THE UNIVERSITY OF SYDNEY

Centre for Disability Research and Policy
Faculty of Medicine and Health

Disability Wellbeing Index (DWI)

Analysis of Qualitative Components with Adult and Young People with Disability

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 first of four reports documenting the contribution of the team at the Centre for Disability Research and Policy. This report was submitted to Monash University on November 18, 2022. It describes the results of a qualitative analysis of focus groups and interviews conducted in 2022 with adults and young people with disability to explore their perspectives on initial versions of the DWI and issues of concern to be addressed in the implementation of the DWI. The findings from this study informed the refinement of DWI domains, items, and descriptors, and helped to identify wider issues that needed to be further explored, including safety considerations such as the context within which people complete the DWI and the accessibility of the DWI.

Recommended Citation: West, R., Bulkeley, K., Llewellyn G., Cooper, E., & Plunkett, K. (2025). *Disability Wellbeing Index (DWI): Analysis of Qualitative Components with Adult and Young People with Disability*. Centre for Disability Research and Policy, University of Sydney. https://doi.org/10.25910/svch-nj48

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ACKNOWLEDGEMENTS

We would like to extend our thanks and gratitude to all the organisations and individuals that chose to participate in this research. We acknowledge their unique lived experience, including use of service systems, and knowledge of debates and tensions in living as a person with a disability in community. We would also like to recognise the contributions of the wider research team and the NSW/ACT CP Register. We hope that all contributions will work towards improving the specific understanding of what wellbeing means for people with disability and that this knowledge works towards empowering the lives of people with disability more broadly.

EXECUTIVE SUMMARY

This research piece, which is part of a three-year project to design and test a wellbeing instrument that captures factors that impact on the wellbeing of people with disability, aimed to canvass views and perspectives of adults and youth (15-25 years) with disability on drafts of a Disability Wellbeing Index (DWI). The overall purpose was to explore the perceptions and understanding of people with disability to the draft statements in the DWI, and most importantly, ensure that the statements in the DWI were *relevant* and had *specific meaning* to the lives of people with disability. The research also explored various elements of the DWI such as the language and descriptors used, length of the DWI and accessibility issues. In addition, participant reactions to the concept of a DWI being widely available for measuring wellbeing at a point in time and over time were considered. Some factors are likely to be distinct to people with disability, and others may be in common with everyone in the population.

The early draft of the DWI for adults was designed by the Monash University (Monash) research team in consultation with the rest of the research team from University of Sydney (Sydney) and Flinders University (Flinders). It was based on elements of existing wellbeing indices gathered by an international review including quality of life, life satisfaction and wellbeing indexes for the population and which although not specifically designed for people with disability had been used for this purpose.

The role of the team based at the Centre for Disability Research and Policy (CDRP) at Sydney was to provide a specific ‘disability lens’ to developing the initial version of the DWI using qualitative methods with people with disability. This was achieved in two ways: (i) by speaking directly with people who identified as having a disability via small focus groups and one-on-one interviews; and (ii) by adopting disability inclusive research approaches that meant 4 of the 7 members of the research team were people with disability with extensive lived experience of disability, experience of services and knowledge of key debates and tensions of concern to the disability community. Our disability inclusive approaches recognised the importance of contributions from both researchers and participants who identified as living with disability acknowledging that unique knowledge would be obtained in this way.

In terms of data collection, we prioritised providing supports to potential research participants in a welcoming and accessible way to ensure they could fully contribute to the research. We provided various forms of access supports such as captioning, interpreters, costs for support workers to attend focus groups/ interviews and pre-meeting correspondence to ensure informed understanding of

participation. As such, we were able to be obtain unique insights from a diverse group of people with disability in terms of age, life experience, type of disability and living situation within our focus groups and interview discussions.

A total of 80 participants from two main cohorts provided their perspectives on versions of the DWI. This included 51 adults and 29 young people aged 15 to 25 years with disability. Data collection was undertaken over a 3-month period between June and August 2022.

The Sydney team undertook an intensive and inductive qualitative research approach. Multiple meetings were held by the research team after receiving the initial draft of the DWI where we identified and debated immediate concerns with the DWI that included: the complexity of the index, participant safety-lack of safety in completing the index, issues with proxies, and if understanding of the lived experience of barriers and discrimination was captured. We also expressed immediate concern with how the DWI might be used, and that if the DWI was only to be used for NDIS purposes, whether the DWI could be perceived as a mechanism to potentially cut plans. The Sydney team's immediate concerns were fully discussed over several team meetings with the Monash and Flinders team. This resulted in changes to some of the DWI headings, the items within these headings and formatting resulting in Version 1 DWI Adult, which was presented to the adult cohort.

Following thematic analysis of the adult cohort data, a further tranche of inductive analysis was undertaken firstly by the Sydney team and subsequently with the Monash and Flinders team. This was driven by the need to have easy to understand statements with a measurable outcome without losing the explicit disability lived experience narrative of each participant in the adult cohort data. This process resulted in a modified, revised and refined DWI Adult. It also resulted in a quite different (from Version 1 DWI Adult) form, the DWI-Young People (DWI (YP)) which was then presented in focus groups to the young people participant cohort.

Following data collection and analysis from the young people cohort, further thematic analysis of the two sets of data from the two cohorts was undertaken, in several iterations and by whole team discussion. This led to further refinement and some rearrangement of statements and some simplified (plain language) headings. A penultimate version of the DWI Adult was presented in mid-October 2022 to the NDIA for review.

Research team process

Extensive, granular levels of debate and discussion were undertaken across the research teams bringing lived experience, instrument development and outcome measurement expertise to the task. This was to ensure that every statement was fit-for-purpose, plain language, concise, appropriate and respectful in tone and content, and that each statement acknowledged real-life elements of the lived experience of disability. It should be noted that NDIA comments made very late-in-the-process immediately prior to soft launch of the on-line Qualtrics trial DWI Adult version were somewhat frustrating. This was because the queries made by the NDIA reviewers were about statements that had already been subject to extended discussion and debate throughout the research process, and that the comments were seemingly made without them having seen any data summaries or analysis workings.

A suggested solution for future DWI/research development could be that all data summaries and analysis workings are sent to NDIA reviewers for review with any version of the DWI/research development to ensure appropriate knowledge and sight of rationales for statement content and changes, including examples, format, and inclusions (as well as exclusions). This would assist with improved understanding by all stakeholders of fit for purpose instrument development processes.

Participant data contribution

Participant data collected on the draft versions of the DWI (Adult) and DWI (YP) led to a number of gaps being identified. This included language complexity with item headings and item terms (later changed to statement headings and statement terms), missing domains (and a resulting change from the term domain to life area), ordering of life areas and refinement of descriptors within the statements. Importantly, from the participant data, areas of the draft DWI that were triggering and appeared to create anxiety or distress for participants were readily identifiable. Participants expressed concern with several statements in relation to content about levels of safety, abuse, respect and dignity, both in the community and in their own homes. Findings also identified problems with multi-concept statements and problematic meaning with statements according to intended reason for inclusion and likely response outcomes. For example, the nuanced difference between ‘access to’ in contrast to ‘getting’ services; ‘opportunity’ versus ‘satisfaction’.

In addition, participants raised the critical issues of technical access to the DWI and the way it would be delivered, as well as privacy with use of support and substitute completion with use of a proxy.

Young people cohort

The young people participant cohort provided deep and amazing insights into generational perspectives on what constitutes wellbeing for individuals with disability. This was evident in the unique language used by the young people, their understanding of their status and entitlement as full citizens and being socially included, and their empowerment, social status and rights. This was apparent in their narratives about education, work experience, employment and careers and despite their awareness of continuing existing - and deeply frustrating barriers in the worlds of post-school education and work. There were also strong narratives on social connections using online platforms and clear narratives of aspirations and expectations around relationships, living independently and participating in leisure activities which were missing from the adult cohort participants.

Data obtained from both participant cohorts spoke strongly to factors that impacted on the lives of people with disability and their wellbeing such as discrimination over and above the anticipated comments about poor services or no services at all. However, it was evident that discrimination was experienced differently by each cohort due to their lived experience in different social-historical contexts. Young people with disability spoke out more freely and willingly about how they were treated with lack of respect or concern for their dignity as a person with disability from people providing services and the community generally. Adults with disability spoke more to the constant and continuing experience of ‘being treated differently’, more frequently with a sense of resigned frustration and hurt. Yet, for both cohorts this systemic discrimination happened across all areas of their lives – in health, education, employment, housing and so on.

Unresolved concerns

Several elements identified as problematic from the earliest version of the DWI Adult remain unresolved. These include:

- An adequate (and appropriate) recall time for completing the DWI when some respondents will have memory gaps and cognitive functioning difficulties and impairments. Is a generic statement such as on average the best possible solution?

- Different access to the DWI and potentially (sub-group analysis) for respondents who require support to complete the DWI and those for whom the DWI will be completed by proxy. How is the manner of completing the DWI, independently, with support, or by proxy to be determined and by who, and how will the voice of the participant be heard? We will be addressing this question in Step 2 Stage 2A over the coming months.
- The issue of safety for respondents when completing the DWI remains unresolved. One solution involved including referral contact details for police and support organisations at the beginning of the DWI and adjacent to the Safety Life Area. This may go some way but not fully to ensuring the safety of an individual completing the DWI. The responses of any individual completing the DWI with support may be compromised if they do not feel safe to record a true assessment of their safety or if they feel influenced to generate a ’higher’ level of satisfaction with wellbeing life areas to appease the person on whom they are dependent. As yet, there is no satisfactory solution for individuals in situations that are unsafe; including contact details for referral organisations seems less than adequate.
- Accessibility of DWI for all Australians with disability. Currently the DWI Adult and DWI (YP) are available in plain English and in Easy Read versions. That said, the current testing of the DWI is through an on-line Qualtrics application which is not accessible to all. Every effort has been made to simplify the DWI format and instructions however screen reader compatibility and alternative access methods to receiving the DWI have not yet been investigated. This work forms part of Step 2 Stage 2A over the coming months.

Overall, the significant, keen and welcomed participation of people with disability in reviewing and refining the adult and young people versions of the DWI produced excellent outcomes that would not have been possible without their generous contributions. Their contributions meant that firstly, these forced the development of simpler and more focused statements in each life area; secondly, they highlighted age/life stage differences in impacts on wellbeing for individuals with disability; thirdly, they foregrounded issues of safety for people with disability when completing a DWI (or with assistance of proxy) in situations which are or may be unsafe; fourthly, they emphasised the critical importance of having the DWI adult and young person versions available in various formats to suit accessibility requirements of all people with disability as was well as those requiring Easy Read (and which will now be addressed in the next phase of DWI development); and lastly, by bringing the lived experience of disability in Australia to the forefront for the entire research team. This means that the DWI versions to be piloted by the NDIA and DSS with people with disability, now reflect the distinct life experiences of Australians with disability as well as those shared in common with their non-disabled counterparts.

These contributions were critical to this stage of DWI development given that, to date no population-based wellbeing index has considered the distinct life experience of living with disability. This new wellbeing index for people with disability is more likely to be well grounded in how people with disability experience wellbeing, what impacts their wellbeing and how these factors (incorporated as statements in life areas) can be examined and assessed using a measure specifically designed by and with people with disability for this purpose. This qualitative component of DWI development provided access to real life, on-the-ground narratives from people with disability on the concept of wellbeing. The significant contribution of people with disability as participants in an inclusive ‘disability lens’ research design approach enabled a more in-depth, relevant and easily understood version of the DWI to come to fruition.

1. RESEARCH DESIGN and METHODS

Aim: To understand and include perspectives of people with lived experience of disability in the development of a DWI for use by and with Australians with disability.

1.1 Methodological framework

The Australian Government estimates that the number of people who are supported by the National Disability Insurance Scheme (NDIS) is expected to grow to 530,000 within a few years. In addition, there are another 2.1 million Australians with disabilities who are supported by Australian Government social services benefits and state-and territory-based disability services. Overall, there are estimated to be 4.4million Australians (18%) who live with disability (AIHW,2020)[1] who are the subject of government policy and services across national and state jurisdictions (Australian Government, 2021). [2]

There is currently limited evidence about which services and supports for people with disability represent good value for money. Bodies, such as the Productivity Commission, have called for only cost-effective services and supports to be funded, but this is not possible without evidence on their cost effectiveness. One reason for the lack of evidence is the lack of a common outcome measure that is suitable to capture changes in the wellbeing of people with a disability. The Disability Wellbeing Index (DWI) Project aims to develop such a measure.

Measures such as these already exist to capture effectiveness of interventions provided for a range of health conditions, usually following the quality adjusted life year (QUALY) approach (Wichmann et al., 2017)[3]. It combines length of life with quality of life into a single outcome so that investment options in different areas can be directly compared in terms of their value for money.

The DWI Project aims to apply this type of approach in a disability context for outcome monitoring, priority setting and investment appraisal. The use of preference-based well-being measures is applicable in the disability context (Crocker, 2021)[4], but there are no existing instruments that can be applied in this way that link with the range of domains in current Australian policy approaches (NDIS n.d. Australian Government 2021). The DWI project began with a comprehensive review of existing preference-based quality of life measures, identifying five instruments with relevant domains and

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[1] Australian Institute of Health and Welfare (AIHW) 2020 https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability/prevalence-of-disability

[2] Australian Government, 2021). National Disability Insurance Scheme n.d. https://www.ndis.gov.au/about-us/publications/outcomes-framework-pilot-study-summary-report-2015#what-is-the-ndis-outcomes-framework

[3] Wichmann, A. B., Adang, E. M., Stalmeier, P. F., Kristanti, S., Van den Block, L., Vernooij-Dassen, M. J., Engels, Y., & Pace. (2017). The use of Quality-Adjusted Life Years in cost-effectiveness analyses in palliative care: Mapping the debate through an integrative review. Palliative medicine, 31(4), 306-322. https://doi.org/10.1177/0269216316689652

[4] Crocker, M., Hutchinson, C., Mpundu-Kaambwa, C., Walker, R., Chen, G., & Ratcliffe, J. (2021). Assessing the relative importance of key quality of life dimensions for people with and without a disability: an empirical ranking comparison study. Health and Quality of Life Outcomes, 19(1), Article 264. https://doi.org/10.1186/s12955-021-01901-x

items, but none of these instruments adequately covered the broader wellbeing constructs relevant to people with disability (Chen, 2017)[5].

Development of a suitable preference-based disability wellbeing measure must include the voices, values and insights of people with disability to inform the domains and items that will be included. Engagement with people with disability is an essential element of instrument development (Hutchinson, 2021)[6] to inform policy and practice and implement principles of co-design (Blomkamp, 2018)[7]. This report details the qualitative component of Stage 1 Development of the DWI carried out at the Centre for Disability Research and Policy (CDRP) University of Sydney led by Dr Kim Bulkeley and Professor Emerita Gwynnyth Llewellyn as described in the following sections.

1.2 Research approach

This qualitative research piece in Stage 1 of the DWI development adopted a disability inclusive research approach, recognising the importance of the contribution of researchers who identified as living with disability as an essential part of the research team.

The research team of seven people, of which four team members were people with disability and three were non-disabled team members, met regularly (weekly or fortnightly as needed) by Zoom and at significant points of the overall DWI project with the entire research team from Monash and Flinders. The overall qualitative research design included on-line focus groups or one-on-one interviews (if requested) and an on-line follow up survey to collect demographic data and provide an opportunity for further reflection and commentary. The structure and content of the data collection approaches were heavily influenced by the principles of inclusion by providing people with disability welcoming and accessible means for contributing to the focus groups and interviews. Data analyses followed inductive processes for text and descriptive statistical procedures for quantitative data (from on-line survey).

1.3 Participant Recruitment

Extensive recruitment for two cohorts of participants, 1. Adults with disability; and 2. Young people with disability aged 15-25 years, was undertaken by third-party distribution of information about the project to Disabled Persons Organisations (DPOs), Disability Representative Organisations (DROs), advocacy groups and through known networks such as lived experience affiliates at the Centre for Disability Research and Policy. DPOs and DROs were approached via email, outlining the project and asking the organisation to forward the recruitment information to members and networks seeking individuals to participate in a focus group. Contact details for DPOs and DROs were obtained from publicly available, national lists of such organisations and from recommendations from the NDIA. The recruitment materials stated that individuals with disability who wanted to participate could contact the research team directly or through their DPO or DRO.

