIONS ABOUT THE PURPOSE OF THE STUDY</b>	
<i>*Many of these questions will be covered in the explanatory statement</i>	
<b>What is the purpose of this study?</b>	<p>We want to develop a new instrument to measure the wellbeing of people with disability. This instrument is called the Disability Wellbeing Index. The DWI will give us a way to measure whether services, such as those provided through the NDIS, are making a difference in the lives of people with disability.</p> <p>In this survey, you will help us understand more about which life areas are more important to the wellbeing of people with a disability, and which areas are less important.</p>
<b>Will this affect my NDIS package?</b>	No, completing the survey will not affect your NDIS plan, your Disability Support Pension or any other services you use. Your individual responses to the survey will not be provided to the NDIA, or to any other organisation.
<b>Why does NDIS want to assess our wellbeing?</b>  <b>How will NDIS participants benefit by having this DWI?</b>	The DWI will give us a way of measuring whether services, such as those provided through the NDIS, have helped you to achieve wellbeing. The disability wellbeing index will be used repeatedly over several years to see how your wellbeing is going.
<b>How is research data, including my personal details, stored?</b>	<p>All the information you provide will remain confidential and be seen only by the researchers involved. Your individual responses will not be provided to the NDIA, or to any other organisation, and they will not know whether or not you have completed the survey. Only anonymous, de-identified data will be made available to NDIS.</p> <p>Your personal details and answers to the survey will be stored securely on the servers at Monash University. Your personal details will only be stored for the study period. Once the research is complete, it will be permanently deleted.</p>

<b>QUESTIONS ABOUT WELLBEING QUESTIONS</b>	
<b>What if my current wellbeing is not typical? My answers right now might not reflect my regular wellbeing.</b>	In this wellbeing index we are asking you to think about your wellbeing right now.
<b>Questions about the specific scope or meaning of items [e.g., What does “living situation” mean?]</b>	This question can mean different things to different people, such as <i>[how happy you are with where you live, or who you live with]</i> . In this question, we are asking you to think overall how satisfied you are with <i>[life area]</i> .
<b>What is a discrete choice experiment?</b>	<p>In this section, we use an approach known as a Discrete Choice Experiment (DCE) to find out your preferences for different states of wellbeing.</p> <p>The survey you just did had questions about different parts of your life. In this section, we will show you two different examples or states of wellbeing. Each example will have 4 life aspects.</p> <p>We want you to tell us which one you would choose. There are no right or wrong answers and this is not a test. We are only interested in your opinion about which state you would choose. This might not be a perfect state for you. Just choose which one you think is better than the other.</p>
<b>Why are we asking you these DCE questions?</b>	<p>The survey you just did had questions about 14 different aspects of your life. We want to know which of these life areas are more important to people with a disability, and which areas are less important.</p> <p>We ask a great many people with a disability to choose between different situations, or states of wellbeing. This way we can work out the relative importance of each statement in determining overall wellbeing. For example, what weight should be assigned to “being satisfied with your friendships” <i>relative to</i> “learning new things as much as you want to”.</p> <p>Remember making these choices is an imaginary exercise only. There are no right or wrong answers, and this is not a test. We are only interested in which of the two wellbeing states in each question you think is better than the other.</p>

<b>QUESTIONS ABOUT DEMOGRAPHIC AND DISABILITY QUESTIONS</b>	
<b>Why do you need to ask about my age, postcode, and other personal details?</b>	This information will help us understand if people with different backgrounds have different preferences about wellbeing.
<b>“How long have you had a disability?” What does this mean?</b>	This question does not want you to say when you were first diagnosed; it is asking you how long you have had difficulty doing daily activities, activities of independent living, or activities of work, education and community life, due to a health problem or disability.