Professor Chen, Monash also provided contact details from the list of NDIS participants who have agreed to participate in research who had been unable to take part in Monash stakeholder focus

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[5] Chen, G., Petrie, D., Richardson, J., Sia, K.L., Jackson, A., & Harris, A. (2017). Rapid Review of Wellbeing Measures to Assist Disability Support Priority Setting. Centre for Health Economics, Monash University. Melbourne

[6] Hutchinson, C., Ratcliffe, J., Cleland, J., Walker, R., Milte, R., McBain, C., Corlis, M., Cornell, V., & Khadka, J. (2021). The integration of mixed methods data to develop the quality of life - aged care consumers (QOL-ACC) instrument. BMC Geriatr, 21(1), 702. https://doi.org/10.1186/s12877-021-02614-y

[7] Blomkamp, E. (2018). The Promise of Co-Design for Public Policy. Australian Journal of Public Administration, 77(4), 729-743. https://doi.org/https://doi.org/10.1111/1467-8500.12310

groups/ interviews earlier in Stage 1. A list of organisations who distributed information about the project (for adults and for young adults) is included as Appendix A.

We aimed to ensure that participants with a broad range of disabilities for example, people with mobility limitations, sight and hearing impairment, intellectual disability, and multiple disabilities were adequately represented through the recruitment processes. We approached organisations that were national as well as ones that were primarily state or territory based.

Prospective individual participants who indicated to their DPO or DRO that they were interested in participating in the research, or who made direct contact with the research team after receiving information about the project were sent an invitation via email with a Participant Information Statement (PIS) attached (see Appendix B). If a participant did not respond, one follow-up contact was made via email or phone. Emails were sent individually so there was no risk of breach of privacy or spam legislation. The wording of the PIS, and the wording in the original approach emails circulated to DPOs and DROs made it clear that participation is voluntary and there will be no adverse consequences if invitees choose not to participate. Participants in the research received a $100 voucher ($50 per hour pro rata) to acknowledge their time and valued contribution to the study.

For participants who required accommodations, an Easy Read version of the Participant Consent Form (PCF) was available. Participants were assisted by a support person of their choice if required when providing their consent. Written consent was requested, however, there was an option to provide oral consent as considered necessary to accommodate the communication requirements of participants (see National Statement, S.2.2.5). Oral consent was recorded, using an audio recording device by the member of the research team who had responsibility for collating responses from prospective participants; an email was then sent to the participant confirming that they had provided oral consent.

Of significant note regarding the recruitment process and our close adherence to the above strategy was that we were victim to a scam attack during the recruitment process. The recruitment flyer was accessed through an international website and we received a high volume of requests in quick succession to participate in the research via email which raised our suspicion. The research team administrator noticed that 3 participants could not provide an Australian phone number which was required from the online company to claim the voucher. We sought advice from the University of Sydney cyber security team who checked the ISPs. They found that 3 of the participants that had just completed a focus group had international ISPs. Geoblockers were then put in place by Sydney IT Cybersecurity to block any further emails from outside of Australia to prevent further occurrences of the scam. The emails and data from those 3 participants were removed from the recruitment list analysis datasets.

1.4 Data Collection

Participants were asked prior to arranging focus groups and interviews about accessibility requirements and we endeavoured to meet all reasonable accommodations requested. The various accessibility arrangements were live captioning, Auslan interpreters, parental support, familiar/known facilitators and support worker participation. All participants received a copy of the draft DWI relevant to their cohort, prior to participating in a focus group or interview for their review and consideration.

Both cohorts of participants in this qualitative component were characterised by significant diversity. We were able to recruit people with psychosocial disability, autistic and neurodivergent people, women with disability, one Aboriginal person, people living in supported housing and independently, a person who contributed as a parent with disability (there may have been other parents with disability in the sample however we did not collect this data) and young adults living both at home with parents and independently. Participants were from various states across Australia (predominantly NSW and Victoria with a smaller number from Queensland, South Australia, Australian Capital Territory and Western Australia and none from Northern Territory). Participants came from both urban and regional areas. The cohort also included two focus groups organised by VALID (Victorian Advocacy League For Individuals With Disability) of people identifying as having intellectual disability, one group of people with intellectual disability from a metro area, and the other, regional people who identified as having diverse disabilities.

All data was collected online through Zoom meetings with a live captioner in most meetings. Data collection involved either a focus group with up to five participants and two researchers who facilitated the group, or individual one-on-one interviews with one or two researchers. Focus groups in general lasted for 1 1/2 hours, and 1:1 interviews approximately one hour. All focus groups and interviews were audio-recorded and transcribed (the majority were also live captioned) for data analysis purposes.

1.4.1 Focus group and interview question guide/ safety protocols

The focus group script was developed as part of team meeting discussions to consider inclusive ways to approach the consideration of the draft DWI. We were guided by the DWI version that was provided from Monash and then adapted this to increase engagement for our participant group with diverse needs based on the insights from our research team. A graphic was included at the beginning of the focus group script document to give an overview of the domains (life areas; see Appendix D). This document included larger fonts, stronger contrast, increased spacing and removal of unnecessary formatting to increase accessibility for screen sharing during the focus group and was used to engage participants in choosing life areas of importance to them for further discussion.

Focus groups and interviews included discussion on:

- The domains in the draft DWI about disability wellbeing
- The explanation of these DWI domains
- The items included in each domain
- Other domains or items that should be included
- Issues of concern (e.g., who will use the DWI, and for what purpose)

The team recognised the potential for negative reactions to some of the life areas in the DWI and were alert and conscious to any issues of safety, discomfort and support for participants in the focus groups and interviews. Helpline numbers were provided in the PIS and if any participant showed signs of distress, we reminded them that they could leave the group at any time if they needed to. We also called / emailed participants who had seemed unsettled after the session. The research team debriefed on a weekly basis and identified ways to adapt the focus group or interview approach to reduce the likelihood of causing any potential distress or discomfort to participants, such as introducing trigger warnings that some participants may find this topic distressing for instance.

1.4.2 Follow up online survey

Approximately five days after the focus group or interview, participants were emailed an online survey to complete. This addressed (i) response format options, with three response options presented and participants asked to indicate preferences or no preference; (ii) domain and item questions (in DWI YP these were called life areas and statements); (iii) disability information and (iv) demographic information. *For survey responses see summary of findings from on-line survey relevant to the DWI later in report (which includes survey questions demographics and findings not reported here).

The initial qualitative data obtained from adult cohort focus groups, interviews and survey data was framed around discussion of Version 1 DWI Adult containing 12 domains (See Appendix D1 and D2). Thematic analysis of this data was then undertaken.

Three focus group co-facilitators (people identifying as having a disability) were recruited to join the research team. The co-facilitator team members undertook interviewing, contributed to thematic analysis and attended and contributed their perspective to team meetings. Data was collected between early June 2022 to the end of August 2022.

1.5 Ethical Approval

University of Sydney Human Research Ethics Committee (HREC) approved the project on 18 May 2022 - HREC No. 2022/318. This included development of participant information and consent forms (see appendices B & C), and all other project materials, all of which were also developed in Easy English. A modification of the original proposal was approved to expand the participant cohort to include young people from 15-17 years of age. This was approved on the 23 June 2022.

1.6 Results and Publication

This report details the results of the qualitative component of the larger DWI development project. It forms part of the deliverables from Sydney to Monash, the lead organisation contracted by the NDIA to develop the DWI. Findings and experiences in working with disability inclusive research approaches may also be published in peer reviewed journals and reported in conference presentations, and briefings to relevant Australian government officials, subject to sub-contract conditions and conditions in the Head Agreement between the NDIA and Monash. Participants will be provided with a summary of findings from the qualitative component in Stage 1 Development of the DWI. This will be provided in accessible formats as required by the participants, including Easy English.

2. ISSUES OF CONCERN WITH VERSION 1 DWI ADULTS

The Sydney research team identified some broad issues with the initial draft – Version 1 DWI Adult (see Appendix D1) developed by the Monash team, most likely because of the extensive 'disability lens' the Sydney team brought to the project. These concerns were reinforced in the first few focus groups where participants expressed similar issues as well as additional ones with the DWI Adult. These concerns are brought together in the following sections.

2.1 Complex and framing language

Firstly, there was consensus from the Sydney research team that the Version 1 DWI Adult contained complex language, and that there was a need to ask questions in plain language and avoid terms that are not in general mainstream use (later versions of the DWI Adult and Young People removed questions and all items became statements). Examples included terms such as productivity, civic participation and self-worth.

There were also questions about how some terms were defined and were very loaded (negatively) within the disability field such as ‘independence’ and ‘meaningful’. There are debates in the literature and within disability organisations and networks about what is meant by independence for people with disability as opposed to dependence. What is regarded as meaningful – for example meaningful occupation, meaningful participation is also debated; the concepts inherent in these terms may be differently understood by people with disability; and critically, differently understood by non-disabled people when they apply these terms to people with disability. For example, a non-disabled person may wonder or indeed question whether a person with significant disability receiving supports and services could be independent. The meaning of independence may be quite different for that person – in other words the outside perspective of the non-disabled person may hold no or little meaning to that of the insider, person with disability perspective.

Secondly, there was confusion where multiple similar terms were used in statements and descriptors, such as self-care and personal care, unpaid work and volunteering, caring-for-others and household duties, and close relationships and intimate relationships. A great deal of discussion time and consideration was given to ensuring a single concept only was embedded in each statement and opting for mutually exclusive examples in language most likely to be recognised by people with disability. A related and immediate concern was the use of ‘NDIS language’ with terms such as choice and control and daily living activities. Use of these terms was considered provocative and potentially quite negative particularly when the intention of the DWI was to develop a wellbeing index for all people with disability not exclusively for NDIS participants (and in the context of current NDIS language).

Thirdly, there were immediate queries about the Version 1 DWI Adult only including positively framed questions. This included discussion about whether there should be questions such as ‘do you experience physical and attitudinal barriers to participation?’ for example. There was also discussion about questions that implied value judgement. It was concerning that for example if a DWI respondent felt they did not meet the implied standard, they might feel that they did not ‘measure up’ to societal standards, for example, “Are you participating in employment or volunteering?” This seemed contrary to the idea of a wellbeing index which was aiming to understand ‘wellbeing’ and the impact of ‘content’ questions (later statements) on individual’s wellbeing at a point in time and over time. This also included adult cohort participant queries on why ‘abuse’ and ‘neglect’ were being included in a ‘wellbeing’ survey in terms of context, in addition to the felt judgement by some participants on the success and life-achievement domains. There was significant likelihood that not measuring up could lead to completion of the DWI as a negative experience. This approach is now regarded as an inappropriate deficits model frequently found in instruments and assessment processes with people with disability.

A fourth common issue was the inclusion of two different concepts in the one question that created complexity in response for example relationships with family and friends (where one may be at the most positive end of the scale, the other at the most negative end), calm and relaxed, (different meanings) dignity and respect (different concepts). One concept per statement therefore became the approach taken for later versions of the DWI Adult and DWI YP. Further, questions varied between those that asked about feelings and others that asked about behaviours/actions. This seemed unnecessarily confusing, particularly if the question asked about something participants were receiving, such as services and supports.

The adult participant group also noted that any tool needed to be:

- not too long
- not too difficult or complex in language to complete
- consistent in terminology within each domain
- accessible to all forms of technology including screen readers if the DWI was to be accessed online

The issues detailed above were not raised by the young people cohort. This may be because the DWI YP was quite a different version from the initial DWI presented to adult participants and these issues had been addressed. The young people group may well have raised some of these issues if they had responded to the initial DWI Adult version.

2.2 How will the DWI be used and by whom?

Immediate questions were raised by the Sydney research team and subsequently by the adult participant cohort about how the DWI tool would be used, and if only by the NDIA, how a completed DWI may eventually impact on NDIS assessment, planning, funding decisions and review of packages. This reflects the distrust that currently exists in the disability community following the efforts by the NDIA in 2020 to introduce Independent Assessments and the high levels of fear that currently exist around cuts to NDIS plans. As one adult participant noted *"...I'm worried that it [DWI] will be linked to the funding we get… then they'll reduce our funding… if your wellbeing does improve, then they could take away aspects of your funding saying, "Oh, she's fine in this domain of life, she doesn't need" such and such"*

Some adult participants felt having another tool such as the DWI was just yet another example of government scrutiny of their lives as people with disability. They highlighted that few other community cohorts have as much scrutiny of their day-to-day living activities and actions and queried why the DWI was needed to 'assess' their wellbeing.

Of note, none of these concerns were raised in the young people cohort. This could be because, as explained above, the young people were presented with a very different DWI. In essence, questions were replaced with statements, and the statements approach had removed the intrusive, inquisitive nature of the questions approach which is more like the dreaded (quite rightly) comparative and deficit model of assessment that so many adults with disability have experienced over their lifetime.

2.3 Overall utility of doing tool

Adult cohort participants reported (i) emotional burden of working through difficult domains of life and (ii) questioned 'for what purpose?' such as is this another government survey or just more ongoing monitoring and scrutiny of their lives with data? Participants also spoke to the 'what's in it for me?' argument asking about when the DWI was completed, what will completing this DWI change for me? Clarification of the potential uses of the DWI by individuals with disability and others could address the issue of utility by broadening the scope of the use of this index.

2.4 Definitional Issues

Understanding definitions of the terms used was raised frequently, firstly, the use of the term ‘domains’. The Sydney research team questioned ‘what does a domain mean anyway?’ and pointed out that it was not an everyday word in relation to one’s life or wellbeing. Life areas was an alternative suggestion noting that this may be more commonly understood. This became the term used in Version 2 DWI Adult and DWI YP.

In the initial version of DWI Adult, a hashtag was used next to each statement. This was viewed as confusing and an added unnecessary description for people with vision impairment using a screen reader. Hashtags were removed in Version 2 DWI Adult and DWI YP.

It was also thought that the DWI needed a clear definition of the concept of wellbeing at the start that is, Wellbeing is…………….

Further, it was felt that there was a need to tidy up the purpose statement in the introduction to the DWI. The Sydney team suggestion was: *This disability wellbeing index aims to assess your wellbeing as a person with a disability and whether services such as those provided through the NDIS (but any public service) have helped you to achieve wellbeing. The disability wellbeing index will be used over numerous years in seeking to assess changes in your wellbeing overtime.*

2.5 Specific Issues with structure

The Sydney team identified structural issues in the Version 1 DWI with the ordering of the domains, and then potential lack of engagement from people with disability with some domains.

It was identified that the existing structure and ordering of the domains could potentially result in anxiety or distress by a participant by the time they got to the end of Version 1 DWI Adult. Many questions involved value judgments, such as querying if participants were in work or not, or were studying or not, or felt connected to community or not, or engaging in social activities or not. The Sydney team were concerned that by the end of completing the DWI, many participants would spiral down into anxiety or distress from judging their lack of participation in socially valued roles.

There was also concern that participants would not engage in certain domains if those did not relate to their life. For example, if a participant had finished school, they might ignore the learning domain or ignore the employment domain if they were not working.

2.6 Safety and Triggering

As the above section flags, a major theme that emerged initially with the Sydney team and subsequently with the adult cohort related to safety and the potential for items to be triggering. This required some serious thinking as to how this could be managed when using the DWI, by whom (what agency, agencies) and in what context.

It raised the question that if an individual completing the DWI marks that they are in an unsafe environment, either at the beginning or at any time during completion of the DWI, what would happen next? For example, how would this be acknowledged, or the person removed from the unsafe situation and so on.

In seeking to address this, Version 2 of the DWI Adult had referrals to several support organisations that respondents could contact listed both at the start of the DWI and inserted next to the Safety life area so if participants felt like they were in an unsafe environment, they had some contact points to connect with.

There were triggering aspects in 3 domains in the Version 1 DWI Adult. These were domain (9) safety and abuse/neglect; domain (11) self-esteem and domain (12) achieving in life. Adult participants noted that they did not expect to be discussing these ‘heavier’ and much more emotive topic issues in an index discussing wellbeing which they thought would supposedly be about the good elements of life that lead to health and good welfare. These topics both surprised and triggered several adult participants.

Following discussion and feedback in the Sydney team and across the entire team, these domains were substantially modified before the DWI YP was presented to the young people cohort and also in the DWI Adult Version for piloting with NDIS participants in October 2022.

2.7 Proxy

The Sydney research team raised discussion about individuals requiring support/assistance or a proxy to complete the DWI, and how this would be accommodated. It was suggested that a statement be inserted in the introduction "Do you require support to fill out this index?" and that if a proxy was completing the form this be recorded in a tick box at the beginning of the DWI.

There is a larger question with use of a proxy in completing the DWI. This is the extent that the proxy is speaking on behalf of the participant. There is also the issue of privacy of the information being provided by the proxy which may be happening without the informed consent of the person with disability. These questions are subject of active debate in relation to supported decision-making and substitute decision-making as envisaged in Article 12 CRPD[8]

A further live question currently unresolved is how to ensure the safety of the person completing the form if the person assisting the person with disability to complete the DWI or as proxy, is the person causing a situation of lack of safety, or control, or abuse? This could be a support worker, or a guardian or a parent or other family member.

2.8 Recall Time

Some participants communicated their anxiety about the requirement of completing the Version 1 DWI Adult considering ‘over the past four weeks’. Participants talked about not having a clear memory of the last four weeks and how the DWI could compensate for faulty memory.

Other participants raised the concern that 4 weeks did not capture episodic fluctuations in disability. This was primarily expressed by people with psychosocial disability, neurodiversity and people with chronic pain.

Some adult participants noted that they wanted the option to indicate that they may be completing the DWI at an atypical time in their life so their answers may not reflect their more regular wellbeing

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[8] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html#:~:text=Convention%20on%20the%20Rights%20of%20Persons%20with%20Disabilities,to%20recognition%20everywhere%20as%20persons%20before%20the%20law.

only their current wellbeing. The frequency of administering the DWI was a key consideration here, for example, if it is planned to be administered twice a year, then that sets a time frame. Currently there are no clear indications about time frame. This needs to be addressed so that future development and testing of the DWI is transparent and accountable about appropriate time frame for administration and follow up administration.

One of the adult focus groups raised the notion of different times of the year being an important consideration that can intersect with some experiences of wellbeing as a person with disability. For instance, one person identified school holidays as a very difficult time for her due to the changes in routine in her role as an autistic mum. Another person identified Christmas time and Mother's Day as difficult times for her as a person with psychosocial disability due to family estrangement.

A suggested statement was '*we realise wellbeing fluctuates with different times of the year, events and circumstances… In this wellbeing index we are asking you to think about your wellbeing on average over a period to time (and without specifying that time period)'.*

The version of the DWI Adult piloted in late October 2022 and the DWI YP presented to the young people cohort does not have a specific recall time, rather it directs respondent to fill out the survey according to how they are feeling at that time (with no fixed time about recall). This may or may not have captured adequately the concerns of focus group and interview participants about fluctuations, including those that may happen daily for those with intense pain flare-ups.

An unresolved issue is whether current negative experiences tend to influence respondent approach and responses on wellbeing indexes such as the DWI. The previously suggested statement about averaging wellbeing without tying this to a specified time frame ought to be reconsidered or a suitable alternative for this reason.

3. SECTION 1 ADULT DWI data summary

Adult DWI data summary

This section and following table provide information and discussion about each Adult DWI domain. The first column notes the Version 1 DWI adult headings and statements with description of each domain. The second column includes the comments and feedback from the adult cohort participants. The final column comprises suggestions and ideas from participants for an improved DWI Adult. As per the method noted under point 1 Executive Summary these suggestions were then considered by the entire research team, and following discussion via email and joint team meetings, adaptations and revisions made to create the penultimate DWI Adult for piloting. Just prior to piloting in late October 2022, further refinements were made following input from the NDIA.

Following the table is a summary discussion of the results of the Adult DWI Online survey. A full copy of the Adult DWI Online Survey and YP DWI Online Survey are available in APPENDIX E of this report.

Adult DWI data summary TABLE 1

Version 1 DWI Adult Domain Items 26/03/2022	Overall Comments/Issues raised/feedback	Suggestions/Remedies/Adaptations
Domain 1: Choice & Control This wellbeing domain looks at the extent to which people have developed independence and the ability to make choices and decisions in their daily lives. (1) I feel in control of my life. ('Control of my life' means having the choice to do things or have things done for you that you want to be done, in ways that you like and when you want). (2) I make my own choices (e.g., where I go, what I do, what I eat, who my friends are).	Change title - NDIS language Control is a broad concept - in what life context, control from by 'the system'/NDIS, control over services, control over what I eat for lunch Choice varies depending on setting Control I have verses control over me - 'many' controls in a group home Is this about decision-making and then supported decision-making rather than control? Is there a need to separate choice from control into 2 statements? For people with disability, the term independence has a lot of different meanings because of the levels of dependency and interdependency in one's life. A person may feel that they have independence because they can still do various tasks for themselves, or feel they don't have independence because of dependencies and relying on people for help and support. However, they may be dependent but still feel they have control over when and how they want things done	title: Choices I make my own lifestyle choices (e.g., where I go, what I do, what I eat, who my friends are) or I make my own lifestyle choices or are supported with decision-making to make my own lifestyle choices (e.g. where I go, what I do, what I eat, who my friends I make my own choice of services I use or I am supported with decision-making to make my own choice of services I use

(3) I have as much independence as I want.		
Domain 2: Daily living activities This wellbeing domain looks at the services and supports received as well as participation in a range of activities in daily lives. (1) Considering the services and supports I received, I participate in a range of daily living activities (e.g., domestic tasks, personal care, travel and transport). (2) I am able to do things for myself (for example, household tasks, self-care, travel). (3) I have access to support and services when needed. (This concerns being able to count on support when you need it, as well as the quality of the support.)	Change title – Daily living activities is an allied health term what does it mean to 'participate in daily living activities'? I can do things myself – I can with help of support and services? Is there a difference between support and services? Does one mean informal supports and the other formal services? Do we need both? Or do we need both and describe difference. Will non-NDIS respondents understand the daily living activity phrase? sounds very NDIS It's fine. Daily living activities are things that you do every day. I don't think it's specific to NDIS (1) was too wordy What is that domain topic asking about? That you can complete personal care/household tasks, and if you can't do this independently, you get supports to help you? Travel and transport a separate domain? Self-care and personal care descriptor: the same thing? Is statement (3) alone enough? Is [3] is asking two different questions in talking about access to support and services and asking about the quality What about people who are deaf? They don't have any needs in relation to that, but they have communication issues, so they might need an interpreter. Is that a daily living activity? they're just enough to gauge how you're doing, but without being too intrusive where you might read them and go oh, stuff this, I'm not sharing that information or I don't feel comfortable doing so	Easy English descriptors *uniform order of terms - support and services and services and support in same domain *don't use term 'e.g.,', use phrase for example Title: Personal care Title: Personal care and household tasks Title: Personal care and Supports and Services I can complete my daily personal care and household tasks I am able to do things for myself and others I get the support and services I need when needed. the support and services I get are of quality

	I don't like the word "considering" "the services and supports I received	
Domain 3: Relationships This wellbeing domain looks at people’s personal and close relationships. (1) I enjoy my close relationships with family and friends. (2) I enjoy my close and intimate relationships. (3) I enjoy my personal relationships. (‘Personal relationships’ refers to how you get along with the people in your life, your friends, your family, your partner(s), the people you live with.)	A fair bit of critique and confusion by most participants on all statements Some people don't have family or don’t get along with family but get along with friends and vice-versa Prefix ‘I enjoy’ – there is a presumption that these relationships are occurring every statement was framed so positively. One person described it as toxic positivity! Should we just be clear and write sexual relationships? Are we being ableist in trying to skirt around the fact that people the disability have sexual relationships just like the rest of community? Then again is it just too much to be asking in a wellbeing index and is it a bit of an invasion of privacy? Some wondered about whether it might make people upset if they read the question and they weren’t in a sexual relationship and they wished to be in one and this could trigger them a little bit? Need clarification of difference between close and intimate? Safety in the relationships with high levels of Domestic violence in Australia? I'd probably have a stronger relationship with my support workers that I see every day than I do with my family and friends. Is that covered in that relationship question? my son wouldn't want to divulge whether he was in a sexual relationship and he enjoys it. That's something really personal that I don't think he would want to share with anybody.TR: I think there's a privacy issue around that as well I think you need an "NA" option	Separate friends and family statements suggest that we don't have a questionnaire that actually points out to people in such a strong way what they don't have use term intimate relationship only relationships with people I love I have close relationships with friends and work colleagues. I have intimate relationships with my partner. I have opportunity to explore sexual relationships and sexual identity I feel safe and respected in my relationships

Domain 4: Housing This wellbeing domain looks at what people think about where they live. (1) I am happy with where I live. (2) I like where I live.	Many thought 2 questions were same thing – preference for 2 Who you live with is a big issue for people with disability – i.e., no choice in group home 'happy' did not capture the concepts of relevance to many people with disability. 'accessible' rental accommodation is difficult to find >limited options; reduced opportunity and choice. Affordability of housing/reduced options of housing if people with disability with a significant proportion of people with disability on DSP. Does 'where' mean location, near shops, near public transport, suburb, safe area, regional or metro? Housing in group house - services that are provided with housing; no choice of who I live with; a lot of people have a disability, if they had another option to live somewhere else, they would. So they don't emotionally feel safe in their house, they're yelled [at], they're abused	I am content with my housing situation I like who I live with I feel physically and emotionally safe where I live I have opportunity to move to accessible housing if I need Housing in group house - services that are provided with housing -My needs are met where I live"?
Domain 5: Health & Wellbeing This wellbeing domain looks at people's mental and physical health, as well as health services. (1) I feel cheerful. (2) I feel calm and relaxed.	Title > just Health? Or physical and mental health or physical and mental health and health services? leave wellbeing out from the title here; the overall aim is to measure wellbeing by doing the entire index so it makes it difficult if wellbeing is one of the definitions or elements of the measure itself And is it about healthcare or health services? Disability doesn't mean unhealthy	Title: health Title: physical and mental health Title: health and health services I feel happy/ stable/ content/ satisfied/ calm I have the energy to do the things I want to do.

(3) I have the energy to do the things I want to do. (4) I am satisfied with my physical health. (‘Physical health’ refers to the state of your physical body and how well it's operating.) (5) I get the health care that is right for me.	Your feelings of health and then about getting healthcare are 2 different things; and then quality of what you get; these are three separate concepts all wrapped up in item (5); 3 separate things. Significant historical barriers for people with disability getting healthcare – physical and attitudinal, yet this is a vital area - a main field that people with disability frequently interact with due to fact that they have bodily diversity Many participants did not like the term cheerful and this was contentious – some felt an overwhelming sense of the positivity issue here. Like ‘I’m happy happy’ The items did not capture the specifics of physical health or mental health and should be worded more directly to address those aspects Just asking [about] health care is conflating mental and physical health	although I have a disability, I am satisfied with my physical health. I am satisfied with my mental health. I get the mental health care that is right for me As a person with a disability, the health care I get is generally accessible. I am able to communicate well with my health care professionals.
Domain 6: Lifelong learning This wellbeing domain looks at opportunities to learn things. (1) I have access to education and training that is right for me. (2) I have access to learning opportunities that are right for me.	Good; like the emphasis on ongoing ownership/agency in the title not just ‘I’ve finished school so I’ve finished education’ Many also felt access was an unnecessary term here. Rather, should it be get in relation to all of the debates in the previous domain instead of access? Saying "I have access" is sort of not really capturing all the barriers - systematic barriers MUST be addressed include informal/formal learning such as acquisition of life skills with examples i.e., new cooking recipe, art; and different forms of knowing and learning e. g., indigenous or other cultures Tech to help you learn/accessible IT – can you access to online courses? get info from online It is important to recognise different life stages. There are different levels of enthusiasm, feelings of having completed education when younger or have left school now. These items do not capture that part of the lifelong element	I have access to/ get education that is right for me. I have access to/ get training that is right for me. I have access to/ get learning opportunities that are right for me. I have access to supports to help me get education or undertake learning [from NDIS or from uni, technical and vocational education or learning centre?]

	Try to have only one concept per statement so separate out education and training I live alone with my family, so this access to education and training that's right for me, that I have access to learning opportunities that are right for me is very much to me distant, unattainable and very much, you know, a question that I automatically feel like I'm failing at because it's not asking about anything in terms of the barriers that I face if somebody scores low on this, it might just be that there's lots of barriers...Or they're not interested or they don't know what's out there there was a difference between the actual opportunities and whether I had supports and accommodations to do it where it says - like "I have access", what does "I have access to" man, does that mean I have the funds, does that mean I have the ability, does that mean being given it, does that mean the things that I want to learn exist? Like it's so vague, I wouldn't know how to answer this question I think it's about being connected to the land… connecting to your land and understanding how your land works with environment … I know a lot of knowledge around that area I would read these two questions and I would be depressed … that's not going to be a fun thing for me to do and I'll probably do it, have a spiral for a few weeks and I'll probably never do it again	
Domain 7: Productivity activities This wellbeing domain looks at how people feel about productivity activities.	Title very unpopular, what does productivity even mean? sounds like an economic unit and not related to the life of people with disability; not plain language. This domain seems to be more about meaningful activities or contributions to community, not just employment, paid work or volunteering, but all sorts of activities; Satisfaction with 'contribution' not necessarily paid work role. People with disability often have reduced opportunities for employment/activity.	I participate in activities that are meaningful to me (e.g., paid employment, unpaid work such as parenting/running a house, volunteering or caring for others).

(1) I participate in productive activities that are meaningful to me (e.g., paid employment, unpaid work, volunteering, and caring for others). (2) I am satisfied with my ability to work.	People with disability often experience discrimination in employment/doing activity? Low pay, attitudes, exclusion, physical barriers; does the employer provide reasonable adjustments? Are you treated well by your employer? 'Employment' is often viewed socially as success – for various reasons employment might not be the priority or something that is doable for people with a disability, so we should ensure we don't perpetuate a stereotype our employment means more value and not being employed is devalued, and this would be discriminatory. We want to give value to all the contributions that people make in community and value the various social roles, and there is particularly a diversity of roles in the diversity of disability. In contrast, if you are wanting to find employment as a person with a disability, can you get employment/activity supports if you need them? e.g., Disability employment services. Are you treated well by employer? Trying to capture the experience of people with disability in sheltered workshops or bad pay or denied career opportunities or discrimination often experienced by people with disability in relation to employment? And does this domain include like hobbies and sports and recreation music, art, creative activities which are meaningful activities? If not need a separate leisure domain? Do people with disability in day centres get included in descriptor? ableism comes over the top of that, so they have no opportunity to work in many cases because as soon as you disclose you're done and that's the reality that a lot of people are experiencing and it's shown in the statistics it means different things to different people and different levels; for some people just getting out of bed is a meaningful activity	I am satisfied with my ability to contribute to community if you are wanting to find employment, can you get employment supports to help you get employment if you need them? e.g., Disability employment services If employed or volunteering, do you get support from your employer to help you in your employment role e.g., reasonable adjustments such as flexible time, accessible equipment, worksite modifications, awareness training of other staff? If employed or volunteering, are u treated well by your employer?

Domain 8: Social connectedness, community & civic participation This wellbeing domain looks at inclusion in the community. (1) I participate in the community as much as I want (e.g., sports, religious, cultural activities). (2) I feel welcomed and included in my community. (3) I feel connected with my social networks.	Change title > viewed his way too long by most participants and terms difficult to understand – why not community inclusion? Many thought 'civic participation' was an unhelpful term that they did not relate to Include a statement that says 'I have access to country or cultural practise' to incorporate aboriginal connectivity to country Inclusion is a very different experience for people with a disability and potentially this should be reflected in the statements In terms of discussions on community inclusion, a lot of participants said 'inclusion by who" so they distinguished between the groups in society that included them or excluded them and these varied with everyone based on their historical experience of disability discrimination. So for example somebody may say I'm included by my local sailing group very much but I'm discriminated against by the local checkout chick or something, so it is about who is doing the discrimination that prevents the inclusion Drawing on the social model what are the physical and attitudinal barriers to inclusion. These need to be captured in the statements You could participate in society in terms of going to the shops with the support worker and having a coffee, but are you really networking and connecting and being included in community, or you're just there physically? Online communities are important for people that disability to prevent isolation so possibly a statement on inclusion in online communities 'I feel' maybe too emotive? Based on external perceptions "I am connected with" - that would be more in alignment with "I participate", so why we've got "I feel" with some and not others, the particular reason behind that? I have lots of different communities, so can you capture that?	I have access to country or my cultural or religious practises I am welcomed in my community. I feel included in my community. I am connected with my social networks. I am connected with online communities I have enough support to help me with community inclusion if required I've experienced physical or attitudinal barriers in accessing my community

	I was stopped because I couldn't get the support to get there in the first place to participate. I think it's a bit of an altruistic view, but I'd love to see a world that considers not just the activity but everything that's required to include someone with physical limitations it's really occurred to me that the first thing I do is not choose where I'm going to go. I choose where I can - I look at where I can go and then when I've got that list I will choose	

Domain 9: Rights protection, Safety & Dignity This wellbeing statement looks at peoples' rights and safety. (1) I am treated with dignity and respect. ('Dignity and respect' refer to other people value you as a person and listen to what you have to say) (2) I feel my rights are promoted, upheld and protected. (3) I feel safe and secure. (4) I am free from abuse and neglect.	Rights, dignity and safety by who? These differ in different social settings; possibly, and at the least, a distinction between how they occur in our operationalized in community and how they occur and are operationalized in the home. This might also then cover support workers in the home and family and respected dignity experienced from them and then also levels of respect and dignity experienced while in the community in general settings. So for example, do I have rights and dignity in community, in the home from the system? Potentially split domain in half with rights protection and dignity in first half; Safety and abuse in another domain The lived experience of people with a disability in relation to these concepts is very different than that of a mainstream person. Probably all people with disability at some stage would have experienced some form of discrimination or abuse of rights or neglect. And if a woman with a disability there are high levels of safety and abuse issues (see findings from disability royal commission). Potentially, start each statement with 'as a person with a disability' to try and capture the unique experience of people with disability in these fields Safety and abuse would be triggering and may need specific warnings at the top of the domain there is considerable concern around the triggering that may occur from these domain statements, so discussion must centre on how they are presented in the survey, precursor warnings, support response referrals and just trying to word the statements in a way that doesn't cause triggering or in the way that causes least impact. People get could get triggered and stop doing the survey or the person with disability might shut down and not answer anything truthfully/ seriously. The comment from one participant was that they were surprised to see these concepts in a wellbeing index because wellbeing was positive, and these things were about difficult areas of life Different people will experience safety in different ways so it might be physical safety or emotional safety	Title: quite a few different concepts in the one domain, possibly just dignity and rights for the first domain end safety in the second domain? As a person with a disability, I feel my rights are promoted, upheld and protected in community. As a person with a disability, I feel my rights are upheld by the community ……/home ……/support system (e.g., NDIS, Centrelink, Medicare) New domain f safety? Intro sentence: This wellbeing statement looks at both your physical and emotional safety As a person with a disability, I feel safe in community as a person with a disability, I feel safe in my home. *I think it's missing 'do other people see you as equal?'*

	people promote about our rights, but they're not upheld and protected. So it's like break it up a little bit Because "I feel safe and secure", that could mean a lot of things as well, like you feel safe and secure when you're talking to someone on the phone, you feel safe and secure at home, you feel safe and secure in your community, so that could mean a lot of things I wouldn't put number 4 because maybe that person has been abused from family members ... when it comes to that stuff but someone with disability I don't think that will be right to say. I think all the other ones 1 to 3 I think is right, but you know, a person might actually get upset if you ask them that last one you have a different life experience of safety and security and rights than a mainstream person your biggest aspects of our rights and dignity being disrespected is the Government and the NDIS I think the "safe and secure" and to a degree the "abuse and neglect" - again, it's a bit tricky, like what do you mean? Like are we talking about, you know, family violence, from carers, …there's a lot of different ways, again understanding that it's difficult to have …a question about everything	*two separate questions, needed, because some people feel safe in their community, which is the outside, but some people don't feel safe in their own home*
Domain 10: Financial security This wellbeing domain looks at peoples' current financial situation.	Participants noted that they needed to have enough money for myself *and their dependants* who they have responsibility for With statement number 2, everyone will say that they need *more* money (human nature) so maybe a clarifier - to look after themselves / live well The control of money for people with a disability by a guardian or a parent is a significant issue historically in disability. Often people with disability are not given opportunity to obtain any learning skills around financial literacy and it is just assumed they don't have	I get enough money to do things that are important to me and my dependents (e. g., children, older parents) I get enough money to meet the living needs [or live well, live comfortably] (e. g., pay bills, buy food, pay rent or

(1) I have access to enough money to do things that are important to me. (2) I have enough money to look after myself. (3) I am happy with my financial security (e.g. situation with money).	knowledge about money and how to manage money oh look after themselves in relation to money Supported decision-making is a fairly important elements in this field A marker of financial security is if you can access a certain amount of money [say $2500] in five days or in unexpected situation that required access to funds "I have enough money" because in what sense? I want to win the Power Ball and $80 million. That's enough money for me I don't manage my money. It's my godparents manage my money	mortgage) of me and my dependents I am able to make decisions for myself, or I'm supported to make decisions, about how I spend my money or I have control over my money I have had opportunities to learn about financial literacy (i.e., how to manage money) In an emergency, I could get $2500 within 5 days
Domain 11: Self-worth / Self-esteem This wellbeing domain looks at how people feel about themselves. (1) I feel my life is important and has a purpose. (2) I feel my life is meaningful. (3) I feel valued in the community.	Change in this title which is little confusing with the two terms and then just the terms themselves, some participants thought that you could change title to how you feel about yourself There seemed to be issues of triggering with this domain come up particularly around psychosocial issues/disability; this included where people felt they didn't have confidence or didn't have good self-esteem, and were wondering why this domain was in there and were sort of reluctant to answer it because it made them feel upset answering that they didn't have a meaningful life or purpose. There is an urgent need to think a way of how to put the question in without it being so triggering Take out the statement of being 'valued by community'; people with a disability don't want to be assessed/judge themselves in relation to an objective value or how the community feels about them, it should just be an assessment by themselves of their own self Self worth to me and self esteem is more about your self confidence, how you see yourself, how you feel. I don't think community really comes into it. I think it's more about how you feel about yourself	My life is important My life has a purpose. My life is meaningful. I feel good about myself I value my identity *I feel valued as a person and* *I like the person I am* *I think questions 1 and 2 are the same ..Is there a difference between "important" and "purpose" and "meaningful"*

	Yeah, this one is hard to answer because I have PTSD so I'm always down on myself. In the past I've had suicide attempts, so yeah, I seriously don't know how to answer this question. I don't know. Because one minute I'm positive and the next minute I'm negative, so I'm up and down all over the place, so I don't know how to answer this question really break down to two streams … personal and professional …my self esteem at work is quite high ..but n my personal life my downtime it needs to have something where you can actually say why and how does that impact on you because I would say my life doesn't have any purpose because I live alone and I have no connection. So what is the point of me existing sort of existentially, if that makes sense? So my life is not meaningful and I have no community, zero, so I would need a means to express my needs and I would need a means to express why I'm in that situation you know, self worth and self esteem is another one of these things that can trigger people a lot. I know that if I was to answer things like that, I would be triggered, you know, I would start [but] probably wouldn't finish answering the question because it would just be too hard; I probably would ignore that … I just probably wouldn't answer it because it would just be too horrific, it would be too harrowing for me	
Domain 12: Achieving in life This wellbeing domain looks at the extent to which people feel they are achieving things in life that are important to them. (1) I feel that I am achieving things in my life that are important to me.	Remove personal goal statement, this is too close to NDIS language and why should people with a disability have to measure themselves against a goal when mainstream people don't The people answering that were triggered by that safety, abuse and self esteem questions above were just even further down the spiral and more triggered by the time they got to this domain 'achieving in life'. This was because if they hadn't been very positive answers and disagreed with most of the other statements, by the time they got to this domain they felt distressed and upset and lacking confidence because they had had to work through so many negative areas of their life by the time they got to this domain, and then this domain throws at them are you achieving anything in life? and if they are upset by now just say no no no…..	do we even need to have achievement as a life domain? What is this like measuring success equals wellbeing? Is living a good life enough or do I have to be successful and achieve? I feel that I am achieving things in my life that are important to me.

(2) I am satisfied with my achievement of personal goals.	It could put a bit of pressure on people because they might not feel like they're achieving in life I achieve what I want to achieve at the time, but I'm just not a future goal setter kind of person. So when I come across these types of things with surveys, I always feel like a bit of a failure because I'm like, "Oh, my gosh, should I be setting these huge goals for me to reach all the time?".. so for me, I don't really - like, I relate to number one in there, but I feel like the name of it being called "achieving in life" I think people on the NDIS and whatever type of funding they're on, everything is goal based. You're constantly made to set goals, whereas people that don't have disability aren't. So I struggle with that the fact that I can do something and I can control it is what's important. Whether it achieves anything is bye the bye". Whereas some people do operate that way and some cultures are that way. Like, Americans are just obsessed with achievement and it has to be really big, whereas other cultures aren't geared that way	I am satisfied with my achievement of personal goals As a person with a disability I've got the supports to help me achieve things I have opportunity to achieve things in life
	Missing Domains?: ○ Transport and mobility? mobility and movement through community ○ Add pain and chronic fatigue into health ○ Leisure holidays -many people with a disability live a very scheduled life around rosters and support and access to a holiday and even just leisure can often be very limited ○ Comms and tech equipment/path in learning domain -the key component of wellbeing ○ something around medication	
	Doman order? i. domains/topics about people with disability and community interaction related to wellbeing [7] Domain 8: Community Inclusion	

	Domain 9: Dignity and Rights Domain 7: Meaningful activities or Contribution to Community Domain ?: transport and community mobility Domain 6: Lifelong learning Domain ?: supports and services Domain ?: healthcare ii. domains/topics about individual's living situation related to wellbeing [4] Domain 4: Home Domain 10: Financial security Domain 2: Personal Care and Household tasks Domain ?: leisure [holidays in here] iii. domains/topics related to the individual's felt self [7] Domain 1: Choice and Independence Domain 3: Relationships Domain ?: Safety Domain 5: Health [pain in here] Domain 11: Feelings about self [delete?] Domain 12: Achieving in life [delete?]	

Online DWI Adult survey data findings

As noted in 1.4.2, approximately five days after the focus group or interview, participants were emailed an online survey to complete. By 15th July 2022, 48 online surveys had been sent. Analysis of responses was completed on the 42 responses received by 4th July of which 8 were incomplete and 3 partial completions, resulting in 36 full completions.

There were 37 responses that completed the 5 questions about the respondent. The majority 67.6% were female, with 29.7% male and one respondent preferring not to say. The age distribution was most frequently represented by 35-44 and 45-54 years with 12 respondents in each of these age ranges. Seven respondents were aged 25-34; 3 were 55-59, and 2 were 60-64 with one respondent preferring not to say.

83.8% of respondents had difficulty participating in activities of work, education and community living; 81.1% of respondents had difficulty participating in activities of daily living such as shopping, making decisions, learning and relationships with people; and 59.5% had difficulty participating in daily activities such as washing, walking and speaking. 47.8% of respondents reported a physical disability; 43.5% reported a psychosocial disability; 30.4 % reported a sensory disability; 28.3% an intellectual disability, 13% a head injury, stroke or acquired brain injury with 7 respondents reporting a disability in the other category. More than one response was possible on this question.

The first question asked about whether the 12 life domains ought to be included in the DWI. There was > 90% agreement for Choice and control, Daily living activities, Home, Health and wellbeing, Social connectedness, Rights protection, and Self worth/ self esteem. The lowest scoring domain was Productivity activities at 75.6%. Twenty-five respondents answered the question about whether any domains were missing, of which 7 answered no. Other potential domains mentioned (and in addition to data from focus groups/ interviews) were hope; emotional and social connectedness; equal opportunity; parenthood; spirituality and worship; recovery and resilience; independence; hobbies and preferences; feeling safe and secure; and systems interaction.

There were 22 responses to the question about any other items that should be included. Of these 9 were no, and one non-applicable; the remainder were mainly concerned with the lack of clarity of many items, the language used, and the meaning of some of the questions. The next question asked whether there was anything else that respondents would like to say. Of the 23 responses, 5 were no and 1 was non/applicable. One comment flagged a common issue, that is, it was uncertain what is expected of respondents in answering the DWI questions – are they answering relative to: 1) their disability expectations, 2) their past, 3) comparing themselves to others with disability, 4) comparing themselves to able-bodied people. The later change in DWI item wording from question format to statement format is anticipated to address this difficulty, along with the introductory statement about completing the DWI according to 'how you feel about your own life'.

Of the four response options, Option A was preferred at (38.9%), followed by Option B (27.8%) closely followed by Option C with three of the 36 respondents choosing this option.

4. SECTION 2 YOUNG PEOPLE DWI data summary

Young People DWI data summary

This section and the following table present each of the [13] separate life areas from the YP DWI data. The left-hand column contains the Life Area Title and statements within the Life Areas. The middle column contains the critiques and responses made by YP participants in the first few days of focus groups and interviews. The last (right hand column) provides suggestions to improve that version of the DWI YP. The suggestions were then considered by the Sydney research team, followed up with full team discussions via numerous emails and joint team meetings and with feedback received from the NDIA, adaptations were made resulting in a second version of the DWI YP (29/07/22 and 19/08/22, see Appendix D3 and D4) being used in later focus groups and interviews. Discussion on the DWI YP online survey results follow Table 2.

Young People DWI data summary TABLE 2

Early DWI YP 29/07/22 and 19/08/22		
LIFE AREA 1. Relationships (5 items) Overall I am satisfied with the way I get along with people (for example, friends, family, carers, support workers) Family I am satisfied with my family life Friends I am satisfied with the friends I talk to and do things with Intimate I have the opportunity for intimate relationships I am satisfied with how often I can spend time with the people I love Supporters	YP undergoing more therapy; support workers including allied health were people that YP saw every day or every week and were people they had strong work relationships with e.g., work relationships with therapist physio and OT 'on a weekly basis, so I would include them in relationships' term supporters confusing [footy team?]; Is the term 'supporters' too close to 'support workers' for YP to differentiate? there needs on be acknowledgement of sexual partner/Intimate partner/significant other/ intimate relationship in YP relationship statement; 'acknowledge romantic and sexual relationships because I think a lot of people have this misconception that disabled people don't have partners and don't date and don't have sex, and that's like young - I know as young adults, that's something we definitely do and I am sure others do too FGA FA; saying "romantic" or "sexual partners" would be the most specific and accurate because also not everyone identifies as a boyfriend or a girlfriend. There's a lot of different terms for all sorts of relationships …if we put "intimate partner"; some people have relationships that might be sexual but not romantic and vice versa. So there's lots of dynamics there; some people don't want romantic relationships or don't want sexual relationships so maybe it's about intimacy; obstacles to relationships? Time (medical condition takes to time to manage), fatigue, my own capacity or even the capacity of other people to be available to want to spend time with them; I have chronic fatigue and that can make my relationships quite complicated because I just don't have the time that other people have to be putting into friendships and stuff, which is - as much as I'm very satisfied with the friendships that I have, there are still valid obstacles that, to an extent, I can't really do anything about FGA EI; My energy for socialising is much less than I'd like it to be. I would like to be able to do more in that way. Spend more time with friends and families and socially, but trying to fit in any other part of	Support team I have opportunity for intimate partner relationships for example, friends, romantic or sexual partners, family, carers, support workers I'm satisfied with how often I can spend time with the people I love I'm satisfied with how much I interact with those people I am satisfied with my intimate partners if I have them I have opportunity to express my identity [within relationships]

I am satisfied with the way I get along with people who support me(for example, support workers, allied health, counsellors)	work or anything means that any energy I have for those things is significantly taken away, trying to then maintain employment Proxy – family > I'm reflecting on the loaded relationship that disabled young people in particular can have with their family and especially if the disabled young person isn't able to complete this index independently and would need their family to do it with them, which might mean that their like responses are skewed and were not able to actually represent the fact Families can look different for YP: Like parents and like grandparents and from all the generations are our flesh and blood and most of it and foster carer, or something like that, like foster parents	
LIFE AREA 2. Daily life (2 items) Personal care I am satisfied with my personal care (for example, eating, washing, dressing, with or without the help of others) Everyday activities I am satisfied with my day-to-day activities (for example, cooking, shopping, sorting out problems, with or without the help of others)	I like that independent and supported are included in both ..yeah, it's good that there isn't like a separate question that's like I am satisfied with how others get like others help me to do everyday activities and then I am satisfied with how I do them. They're the same thing because they are the same thing, they're doing everyday activities. It's just some people need support and some people don't Motivation and wellbeing: I know that some people, just due to mental health reasons or like physical reasons or any other reasons - some people don't have the motivation or the willpower to take care of themselves and they feel - some of us like just feel completely bad about it. So yeah, like I think saying like I am satisfied - like probably like I think it's better to scale it from like 1 to 10 Support from others: I don't personally love the get others to do for me. There's something about the phrasing that I'm not 100% loving. Or have others support me with… I'm about wording and about empowering, and if I need others to do it for me I can't, versus other people support me because... It feels [inaudible], but it feels a little bit more like you've got the power and they're just supporting you with it. Does that make any sense?	I am satisfied with how I look after myself or have other support with my personal care (for example, eating, washing, dressing) I am satisfied with how I do my day-to-day activities or get others to help me (for example, cooking, shopping, solving problems)

LIFE AREA 3. Community (3 items) Participating I contribute in my community as much as I want to (for example, doing sports, going to music and cultural events, access to Country, religious groups) Belonging I feel accepted and included in my communities, in person or online Meaning I do things in my life that are of meaning to me	are participating and contributing different? What do you mean by contributing? maybe some more clarification would be good because I don't really understand; Yeah, because I mean like I personally can't really help with like physical tasks, but if my friend's, "Hey, can you read my resume for a job interview?", I can do that easily and stuff What do we mean by community? I think in the community, the option 1 might be better because it sort of also includes like the broader population, I guess, of your local community, you know, like your neighbours, whereas the people you spend time with to me it just means my friends and family and stuff, people I'm already close with who will treat me nicely anyway meaning in a community is not only that you belong to it but that it belongs to you, that you are an integral part, that not only do you need it, it needs you. So maybe something that reflects the fact that you are integral and other people are benefitting from you being in community maybe for community could add in school for YP: maybe for community could add in school as well maybe for like youth and students will YP with autism understand phrase meaning to me? I wonder if the phrase like "mean a lot to me" isn't maybe the most accessible in terms of like the words themselves are accessible, but something meaning a lot to you isn't like a literal interpretation of those words, so like autistic people, for example, might not know what that phrase means. So I don't know if there's another way to phrase that. accessibility needed for YP to participate in community: not understanding ATSI concept of Country	**I** take part in my community as much as I want to I assist others as much as I want to I am welcomed in community I am valued and appreciated in my communities I can access community I feel accepted and included in all of my communities I have opportunity to be involved in the communities I wish to be a part of
LIFE AREA 4. Leisure time (1 item)	Use term free time?	Descriptors Netflix, online TV streaming,

I spend my leisure time doing things I enjoy (for example, reading, social media, sport, hobbies, holidays, going out, online streaming)	YP engaged in more online activities young are mostly very active not passive: a lot of the examples in the list are quite passive hobbies in some way, so it would be good to have some examples of active hobbies Leisure = fun: leisure time it's fun things …I know what it means, but I think like people might not know what leisure means, but then they see it means fun things to do Embedding choices: Embedding choices into each existing item so, for example, under leisure it might be "I have choices about how I spend my leisure time … so having that front of mind under each of the items might be a way to sort of get a really good perspective on how much agency people have Nature as leisure: Maybe going outside or like being in nature could be one of these because that can like - for some people that looks like going on a fancy holiday and like swimming in the ocean, or whatever, but for other people that can look like going on a walk down your street and looking at the plants that people have in their gardens YP doing things they enjoy and that make us happy: I Time for leisure accessibility: to leisure holidays are a whole different ballgame in my opinion, because you have to have the money. You have to be able to... The transport. Trying to get around. Do you have family or support workers that can take you, and that can take that time off? I would say I want to do way more holidays then, holidays are... So many people I talk to with disabilities, they really, really want to travel. They really want to see the world, but they do not have the money or the resources	[active] sport I spend my free time doing things I enjoy (for example, online streaming, gaming, reading, social media, sport, going out, hobbies, holidays)

LIFE AREA 5. Health (3 items) I am satisfied with my physical health I am satisfied with my mental health (happy and content) I am satisfied with the way my pain is managed	Sleep and then overall wellbeing: I have good physical health. I have good mental health. I'm onto it, but I sleep shit… Am I functioning well? Do I have good resilience in my body and my immune system? When I look at health, I often think of some people, spiritual health is really important and emotional health as well ...But for me, I think it would be a little bit all-encompassing … I do think sleep is worth adding one, too, because… That's such a 50% of our life one Descriptors ableist? Remove? I would maybe suggest even taking away the example "happy and content, not anxious or depressed", because I do believe there's individuals out there who live like being content with being chronically anxious or depressed. I think those two things can, I guess - I believe words coincide among each other Disability isn't Unhealthy - Differing definitions of what constitutes physical health for YP with disability YP equate physical health with exercise, gym, diet: be able to improve upon. That's what I question myself anyway and I've been thinking about taking action with my physical health for a while, but I just haven't made my decision yet … Yeah, I would go to fitness when I think physical health Mental health descriptors for YP: Also I don't like the examples for "I am satisfied with my mental health" because I don't think it's realistic for most disabled people to be happy and content, not anxious or depressed, especially given psychosocial disability is very real and so I think that that automatically means that disabled people in response to this would not be able to be satisfied, which I think is untrue … Like I have many psychosocial disabilities, but I am satisfied with my mental health because of the supports that I get for it and the understanding I have of what my brain does … Somebody else might look at you and say, "I think their physical health is awful", you know, like from an outsider's point of view, but it's got nothing to do with them, it's just how you see it... a box there where you can write in "I still don't think this is enough, I think it needs to say something like about physical disability in there"	Delete descriptors Add pain statement

	Pain [was a suggestion in an earlier version?? Pain has a very big impact on wellbeing]	
LIFE AREA 6. Housing (3 items) I am satisfied with my living situation I like where I live I like who I live with I can make a choice about accessible housing	*a lot of people 15 to 25 might still be living with parents, so we must acknowledge that. They might be looking to start moving out as they're getting older, but maybe not. Transition of YP out of family home: because I'm currently trying to move out of home and, you know, physically my home is accessible because my parents made it accessible Accessibility/reduced options: do I like the place I live? I do …do I like the people I live with, do I - you know, like I guess am I satisfied with the accessibility of where I live as well …because I've been looking at, you know, different properties and stuff and they're all not accessible Facilities around house for YP: facilities around you, like what's around you. Like around my house there's like a park, so sometimes I go down there and do a bit of like training drills for soccer just on my own FGB BI; the surroundings of where you live, like it could be like is it noisy around there Because your living situation is also not necessarily where you live or you live with. It could also be how you're paying for it. Are you renting or buying? Are you on housing SA and are they shit to deal with? Because a lot of the time they are, or your landlord might be awful and not fixing the things that need to be fixed. Where you live might be in regards to the street you're on, the house you're in, the locality Affordability: “I can afford to live where I want” I think could be valuable, both in terms of layers around public housing and accessible housing 2 questions: making “I like where I live” and then as a separate question “I like who I live with”, as it seems almost like a double - I think it’s called a double-barrelled question FGF CO	I have opportunity to get accessible housing I can make a choice about accessible housing I can afford accessible housing where I want to live

	Housing security: things about accessibility of the house or feeling secure with your housing situation. You’re not worried that you’re not going to be able to make rent or that you’re not going to be able to live in this house long term	
LIFE AREA 7. Work (4 items) Overall I am satisfied with the work I do (for example, paid employment, unpaid caring, volunteering) Paid I am satisfied with the paid work I do Unpaid I am satisfied with the unpaid activities that I do for others I am satisfied school work experience and/or student placement	work becomes a strong part of YP identity include ADEs [supported employment] *are internships or like TAFE or university placements work/unpaid labour? *generally YP understood term unpaid caring * ‘colleagues’ was not included in the relationships section YP SLES - School Leavers Education Supplement - some funding that YP get so it sort of pays for support to learn job skills Existing stigma for YP with intellectual disability trying to get employment: Capacity for YP to speak up about dis needs in employment: *issue of how those not currently in work will view statements? YP still transitioning into work; Do we need an N/A? and does life area require instruction -if not working or if you haven’t worked yet I don't really have a job, but I am studying, like I'm a student, so would that count as work? *YP and career trajectory? – as a person with a disability, do you have opportunity to follow your chosen career? "I feel like I can explore different work experience opportunities" …around people not having to settle for jobs that they don't want just because we're disabled *the day program/ a day service/ day centre – will this be categorised as learning, because it isn’t work??> ADE yes is work	I am satisfied with the opportunity to follow my chosen career as a person with a disability, do you have opportunity to follow your chosen career I am paid well enough for the work I do I feel like I can explore different work experience opportunities is it a work that you have seen yourself doing how comfortable are you sort of expressing your needs as a person with a disability in a workplace Are you getting the right supports during your work

	some people who use a disability support service and they go to a day service or a day centre or whatever you want to call it these days, they often see that as work, but they're actually paying for it through their funding, they're paying to be there Treatment by colleagues at work, as a YP with disability: If respect and dignity wasn't its own category, I would be thinking this feels like it's missing "am I treated with respect at work"… I think being respected at work can make a huge difference to your wellbeing	
LIFE AREA 8. Learning I learn new things as much as I want to I am satisfied with the education I am getting (for example at school, vocational training, university)	Life experience of YP is centred on school/TAFE/uni/leaning These statements don't really talk about the barriers that people have to education and learning as people with a disability at all. We had a query about do we need a statement in there something like "I have supports to make learning accessible", or something like that, because there are so many barriers discrimination in the universities and schools, and so it's one little domain like area, but it's massive ...I don't know if this is specific enough for disability YP in a really big transition time in life. Like we're talking to young people at the moment and that sort of finishing schooling where you've got a fairly structured life and education setting and then it's okay, what comes next, you know, we've got to find what's the rest of life going to bring and we've got to set up supports for that and what's going to work the best Learning not being the same as formal education in terms of experience and barriers impacting wellbeing Segregated schooling still exists Day programs?	I have supports to make learning accessible I have opportunity to learn I am satisfied with access to learning I am satisfied with my access to learning opportunities/education or training

	Barriers to learning: because that can be money, transport. Are they even around in your area? If they're not, are you forced to do them online, but you have no WIFI or no way to get to that? So I do think that's a good one. I'm all about accessibility and inclusion	
LIFE AREA 9. Respect and Dignity (5 items) Overall I am satisfied with how people treat me Detailed aspects I am satisfied with how people treat me at home I am satisfied with how people treat me in the community I am satisfied with how people treat me when I get services (for example, health services, education, employment, community services) I am able to speak up about the things that are important to me	Experience of discrimination – 'the worry': Yes…. but I could see it also applying to interactions with strangers or acquaintances that don't fall into these categories, like when I go to a shopping centre and they refuse to talk to me because I use a wheelchair Situational for YP – where and who plus the system: sort of like who do you mean by people because like some people treat me very well, but then others treat me very badly. So it's sort of hard to get a middle ground three questions: one about how the people that you have relationships with, like the people that we talked about on the first slide, how they treat you, how institutions treat you, like health care places and the NDIS and whatever, and then how strangers treat you. Because I could say all the people I love in my life treat me with a lot of respect and dignity but I can't say the same when I step into a health care facility, and then it's always an each-way bet when it comes to interactions with strangers on the street and whatnot Actions more than just words Discrimination: I think it comes back to the point around like this is a wellbeing check and like every single disabled person has experienced discrimination and barriers, but that doesn't necessarily give you a response as to how well we are in response to that YP wanting to express feelings related to treatment YP still developing confidence and identity	I feel like people understand my disability and how it impacts my life I know what my rights are I have experienced barriers and discrimination as a person with a disability people acknowledge my diversity and intersectionality people listen to me when I share what I think
LIFE AREA 10. Choices (1 item) I control how I live my life	system choice? I've got limited choices in the organisations I contact and my choices like I can make them, but I've got limited sample size to make them from	none

(for example, where I go, what I do, what I eat, who I have as friends, who my services providers are)	YP having less choice because of disability-Les spontaneity: all choices must be planned: my disability is what I consider first and foremost when I make decisions, you know. Like my friends and stuff, they say, "Oh, I want to go on holidays somewhere" but I can't because there's a lot of planning involved and a lot more so I guess I don't have that freedom that other people have, you know, but that's just the way it is Learning decision making and choice making as a YP, it is a skill that you develop, who teaches you about decision making, it isn't just inherent as a YP maturity of decision: being 18 years old, you don't have full maturity over life choice Support in making choices as a YP: service coordinators, parents, advocates Respecting YP choice even if frustrating to adult/others > life learning > dignity of risk Ensuring the most amount of choice is given to YP as is possible; where are the limitations on choice for YP?	
LIFE AREA 11. Safety (3 items) Overall I feel safe in my life Detailed aspects I feel safe in my home I feel safe when I am out in the community I feel supported to speak out about my safety	*deaf referrals need webpage or National Relay Service Speaking up about safety: another question to follow up that question is like, when I did speak out about my safety concerns, was I supported through that process, was the issue resolved knowing who to contact if you feel unsafe, because I noticed you have the Lifelines and things down there, which is really important because people can feel unsafe and not know where to go... If they feel confident that even though if they currently feel really safe, they go, "I know who I can contact when, if I don't feel safe what would happen if people aren't safe? it's situational: well, yeah, I'm safe in my home, but the community is slightly less safe because as a person with disability there's some vulnerabilities not a lot, but there's some. [And then people in the group house were like the opposite. They're like "I'm safe at school	Add NRS references

*If you are in danger, call 000. Lifeline 131114 1800RESPECT (1800 737 732) is a free counselling service for people impacted by sexual assault, domestic or family violence and abuse. Beyond Blue is an Australian mental health and wellbeing support organisation. The National Disability Abuse and Neglect Hotline (the Hotline) 1800 880 052 is for reporting abuse or neglect of people with disability	and work, but I'm having conflict with the other person that I live with at the group house, the other resident, so I'm not safe in my home but I'm safe when I'm outside"]	
LIFE AREA 12. Finances (2 items) I have enough money to do things that are important to me(for example, going out with friends, buying food, buying medication) I have control over my money to do the things I want to do *The National Debt Hotline help people with money problems. You can call them	Extra cost with disability Financial security/future/living week-by-week: YP and control of money: personally, I guess my parents still have control over my money and what I spend it on, so I don't know, that might be something to consider [it's not just having the amount, but it's having access and control to it… do you have enough money as a young person just to do the social things you want to be doing and have your internet connected and pay for your uni things?] yes YP costs of living: It's like it's hard for me like it's hard to get like money, you know, like from like not enough money from the government for your pension, it's not enough ...Like they only give me like $516, or something. It's not enough to cover my rent [board?], you know, to help out my parents. Like I have to pay like at least $100 of rent [board]	none

on 1800 007 007 or chat with them on their website	YP providing you've been given the opportunity to learn about money: when we go to the shops, we go for a walk to the shops, we help him hand over hand and let him tap. He knows about things like that .. When you go to the checkout, if you help him, he can scan it or swipe it. We do things like that. So he has an idea of money, but where it comes from, how much you get, what do you do with it [not sure]	
LIFE AREA 13. SUPPORT Overall I am satisfied with the overall support I get (services, paid support, unpaid support) Unpaid support I am satisfied with the unpaid support I get (friends, family members, volunteers) Services I am satisfied with the services that I get when I need them (for example, education, employment and government services) Health services I am satisfied with the health services I get when I need them	do these statements canvas quality of support not just getting support? In satisfied Confusion of where support is from: But if people didn't know that, they would probably think supports, they might think NDIS supports or Centrelink income or hospital supports or something Do YP understand what unpaid support is? So-so I think with both of those it's not 100% clear what you mean by unpaid support or informal support … I would be a bit confused, I'd be like what is that, but then I probably would have gone okay, it probably means like sometimes I can't get a support worker, like my mum helps me get dressed and stuff like that or my sister helps me grab something. Services - massive areas to be in one statement Was probably 50-50 in terms of YP and who manage their own Centrelink or NDIS and who had parents to it for them: my family is in charge of like the NDIS and Centrelink side of stuff….Yeah, with the reporting thing, like reporting your income when working FGB BI is health services in the right spot? Level of understandability? Deaf people will be very confused with this. I think what we need to do is what the services are, then put in brackets maybe paid or unpaid, or even get a facility where they can tick the point and make things very, very specific and good examples. Because some deaf people might sort of realise that, as you said before, that unpaid work may relate to anything but it could be volunteering. It could be support work. It could be looking after family at home	none

Online DWI Young People survey data findings

Twenty-four surveys were submitted however 4 were not completed, with one answering only up to Question A17. Analysis of responses was completed on the 19 submitted surveys by young people where overall there were only a few incomplete question responses.

There were 7 male and 7 female respondents (36.8% each), another four (21.1&) reported indeterminate/ intersex/ unspecified and one respondent preferred not to say. Most respondents (n=15) were aged 18-24 (78.9%) with two in each of the age ranges 15-17 and 25-34 years.

Most respondents (76.5%) reported difficultly participating in activities of work, education and community living, followed by 72.2% of respondents reporting difficulty participating in activities of independent living, and 47.1% reporting difficulty in daily activities. The majority of respondents reported a psychosocial (n=14), sensory (n=12) or physical (n=12) disability, with fewer reporting an intellectual disability (n=9), other disability (n=7), and head injury, stroke or acquired brain injury (n=3). More than one response was possible on this question.

In this survey the young people respondents were asked about each statement in each life area to answer the question: "Do you think the description of each statement is clear? Yes or No and if No, why the statement is unclear. They were also asked which response option they preferred for each life area and lastly whether each life area should be included in the DWI.

A1 Relationships

This life area began with an overall statement about satisfaction with relationships. This life area received 100% support for inclusion in the DWI and >80% on the clarity question for each of its four statements, including the overall statement. Of note 70% of respondents thought there should be an additional statement about intimate and/or romantic relationships. All comments about why the statements were unclear in any life area as well as the comments relating to any other statement to be included were taken into consideration when revising and refining the DWI YP to produce the version to be trialled by the NDIA.

A2 Daily life

This life area had two statements one on personal care and one on everyday activities. The first was considered clear by nearly 80% (78.9%) and second by nearly 90% (89.5%). Eighteen of the nineteen respondents agreed with daily life being included in the DWI with one respondent reporting probably yes.

A3 Community

There were four statements in this life area: participating, contributing, belonging and meaning. These all received over 80% support for clarity by 17, 16, 15, and 19 respondents respectively. Seventeen of the respondents agreed with Community life being included in the DWI with one respondent reporting unsure.

A4 Leisure

There was only one statement in this life area; over 80% (83.3% n=15) agreed the statement was clear. Seventeen respondents thought the leisure aspect ought to be included in the DWI with two respondents reporting probably yes.

A5 Health

There were two statements in this life area one on physical health and the other on mental health. The responses here were more mixed with 15 respondents supporting the physical health statement as clear, and five did not; on the mental health statement 14 respondents through the statement was clear, five did not. Just over a quarter, five respondents thought additional statements could be included in this life area. Eighteen respondents thought that health ought to be included the DWI with one respondent reporting probably yes.

A6 Housing

There was only one statement in this life area to which 15 (78.9%) respondents agreed it was clear with four (21.1%) respondents not agreeing. Nearly one-third (31.6%) of respondents thought there should be additional statements in this life area. Seventeen (89.5%) respondents thought that housing ought to be included in the DWI with two respondents reporting probably yes.

A7 Work

This life aspect had an overall statement and two specific statements. The two specific statements were supported as clear by sixteen respondents (84.2%) however the overall statement was only supported by fourteen (73.7%) respondents as clear. Again, over one-quarter (26.3%) thought other statements ought to be included in this life area. All respondents (18 on this life area) agreed that Work ought to be included in the DWI.

A8 Learning

This life area had only one statement. Fifteen (84.2%) respondents thought this was clear. Less than one-quarter (n=4, 21.1%) thought there could be additional statements in this life area. The responses to whether this life area ought to be included were more spread. Sixteen (84.2%) respondents agreed, two (11.1%) reported probably yes, with one (5.6%) respondent reporting unsure.

A9 Respect and dignity

This life area had one statement only. Sixteen (84.2%) respondents thought this statement was clear with three (15.88%) not agreeing. Nearly one-third of respondents (n=6, 31.6%) thought additional statements could be included in this life area. Eighteen of the respondents thought this life area should be included in the DWI with one respondent reporting probably yes.

A10 Choices

There was one statement in this life area. Sixteen (88.9%) respondents thought the statement was clear, while two (11.1%) did not. The majority (89.5%) did not think there needed to be any additional statements. Sixteen (84.2%) thought this life area should be included in the DWI with two (10.5%) respondents reporting probably yes, and one (5.3%) respondent reporting no – stating “ I think this needs to be embedded into all items, not stand alone’.

A11 Safety

There was only one item in this life area. Fourteen (73.7%) of the respondents agreed the statement was clear however five (26.3%) did not. Again, over one -quarter (n=5, 26.3%) thought additional statements ought to be included in this life area. Sixteen (84.2%) of the respondents thought this life area ought to be included in the DWI, with one (5.3%) respondent reporting probably yes, another reporting unsure, and the remaining respondent reporting this life area could be merged with Respect and Dignity.

A12 Finances

There was only one statement in this life area. Seventeen (89.5%) of the respondents thought the statement was clear. Over one-third (n=7, 36.8%) thought there ought to be additional statements. Less than 80% of respondents (n=15, 78.9%) thought this life area ought to be included in the DWI, with four (21.1%) respondents reporting probably yes.

A13 Support

This life area included an overall statement and three specific statements. Seventeen respondents supported all four statements for clarity. Eighteen respondents (94.7%) supported this life aspect being in the DWI.

A final question asked about any other life aspects that ought to be included in the DWI. Of note of the 7 comments made three talked about identity being included.

DISCUSSION

Monash University, the University of Sydney and Flinders University are collaborating to develop and validate a preference-based Disability Wellbeing Index based upon the outcomes contained within the Australian Disability Strategy, the NDIS Outcomes Framework and other state-based Disability Inclusion Plans that can estimate the benefits and thus the cost-effectiveness of investments for people with disabilities. This index will also provide NDIS participants (and other people with disability who are not NDIS participants) an easy signal as to how certain types of funded supports have improved the wellbeing of other participants. This qualitative study privileged the voices of people with lived experience of disability, both in the research team and in focus groups and interviews. The findings of this study confirm that there are differences in the way wellbeing is framed and experienced by people with lived experience of disability which have been incorporated into the pilot version of the DWI.

A further benefit of the proposed index will be the availability of population data about changes in outcomes for people with disability to inform Australia’s obligations as a signatory to the United Nations Convention on the Rights of Persons with Disability (UNCRPD United Nations 2006). This is not currently possible with the existing outcomes frameworks (e.g., The NDIS Outcomes Framework (NDIS n.d. Australian Government 2021; Australian Disability Outcomes Framework (2021) as these are not linked with measurement tools that capture changes in the wellbeing of people with disability in a meaningful, robust and defensible way. The proposed index will provide a preference based measure that comprehensively covers the domains of interest to people with disability. A feasible summary outcome measure that captures the value of the elements of wellbeing that are critical to people with disability will enhance monitoring of both social equity outcomes and value for money in public spending. This study has been able to capture some of the nuance and detail expressed by people with disability to shape the content and structure of the pilot DWI.

The areas identified by the participants in our research that were incorporated into the pilot DWI included:

1. Reduced complexity in the language used, with careful consideration of precise and deliberate language that was not combining multiple concepts in one statement.
2. A shift from the use of the term ‘domain’ to ‘life areas’ to provide a more relatable term.
3. A recognition that some of the areas of the DWI were triggering and therefore restructuring the order of the life areas in recognition of this.
4. Recognition of discrimination as a significant impact on the wellbeing of people with lived experience of disability.
5. Recognition of the importance of relationships as a key factor in wellbeing
6. Awareness of differences in the framing of wellbeing by young people with disability that reflects generational perspectives and experiences.

Of significance, was the fact that several elements identified as problematic throughout the analysis process of the DWI drafts remained unresolved:

1. What is an adequate recall time to list in instructions for completion when some of the individuals with disability that will have memory gaps and issues with cognitive function/memory

2. The issue of some individuals requiring supported decision-making or proxy decision-making remains, and the Sydney team will continue to work on a a pathway that could ensure the voice on wellbeing of all people with disability was expressed independently by every individual.

3. Issues relevant to safety remain problematic. Although referral numbers and references to police and support organisations were included in later drafts of the DWI, ultimately any individual completing a DWI with support from another individual may be compromised in not being able to mark a true assessment of their safety if they are dependent on the person assisting them, or they may be influenced in marking up levels of satisfaction with wellbeing life areas to appease the person they are dependent on.

4. It was also thought that the early version of the DWI needed a clear definition of the concept of wellbeing at the start as mentioned earlier in this report.

5. It was thought that there was a need to tidy up the purpose statement in the introduction to the DWI. Our team suggestion was: *This disability wellbeing index aims to assess your wellbeing as a person with a disability and whether services such as those provided through the NDIS (but any public service) have helped you to achieve wellbeing. The disability wellbeing index will be used over numerous years in seeking to assess changes in your wellbeing overtime.*

The significance of this component of the DWI Project is the contribution of people with disability as research team members and the participation of a diverse group of people with disability in on-line focus groups and interviews. Without their contribution it would not be possible to develop the much-needed measure of wellbeing for people with disability that reflected lived experience of disability.

The inclusion of people living with disability in the development of meaningful and relevant life areas and items is essential to target the focus of the DWI in life areas and with statements that impact on wellbeing for people with disability, from their perspective. It was also critically important to ensure the co-facilitators of the focus groups are people with disability, adding expertise and understanding that is not possible to grasp in the same way from the perspective of non-disabled research team members. Together, this approach ensured that outcomes of importance were included in the DWI and that findings were framed in ways that were accessible, inclusive and meaningful to people with disability. The task of measuring outcomes that matter for people with disability is complex and must include a diversity of voices and perspectives to make the DWI as robust as possible, as well as being meaningful and acceptable to people with disability. This component of the development of the draft DWI has resulted in a more informed and relevant instrument to progress for pilot testing.

APPENDIX A: Organisational Contributions

Adult Focus Groups

Organisations who sent representatives to participate at Adult Focus Focus Groups and/or distributed information about the project

Organisations
ASPECT Research Centre for Autism Practice (National)
Being - Mental Health Consumers (NSW)
Centre for Disability Research and Policy Lived experience affiliates, University of Sydney
Parents with Disability Network (NSW)
Peer Network – People with Spinal Cord Injuries (NSW)
People with psychosocial disability (Australia)
Queenslanders with Disability Network Ltd (QDN)
Reframing Autism Ltd.
Spinal Cord Injuries Australia
VALID (Victorian Advocacy League For Individuals With Disability)
VALID Victoria - VALID Peer Action Groups (Regional Victoria)
Victorian Mental Illness Awareness Council (VMIAC)
Women with Disabilities Australia
Women with Disabilities Victoria – Experts by Experience Advocates

Young People Focus Groups

Organisations who sent representatives to participate at Young People Focus Groups and/or distributed information about the project

Organisations
AMAZE (shaping better future for Autisms)
Autism CRC (National)
Blind Citizens of Australia
Burke and Beyond, VIC (registered disability service provider)
Cerebral Palsy Alliance, NSW
Children and young People with Disability Australia (CYDA) and CYDA Youth Action team
Chronic Pain FB Group
CP-Achieve (Australian Centre for Health, Independence, Economic Participation and Value Enhanced Care for adolescents and young adults with Cerebral Palsy), VIC
Deafness Forum Australia
Down Syndrome Australia – Health Ambassadors
Enabled Youth Disability Network (EYDN), SA
Melbourne Disability Institute, VIC
Telethon Kids Institute, WA
The Visibility Movement (Dr Stephanie Mantilla)
Usher Kids Australia Network
VALID (Victorian Advocacy League for Individuals With Disability)
WWILD Sexual Violence Prevention Assn. Inc.
YES study University of Melbourne
Youth Disability Advocacy Service (YDAS), VIC

APPENDIX B: Participant Information Statement(s)

- Appendix B1: Adult PIS
- Appendix B2: Adult PIS Easy English
- Appendix B3: Young People PIS
- Appendix B4: Young People PIS Easy English

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Developing a Preference-based Wellbeing Index: The Disability Wellbeing Index (DWI)

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to participate in a focus group to share your views on the development of a disability wellbeing index (DWI) that will measure changes in various components of wellbeing over time. This measure

Monash University, the University of Sydney and Flinders University are collaborating to develop and validate a preference-based wellbeing index based upon the outcomes contained within the Australian Disability Strategy, the NDIS Outcomes Framework and other state-based Disability Inclusion Plans that can estimate the benefits and thus the cost-effectiveness of investments for people with disabilities. This index will also provide people with disability, including NDIS participants an easy signal as to how certain types of funded supports have improved the wellbeing of other participants.

It is important for multiple stakeholders to have input into how disability wellbeing is framed in the DWI. The purpose of this research is to gather input from people with disability to ensure that the domains and items in the DWI are relevant, of importance and accessible to people with disability.

Focus groups will discuss:

- The domains in the draft DWI about disability wellbeing
- The explanation of these DWI domains
- The items included in each domain
- Other domains or items that should be included
- Issues of concern (e.g., who will use the DWI, and for what purpose).

The findings of this research will inform development of a draft DWI that will be used in further testing and development to refine the index and ensure the accessibility and rigour of the DWI.

You have been invited to participate in this research because of the particular insights and perspectives you can contribute as a person with disability.

This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study. Please read this document carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

This study is being undertaken by a research team at the University of Sydney:

- Dr Kim Bulkeley, Senior Lecturer, Centre for Disability Research and Policy, The University of Sydney, Chief Investigator
- Professor Emerita Gwynnyth Llewellyn, Centre for Disability Research and Policy, Co-Director, Centre of Research Excellence in Disability and Health, The University of Sydney
- Assoc Professor Gang Chen, Monash University
- Assoc Professor Dennis Petrie, Monash University
- Professor Anthony Harris, Monash University
- Professor Julie Ratcliffe, Flinders University
- Ms Imelda Noti, Faculty of Medicine and Health, The University of Sydney

This research has been commissioned by the Australian Government National Disability Insurance Agency and Monash University.

(3) What will the study involve for me?

There are two phases to this study. If you agree to participate, in Phase 1 of the study, you will be invited to take part in a focus group consultation, with approximately 4-8 participants, held via video conference. The focus group will be facilitated by a member of the research team and another researcher with lived experience of disability. The session will run for approximately 1 ½ hours. You will receive a short background document in advance, which will contain information about the DWI domains and items. You are welcome to provide further input in writing after the focus group discussion if you wish.

If you require, accessibility arrangements can be made to ensure that you can participate fully in the consultation process. Accessibility accommodations may include holding discussions using live videoconference captioning, or arranging for participants to provide input in writing or via phone or individual interview. Where required, documents can be provided in a form compatible with software used by participants who use alternative and augmentative communication devices, in Easy Read form, or in accessible screen reader formats.

You will be asked whether you consent to an audio recording being made of the focus group discussion (or interview if you are unable or unwilling to participate in a focus group) in which you take part. The discussion will be recorded only if all participants provide their consent; if not, one of the researchers will take notes on the views expressed during the discussion.

In Phase 2 of the study, between 1 and 2 weeks after you participate in Phase 1 above, we will invite you to complete a follow-up online questionnaire. This will ask you to:

- indicate your preferred set of domains and items from two or three options given
- indicate your preferred explanatory statement about the domains
- provide additional comments if you wish.

The options in the questionnaire will be developed following Phase 1 consultations. You will also be asked several questions about yourself. We anticipate the questionnaire can be completed in 10-15 minutes.

You may respond to the questionnaire via other means (e.g., over the phone, in person) if necessary to accommodate accessibility requirements.

(4) How much of my time will the study take?

Your participation will involve a time commitment of approximately 2 to 2.5 hours, allowing an hour and half for focus group (or interview) participation, and 30 minutes for email communications (e.g., providing your Participant Consent Form) and completing the online questionnaire.

(5) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by informing a member of the research team, verbally or in writing, that you no longer want to participate.

If you provide any written input, within two weeks of providing that input you can request that it should not be included in the research findings. After this time, it may not be possible to remove your responses from the analysis. If you participate in a focus group it may not be possible to exclude individual data once the session has commenced, however you are free to leave the focus group at any time.

(6) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

If at any stage during your participation in the study you become distressed, you can contact Lifeline’s 24 Hour Crisis Support Service on 13 11 14.

(7) Are there any benefits associated with being in the study?

If you participate in a focus group or interview you will receive a $100 voucher to recognise and thank you for your input.

The proposed index will not provide a direct benefit to participants but has the potential to provide a preference-based measure that comprehensively covers the domains of interest to people with disability to enhance monitoring of both social equity outcomes and value for money in public spending.

(8) What will happen to information about me that is collected during the study?

Your information will be stored securely and your identity/information will only be disclosed with your permission, except as required by law. Study findings may be published and presented orally, but you will not be identified in these publications or presentations.

Audio recordings will be used solely to produce a transcript of the focus group or interview so that the researchers can analyse the views expressed by participants. No third parties will have access to the audio recordings or to any written input you provide as part of this study.

During the project, all study materials will be stored digitally on the University of Sydney Research Data Store, a secure system. All files that contain identifying information will be encrypted. Electronic files containing written input from participants and audio recordings will be labelled using participant and focus group codes, not participant names. Upon completion of the project, all study materials will be stored digitally on Research Data Store. Study materials will be retained for 5 years after project completion.

(9) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(10) What if I would like further information about the study?

When you have read this information, a member of the research team will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact a member of the research team:

Kim Bulkeley E-mail: kim.bulkeley@sydney.edu.au Ph: 0430 431 292
Gwynnyth Llewellyn E-mail: Gwynnyth.llewellyn@sydney.edu.au
Imelda Noti E-mail: imelda.noti@sydney.edu.au Ph: 0434 980 877

(11) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You will receive a summary report on findings from the focus groups and follow-up questionnaires including in accessible formats.

(12) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney (Project number 2022/318). As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** ro.humanethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep

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Stakeholder consultation: Disability Wellbeing Index - Qualitative Study

PARTICIPANT INFORMATION STATEMENT

What is this study about?

The Australian government wants to know how people with disability are feeling about their lives.

We are looking at different ways to ask people with disability how they are feeling about their lives.

We want to have focus groups to get feedback on what questions and information we should ask people with disability about their wellbeing.

This information will be made into a Disability Wellbeing Index (DWI).

The Index will be filled out by people with disability to let others know how they are feeling about their lives.

The person can choose if they want to give information about their disability.

We are inviting you to be part of this study to help make sure the questions on the Disability Wellbeing Index are important to people with disability.

This Participant Information Statement tells you about the study.

You can choose to be part of this study or not. It is your choice.

In the focus groups, we will talk about:

- What questions should be on the Disability Wellbeing Index?

- what areas of their lives (we call these domains) do we need to ask people with disability to know more about their wellbeing.

- the good things and problems that could happen if people with disability give information about how they feel about their lives.

By saying you want to be part of this study you are telling us that you:

- understand the information on this Participant Information Statement.

- are OK with being part of the study. There is more information about the study later in this paper.

- are OK to have information about you used in the way you have been told.

Who is doing the study?

This study is being done by a research team at the University of Sydney.

The Australian Government and the National Disability Agency has asked for this study to be done.

What will I need to do for this study?

If you say you want to be part of this study, you will be asked to give your feedback in a focus group, with 4 people with disability. This will be on a video call or in person.

A person on the research team at the University of Sydney and a person with a disability will lead the focus group.

Before the meeting you will get a paper with questions that have already been asked about the wellbeing of people with disability.

You can write to us after the focus group meeting if you want to give more information.

If you need support to be part of the focus group we can help with things like:

- Having what people say in video calls come up in writing on the screen (Live videoconference captioning).

- Having your say by writing to us or talking to us.

  This could be on the phone or face to face.

- Giving papers in Easy English, or in a way that works on people's computers, like screen readers.

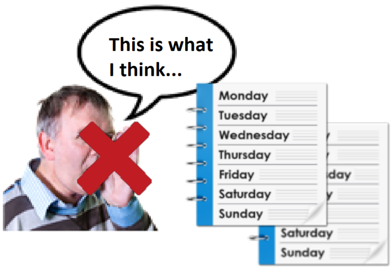
You will be asked if it is OK to record your voice in the focus group talk. The talk will only be recorded if everyone says it is OK. If it is not OK, someone from the team will write down what people say.

Being part of this study will take about 2 hours. 1.5 hours for the focus group and 30 minutes for emails and feedback (like sending your consent form).

Do I have to be part of the study? Can I stop being part of the study if I want to?

It is your choice if you want to be part of this study. You do not have to. No one at the University of Sydney will think anything bad about you if you do not want to be part of it.

If you say you will be part of the study, you can stop at any time. You can tell someone on the study team, or write to them, to say you want to stop.



You need to tell us before 2 weeks if you do not want anything you have put in writing to be part of the study report. After 2 weeks we might not be able to take out your answers.

If you are part of the focus group we might not be able to take out what you have said once everyone starts talking, but you can leave the focus group at any time.

Is there anything that could be a problem for me, will I have to pay for anything if I'm part of this study?

You will need to give your time to be part of the study. We don't think there will be any other problems or anything you will need to pay for.

If you get upset and feel really bad while you are part of the study, you can call Lifeline's 24 Hour Crisis Support Service on 13 11 14 at any time.

What are the good things about being part of the study?

If you are part of a focus group, you will get a $100 voucher to say thank you.

Getting information about the wellbeing of people with disability on the Disability Wellbeing Index is something the Australian Government wants to do.

It is important that people have a say about making sure the Disability Wellbeing Index has the right questions about wellbeing.

What will happen with the information I give about me while I am part of the study?

By saying you want to be part of the study, you are saying it is OK for us to know your name and what you have to say (in the focus group, in writing, on the phone).

We will only use your information for what we have said we will, unless you say it is OK for us to use it for other things.

Information about you will be kept safe and will only be used if you say it is OK, unless we need to use it because of the law.

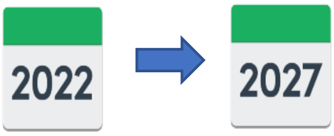
The report from the study might be read by other people, or talked about, but no one will know it is you in the report.

If we have recorded your voice, we will only use it to write down what people said in the focus group. Only the study team will listen to what you said or read anything you have written.

All information will be put onto a computer at the University that is safe and private.

Anything that has information about you will not have your name on it. We will use codes so people can't get into it.

Before we get rid of any papers (like consent forms) they will be put onto a computer at the University that is safe and private.



When we finish the study, all the information will be kept on a computer at the University that is safe and private for 5 years.

Can I tell other people about the study?

Yes, you can tell other people about the study.

What if I want more information about the study?

After you have read this Participant Information Statement, you can talk to someone on the study team if you have any questions.

You can contact these people from the study team if you want to know or ask anything:

- Kim Bulkeley

  E-mail: kim.bulkeley@sydney.edu.au

  Ph: 0430 431 292

- Imelda Noti

  E-mail: imelda.noti@sydney.edu.au

  Ph: 0434 980 877

Will I be told the results of the study?

You have the right to know about what the study said. You will get a report about it.

What if I have a problem or am not happy about the study?

Studies in Australia that people are part of are looked at by a group called a Human Research Ethics Committee (HREC).

The HREC of the University of Sydney has said this study is OK to do.

We will do the study the way the National Statement on Ethical Conduct in Human Research (2007) says we need to. This is to keep people who are part of studies safe.

If you have a problem with the way this study is being done, or you want to speak up about a problem to someone who is not part of the study, please tell Sydney University:

The Manager, Ethics Administration, University of Sydney:

THE UNIVERSITY OF SYDNEY

- **Telephone:** +61 2 8627 8176
- **Email:** ro.humanethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

Please give them the study name and protocol number (2022/318) so they know which study you are part of.

You can keep this Participant Information Statement.

Easy English words by VALiD made with photosymbols®

Centre for Disability Research and Policy
Faculty of Medicine and Health

ABN 15 211 513 464

Kim Bulkeley

Senior Lecturer
Sydney School of Health Sciences

Centre for Disability Research and Policy

Susan Wakil Health Building
The University of Sydney
NSW 2006 Australia
Telephone: +61 430 431 292

Email: kim.bulkeley@sydney.edu.au

Web: http://www.sydney.edu.au/

Developing a Preference-based Wellbeing Index: The Disability Wellbeing Index (DWI)

PARTICIPANT INFORMATION STATEMENT – Young People

(1) What is this study about?

You are invited to participate in a focus group to share your views on the development of a disability wellbeing index (DWI) that will measure changes in various components of wellbeing over time.

Monash University, the University of Sydney and Flinders University are collaborating to develop and validate a preference-based wellbeing index based upon the outcomes contained within the Australian Disability Strategy, the NDIS Outcomes Framework and other state-based Disability Inclusion Plans that can estimate the benefits and thus the cost-effectiveness of investments for people with disabilities. This index will also provide people with disability, including NDIS participants, an easy signal as to how certain types of funded supports have improved the wellbeing of other participants.

It is important for multiple stakeholders to have input into how disability wellbeing is framed in the DWI. The purpose of this research is to gather input from people with disability to ensure that the domains and items in the DWI are relevant, of importance and accessible to people with disability. The input of young people with disability, between 15 and 24 years, will help shape the DWI to be inclusive of young people's perspectives and needs.

Focus groups will discuss:

- The domains in the draft DWI about disability wellbeing
- The explanation of these DWI domains
- The items included in each domain
- Other domains or items that should be included
- Issues of concern (e.g., who will use the DWI, and for what purpose).

The findings of this research will inform development of a draft DWI that will be used in further testing and development to refine the index and ensure the accessibility and rigour of the DWI.

You have been invited to participate in this research because of the particular insights and perspectives you can contribute as a young person with disability.

This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study. Please read this document carefully and ask questions about anything that you don't understand or want to know more about. Your parent/person responsible/guardian will also be asked to consent to your involvement in this study if you are under 18 years of age.

Participation in this research study is voluntary.

By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

This study is being undertaken by a research team at the University of Sydney:

- Dr Kim Bulkeley, Senior Lecturer, Centre for Disability Research and Policy, The University of Sydney, Chief Investigator
- Professor Emerita Gwynnyth Llewellyn, Centre for Disability Research and Policy, Co-Director, Centre of Research Excellence in Disability and Health, The University of Sydney
- Assoc Professor Gang Chen, Monash University
- Assoc Professor Dennis Petrie, Monash University
- Professor Anthony Harris, Monash University
- Professor Julie Ratcliffe, Flinders University
- Ms Imelda Noti, Faculty of Medicine and Health, The University of Sydney

This research has been commissioned by the Australian Government National Disability Insurance Agency and Monash University.

(3) What will the study involve for me?

There are two phases to this study. If you agree to participate, in Phase 1 of the study, you will be invited to take part in a focus group consultation, with approximately 4-8 participants, held via video conference. The focus group will be facilitated by a member of the research team and another researcher with lived experience of disability. The focus group will include other young people with disability, between 15-24 years. The session will run for approximately 1 ½ hours. You will receive a short background document in advance, which will contain information about the DWI domains and items. You are welcome to provide further input in writing after the focus group discussion if you wish.

If you require, accessibility arrangements can be made to ensure that you can participate fully in the consultation process. Accessibility accommodations may include holding discussions using live videoconference captioning, or arranging for participants to provide input in writing or via phone or individual interview. Where required, documents can be provided in a form compatible with software used by participants who use alternative and augmentative communication devices, in Easy Read form, or in accessible screen reader formats.

You will be asked whether you consent to an audio recording being made of the focus group discussion (or interview if you are unable or unwilling to participate in a focus group) in which you take part. The discussion will be recorded only if all participants provide their consent; if not, one of the researchers will take notes on the views expressed during the discussion.

In Phase 2 of the study, between 1 and 2 weeks after you participate in Phase 1 above, we will invite you to complete a follow-up online questionnaire. This will ask you to:

- indicate your preferred set of domains and items from two or three options given
- indicate your preferred explanatory statement about the domains
- provide additional comments if you wish.

The options in the questionnaire will be developed following Phase 1 consultations. You will also be asked several questions about yourself. We anticipate the questionnaire can be completed in 10-15 minutes.

You may respond to the questionnaire via other means (e.g., over the phone, in person) if necessary to accommodate accessibility requirements.

(4) How much of my time will the study take?

Your participation will involve a time commitment of approximately 2 to 2.5 hours, allowing an hour and half for focus group (or interview) participation, and 30 minutes for email communications (e.g., providing your Participant Consent Form) and completing the online questionnaire.

(5) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by informing a member of the research team, verbally or in writing, that you no longer want to participate.

If you provide any written input, within two weeks of providing that input you can request that it should not be included in the research findings. After this time, it may not be possible to remove your responses from the analysis. If you participate in a focus group it may not be possible to exclude individual data once the session has commenced, however you are free to leave the focus group at any time.

(6) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

If at any stage during your participation in the study you become distressed, you can contact Lifeline’s 24 Hour Crisis Support Service on 13 11 14.

(7) Are there any benefits associated with being in the study?

If you participate in a focus group or interview you will receive a $100 voucher to recognise and thank you for your input.

The proposed index will not provide a direct benefit to participants but has the potential to provide a preference-based measure that comprehensively covers the domains of interest to people with disability to enhance monitoring of both social equity outcomes and value for money in public spending.

(8) What will happen to information about me that is collected during the study?

Your information will be stored securely and your identity/information will only be disclosed with your permission, except as required by law. Study findings may be published and presented orally, but you will not be identified in these publications or presentations.

Audio recordings will be used solely to produce a transcript of the focus group or interview so that the researchers can analyse the views expressed by participants. No third parties will have access to the audio recordings or to any written input you provide as part of this study.

During the project, all study materials will be stored digitally on the University of Sydney Research Data Store, a secure system. All files that contain identifying information will be encrypted. Electronic files containing written input from participants and audio recordings will be labelled using participant and focus group codes, not participant names. Upon completion of the project, all study materials will be stored digitally on Research Data Store. Study materials will be retained for 5 years after project completion.

(9) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(10) What if I would like further information about the study?

When you have read this information, a member of the research team will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact a member of the research team:

Kim Bulkeley E-mail: kim.bulkeley@sydney.edu.au Ph: 0430 431 292
Gwynnyth Llewellyn E-mail: Gwynnyth.llewellyn@sydney.edu.au
Imelda Noti E-mail: imelda.noti@sydney.edu.au Ph: 0434 980 877

(11) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You will receive a summary report on findings from the focus groups and follow-up questionnaires including in accessible formats.

(12) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney (Project number 2022/318). As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** ro.humanethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep

THE UNIVERSITY OF SYDNEY

Centre for Disability Research and Policy
Faculty of Medicine and Health

ABN 15 211 513 464

Kim Bulkeley

Senior Lecturer
Sydney School of Health Sciences

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Telephone: +61 430 431 292

Email: kim.bulkeley@sydney.edu.au

Web: http://www.sydney.edu.au/

Stakeholder consultation: Disability Wellbeing Index - Qualitative Study

PARTICIPANT INFORMATION STATEMENT – Young People

What is this study about?

Australian Government

The Australian government wants to know how people with disability are feeling about their lives.

We are looking at different ways to ask people with disability how they are feeling about their lives.

We want to have focus groups to get feedback on what questions and information we should ask people with disability about their wellbeing.

This information will be made into a Disability Wellbeing Index (DWI).

The Index will be filled out by people with disability to let others know how they are feeling about their lives.

The person can choose if they want to give information about their disability.

We are inviting young people with disability to be part of this study to help make sure the questions on the Disability Wellbeing Index are important to people with disability.

This Participant Information Statement tells you about the study.

You can choose to be part of this study or not. It is your choice.

In the focus groups, we will talk about:

- What questions should be on the Disability Wellbeing Index?

- what areas of their lives (we call these domains) do we need to ask people with disability to know more about their wellbeing.

- the good things and problems that could happen if people with disability give information about how they feel about their lives.

By saying you want to be part of this study you are telling us that you:

- understand the information on this Participant Information Statement.

- are OK with being part of the study. There is more information about the study later in this paper.

- are OK to have information about you used in the way you have been told.

Who is doing the study?

This study is being done by a research team at the University of Sydney.

The Australian Government and the National Disability Agency has asked for this study to be done.

What will I need to do for this study?

If you say you want to be part of this study, and your parent/person responsible/guardian also agrees you will be asked to give your feedback in a focus group, with 4 people with disability. This will be on a video call or in person.

A person on the research team at the University of Sydney including a person with a disability will lead the focus group.

Before the meeting you will get a paper with questions that have already been asked about the wellbeing of people with disability.

You can write to us after the focus group meeting if you want to give more information.

If you need support to be part of the focus group we can help with things like:

- Having what people say in video calls come up in writing on the screen (Live videoconference captioning).

- Having your say by writing to us or talking to us.

  This could be on the phone or face to face.

- Giving papers in Easy English, or in a way that works on people's computers, like screen readers.

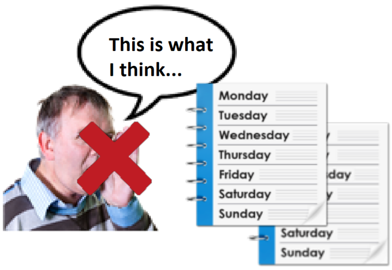
You will be asked if it is OK to record your voice in the focus group talk. The talk will only be recorded if everyone says it is OK. If it is not OK, someone from the team will write down what people say.

Being part of this study will take about 2 hours. 1.5 hours for the focus group and 30 minutes for emails and feedback (like sending your consent form).

Do I have to be part of the study? Can I stop being part of the study if I want to?

It is your choice if you want to be part of this study. You do not have to. No one at the University of Sydney will think anything bad about you if you do not want to be part of it.

If you say you will be part of the study, you can stop at any time. You can tell someone on the study team, or write to them, to say you want to stop.



You need to tell us before 2 weeks if you do not want anything you have put in writing to be part of the study report. After 2 weeks we might not be able to take out your answers.

If you are part of the focus group we might not be able to take out what you have said once everyone starts talking, but you can leave the focus group at any time.

Is there anything that could be a problem for me, will I have to pay for anything if I'm part of this study?

You will need to give your time to be part of the study. We don't think there will be any other problems or anything you will need to pay for.

If you get upset and feel really bad while you are part of the study, you can call Lifeline's 24 Hour Crisis Support Service on 13 11 14 at any time.

What are the good things about being part of the study?

If you are part of a focus group, you will get a $100 voucher to say thank you.

Getting information from young people with disability about the wellbeing of people with disability on the Disability Wellbeing Index is something the Australian Government wants to do.

It is important that people have a say about making sure the Disability Wellbeing Index has the right questions about wellbeing.

What will happen with the information I give about me while I am part of the study?

By saying you want to be part of the study, you are saying it is OK for us to know your name and what you have to say (in the focus group, in writing, on the phone).

We will only use your information for what we have said we will, unless you say it is OK for us to use it for other things.

Information about you will be kept safe and will only be used if you say it is OK, unless we need to use it because of the law.

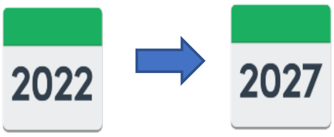
The report from the study might be read by other people, or talked about, but no one will know it is you in the report.

If we have recorded your voice, we will only use it to write down what people said in the focus group. Only the study team will listen to what you said or read anything you have written.

All information will be put onto a computer at the University that is safe and private.

Anything that has information about you will not have your name on it. We will use codes so people can't get into it.

Before we get rid of any papers (like consent forms) they will be put onto a computer at the University that is safe and private.



When we finish the study, all the information will be kept on a computer at the University that is safe and private for 5 years.

Can I tell other people about the study?

Yes, you can tell other people about the study.

What if I want more information about the study?

After you have read this Participant Information Statement, you can talk to someone on the study team if you have any questions.

You can contact these people from the study team if you want to know or ask anything:

- Kim Bulkeley
  E-mail: kim.bulkeley@sydney.edu.au

  Ph: 0430 431 292

- Imelda Noti
  E-mail: imelda.noti@sydney.edu.au

  Ph: 0434 980 877

Will I be told the results of the study?

You have the right to know about what the study said. You will get a report about it.

What if I have a problem or am not happy about the study?

Studies in Australia that people are part of are looked at by a group called a Human Research Ethics Committee (HREC).

The HREC of the University of Sydney has said this study is OK to do.

We will do the study the way the National Statement on Ethical Conduct in Human Research (2007) says we need to. This is to keep people who are part of studies safe.

If you have a problem with the way this study is being done, or you want to speak up about a problem to someone who is not part of the study, please tell Sydney University:

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
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Please give them the study name and protocol number (2022/318) so they know which study you are part of.

You can keep this Participant Information Statement.

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APPENDIX C: Participant Consent Forms

Appendix C1: Adult Participant Consent Form

Appendix C2: Adult Participant Consent Form Easy English

Appendix C3: Young People Consent Form

Appendix C4: Young People Consent Form Easy English

Appendix C5: Participant Consent Form Parent

Centre for Disability Research and Policy
Faculty of Medicine and Health

ABN 15 211 513 464

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Senior Lecturer
Sydney School of Health Sciences

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NSW 2006 Australia

Telephone: +61 430 431 292
Email: kim.bulkeley@sydney.edu.au

Web: http://www.sydney.edu.au/

Developing a Preference-based Wellbeing Index: The Disability Wellbeing Index (DWI)

PARTICIPANT CONSENT FORM

I, ... [PRINT NAME], agree to take part in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.

- I have read the Participant Information Statement and have been able to discuss my involvement in the study with the researchers if I wished to do so.

- The researchers have answered any questions that I had about the study and I am happy with the answers.

- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney, now or in the future.

- I understand that I can withdraw from the study at any time.

- I understand that I may leave the focus group discussion/interview at any time if I do not wish to continue. I also understand that it will not be possible to withdraw my comments once the focus group has started as it is a group discussion.

- I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.

- I understand that the results of this study may be published, but these publications will not contain my name or any identifiable information about me.

I consent to audio recording of the focus group discussion or interview in which I participate: YES ☐ NO ☐

I would like to receive a summary report of research findings: YES ☐ NO ☐

If you answered **YES**, please write the email address would you like the report to be sent to:

Email:____

....

Signature

....

PRINT name

....

Date

Centre for Disability Research and Policy
Faculty of Medicine and Health

ABN 15 211 513 464

Kim Bulkeley

Senior Lecturer
Centre for Disability Research and Policy

Susan Wakil Health Building
The University of Sydney
NSW 2006 Australia

Telephone: +61 430 431 292
Email: kim.bulkeley@sydney.edu.au

Web: http://www.sydney.edu.au/

Consent Form

This study is called **Disability Wellbeing Index: Qualitative study**

The study is being done by the University of Sydney

☑ Tick the boxes you say yes to

☐ I know:

- what this study is for
- what I will need to do
- any good things or problems that could happen.

☐ I have read the Participant Information Statement.

I talked to the people leading the study if I wanted to.

These people are called researchers.

☐ The researchers have answered any questions that I had about the study, and I am happy with the answers.

☐ I know it is my choice if I want to be part of this study.

If I do not want to be part of this study, the researchers or anyone from the University of Sydney will not get upset with me.

☐ I know I can stop being part of this study at any time.

☐ If I choose to stop being part of the focus group at any time, I know anything I have said to the group might still be used by the researchers.

☐ I know the information about me will be safe and private.

My information will only be used if I say it's okay unless my information is needed by law.

☐ I know my name will not be used.

People will not know that it is me in any of the information I give. The name of the organisation that I am part of might be in papers or presentations.

☐ It is OK that what I say is recorded.

☐ I would like to get a report about the study.

If you said **YES**, please write the email address you want the report to be sent to:

Email: ____

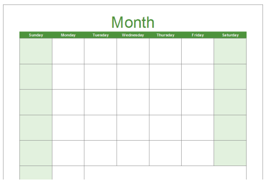
☐ I want to be part of this project.

Name:

Signature:

Organisation you are part of

(if you choose to tell us):



Date:

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Sydney School of Health Sciences

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The University of Sydney
NSW 2006 Australia

Telephone: +61 430 431 292
Email: kim.bulkeley@sydney.edu.au

Web: http://www.sydney.edu.au/

Developing a Preference-based Wellbeing Index: The Disability Wellbeing Index (DWI)

CONSENT FORM – Young People

I, ... [PRINT NAME], consent to take part in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.

- I have read the Participant Information Statement and have been able to discuss my involvement in the study with my parent/person responsible/guardian who will also provide consent for my participation in this research if I am under 18 years of age .

- The researchers have answered any questions that I had about the study and I am happy with the answers.

- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney, now or in the future.

- I understand that I can withdraw from the study at any time.

- I understand that I may leave the focus group discussion/interview at any time if I do not wish to continue. I also understand that it will not be possible to withdraw my comments once the focus group has started as it is a group discussion.

- I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.

- I understand that the results of this study may be published, but these publications will not contain my name or any identifiable information.

I consent to audio recording of the focus group discussion or interview in which I participate:

YES ☐ NO ☐

I would like to receive a summary report of research findings: YES ☐ NO ☐

If you answered **YES**, please write the email address would you like the report to be sent to:

Email:____

....

Signature

....

PRINT name

....

Date

THE UNIVERSITY OF SYDNEY

Centre for Disability Research and Policy
Faculty of Medicine and Health

ABN 15 211 513 464

Kim Bulkeley

Senior Lecturer

Centre for Disability Research and Policy

Faculty of Medicine and Health

Susan Wakil Health Building
The University of Sydney
NSW 2006 Australia

Telephone: +61 430 431 292
Email: Kim Bulkeley@sydney.edu.au

Web: http://www.sydney.edu.au/

Consent Form

This study is called **Disability Wellbeing Index** and we will speak with young people with disability about wellbeing .

The study is being done by the University of Sydney

☑ Tick the boxes you say yes to

☐ I know:

- what this study is for
- what I will need to do
- any good things or problems that could happen
- My parent/person responsible/guardian will also consent to my involvement in this project if I am under 18 years

☐ I understand the Participant Information Statement.

I talked to the people leading the study if I wanted to.

These people are called researchers.

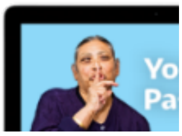
☐ The researchers have answered any questions that I had about the study, and I am happy with the answers.

☐ I know it is my choice if I want to be part of this study.

If I do not want to be part of this study the researchers or anyone from the University of Sydney will not get upset with me.

☐ I know I can stop being part of this study at any time.

☐ If I choose to stop being part of the focus group at any time, I know anything I have said to the group might still be used by the researchers.



☐ I know the information about me will be safe and private.

My information will only be used if I say it’s okay unless my information is needed by law.

☐ I know my name will not be used.

People will not know that it is me in any of the information I give. The name of the organisation that I am part of might be in papers or presentations.

☐ It is OK that what I say is recorded.

☐ I would like to get a report about the study.

If you said **YES**, please write the email address you want the report to be sent to:

Email: ____

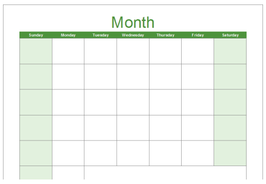
☐ I want to be part of this project.

Name:

Signature:

Organisation you are part of

(if you choose to tell us):



Date:

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Email: kim.bulkeley@sydney.edu.au

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Developing a Preference-based Wellbeing Index: The Disability Wellbeing Index (DWI)

Parent/PersonResponsible/Guardian CONSENT FORM

I, ... [PRINT NAME], consent for my child who is under 18 years of age

…………………………………………….…. (PRINT NAME), to take part in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Statement and have been able to discuss my child's involvement in the study with my child.
- The researchers have answered any questions that I had about the study and I am happy with the answers.
- I understand that being in this study is completely voluntary and my child does not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney, now or in the future.
- I understand that my child can withdraw from the study at any time.

- I understand that my child may leave the focus group discussion/interview at any time if they do not wish to continue. I also understand that it will not be possible to withdraw my childs comments once the focus group has started as it is a group discussion.

- I understand that personal information about my child that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about my child will only be told to others with my permission, except as required by law.

- I understand that the results of this study may be published, but these publications will not contain my child's name or any identifiable information.

I consent to audio recording of the focus group discussion or interview in which my child participates:

YES ☐ NO ☐

I would like to receive a summary report of research findings: YES ☐ NO ☐

If you answered **YES**, please write the email address would you like the report to be sent to:

Email:____

....

Signature

....

PRINT name

....

Date

APPENDIX D: Versions of DWI Adult and Young People / Discussion Guides

Appendix D1: Version 1 of DWI Adult

Appendix D2: DWI Adult Easy English Discussion Guide

Appendix D3: Version DWI Young People 29/07/22

Appendix D4: Version DWI Young People 19/08/22

APPENDIX D1: Version 1 of DWI Adult

Disability Wellbeing Index (Draft for discussion)

The following questions ask how you feel about your own life. There are no right or wrong answers – it is just about you and your life.

Please answer all the questions. If you find it is hard to decide among the alternative described answers, please choose the one that comes closest to what you feel.

Please think about your life in the last 4 weeks.

1.Choice & control	2. Daily living activities	3. Relationships	4. Home
5. Health & wellbeing	6. Lifelong learning	7. Productivity activities	8. Social connectedness, community & civic participation
9.Rights protection, safety & dignity	10. Financial security	11. Self worth/self esteem	12. Achieving in life

Domain 1: Choice & Control

This wellbeing domain looks at the extent to which people have developed independence and the ability to make choices and decisions in their daily lives.

1 I feel in control of my life.

(‘Control of my life’ means having the choice to do things or have things done for you that you want to be done, in ways that you like and when you want).

2 I make my own choices (e.g. where I go, what I do, what I eat, who my friends are).

3 I have as much independence as I want.

Domain 2: Daily living activities

This wellbeing domain looks at the services and supports received as well as participation in a range of activities in daily lives.

1 Considering the services and supports I received, I participate in a range of daily living activities (e.g. domestic tasks, personal care, travel and transport).

2 I am able to do things for myself (for example, household tasks, self-care, travel).

3 I have access to support and services when needed.

(This concerns being able to count on support when you need it, as well as the quality of the support.)

Domain 3: Relationships

This wellbeing domain looks at people's personal and close relationships.

1 I enjoy my close relationships with family and friends.

2 I enjoy my close and intimate relationships.

3 I enjoy my personal relationships.

('Personal relationships' refers to how you get along with the people in your life, your friends, your family, your partner(s), the people you live with.)

Domain 4: Home

This wellbeing domain looks at what people think about where they live.

1 I am happy with where I live.

2 I like where I live.

Domain 5: Health & Wellbeing

This wellbeing domain looks at people's mental and physical health, as well as health services.

1 I feel cheerful.

2 I feel calm and relaxed.

3 I have the energy to do the things I want to do.

4 I am satisfied with my physical health.

('Physical health' refers to the state of your physical body and how well it's operating.)

5 I get the health care that is right for me.

Domain 6: Lifelong learning

This wellbeing domain looks at opportunities to learn things.

1 I have access to education and training that is right for me.

2 I have access to learning opportunities that are right for me.

Domain 7: Productivity activities

This wellbeing domain looks at how people feel about productivity activities.

1 I participate in productive activities that are meaningful to me (e.g. paid employment, unpaid work, volunteering, and caring for others).

2 I am satisfied with my ability to work.

Domain 8: Social connectedness, community & civic participation

This wellbeing domain looks at inclusion in the community.

1 I participate in the community as much as I want (e.g. sports, religious, cultural activities).

2 I feel welcomed and included in my community.

3 I feel connected with my social networks.

Domain 9: Rights protection, Safety & Dignity

This wellbeing statement looks at peoples' rights and safety.

1 I am treated with dignity and respect.

('Dignity and respect' refer to other people value you as a person and listen to what you have to say)

2 I feel my rights are promoted, upheld and protected.

3 I feel safe and secure.

4 I am free from abuse and neglect.

Domain 10: Financial security

This wellbeing domain looks at peoples' current financial situation.

1 I have access to enough money to do things that are important to me.

2 I have enough money to look after myself.

3 I am happy with my financial security (e.g. situation with money).

Domain 11: Self-worth / Self-esteem

This wellbeing domain looks at how people feel about themselves.

1 I feel my life is important and has a purpose.

2 I feel my life is meaningful.

3 I feel valued in the community.

Domain 12: Achieving in life

This wellbeing domain looks at the extent to which people feel they are achieving things in life that are important to them.

1 I feel that I am achieving things in my life that are important to me.

2 I am satisfied with my achievement of personal goals.

Further Information Contact: Dr Kim Bulkeley,
Centre for Disability Research and Policy,
University of Sydney, kim.bulkeley@sydney.edu.au

APPENDIX D2: Things for the focus groups to talk about:

The National Disability Insurance Agency (NDIA) and the Department of Social Services (DSS) is thinking about using a Disability Wellbeing Index (DWI).

The DWI is so people with disability can choose to let the NDIA and DSS know about the different areas of their life.

The NDIS and DSS could use the DWI to find out if the supports and services that people with disability get makes their lives better. This is to make sure people's supports and services help with their wellbeing.

The person with disability can choose to do the DWI on paper or online. They can have help from their support person.

There are three parts to making the DWI.

This part is to choose the items to go into the DWI.

Today we will be talking about the items that go in the DWI.

The items will be put into groups called domains.

These are like the domains used by the NDIS and in the Outcomes Framework for the Australian Disability Strategy (ADS).

What we will do today.

We will look at each domain and its items one by one.

This is an example of what we will be doing.

We are using the first domain called Choice and Control.

The items all ask about your own life.

Please think about your life over the last 4 weeks.

Then answer the following questions:

1. Domain: Choice & Control

- Is the wellbeing statement easy to understand?

- Is each item easy to understand? We will go through each item one by one.

- Do any of the items need more information on what they mean?

  Which ones?

- Which of the items do you like the best and why?

Let's start now. We will start with Domain Choice and Control on Page 1 and finish with Domain 12 on page x

Now we are near the end of the questions today.

The next questions are about the whole DWI.

a. Are there any other life domains that are important to the wellbeing of people with disability?

b. Are there any life domains that are not important and could be taken out?

c. Would you feel OK about doing the DWI?

Thank you for being part of the meeting today.

We will contact you in the next 2 weeks to ask you to do a short survey.

This survey will have the next draft of the DWI on it.

You can contact these people from the study team if you want to know or ask anything:

- Kim Bulkeley

  E-mail: kim.bulkeley@sydney.edu.au

  Ph: 0430431292

- Gwynnyth Llewellyn

  E-mail: Gwynnyth.llewellyn@sydney.edu.au

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  Ph: 0434 980 877

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APPENDIX D3: Disability Wellbeing Index (DWI) Young People

Disability Wellbeing Index (Draft for discussion)

Draft (29 July 2022)

Life Aspects & Items

Overview

1. Relationships	2. Daily life	3. Community
4. Leisure	5. Health	6. Housing
7. Work	8. Learning	9. Respect & dignity
10. Choices	11. Safety	12. Finances
13. Support		

1. Relationships

Overall

I am satisfied with the people I talk to and do things with (for example, friends, family, carers, support workers)

Family

I am satisfied with my family life

Friends

I am satisfied with the friends I talk to and do things with

Supporters

I get along with people who support me

2. Daily life

Personal care

I am satisfied with how I look after myself or get others to do personal care for me (for example, eating, washing, dressing)

Everyday activities

I am satisfied with how I do everyday activities or get others to help me (for example, cooking, shopping, solving problems)

3. Community

Participating

I participate in the community as I want (for example, sports, religious groups, cultural activities, connection to Country)

Contributing

I contribute to others in the community as much as I want to

Belonging

I feel accepted and included in all of my communities, in person and online

Meaning

I do things in my life that mean a lot to me

4. Leisure

I spend my leisure time doing things I enjoy (for example, hobbies, movies, holidays)

5. Health

I am satisfied with my physical health

I am satisfied with my mental health (for example, happy and content, not anxious or depressed)

6. Housing

I like where I live and who I live with

7. Work

Overall

I am satisfied with the work I do and I work as much as I want to (for example, paid employment, unpaid caring, volunteering)

Paid

I am satisfied with the paid work I do and I work as much as I want to

Unpaid

I am satisfied with what I do for others and I do this as much as I want (for example, volunteering and unpaid caring)

8. Learning

I learn new things as much as I want to

9. Respect & dignity

I am satisfied with how people treat me

10. Choices

I control how I live my life (for example, where I go, what I do, what I eat, who I have as friends, who my services providers are)

11. Safety

I feel safe in my life

12. Finances

I have enough money to do things that are important to me

13. Support

Overall

I am satisfied with the overall support I get

Unpaid support

I am satisfied with the unpaid support I get when I need it

Services

I am satisfied with the services that I get when I need them (for example, health, education, employment and government services)

Health services

I am satisfied with the health services I get when I need them

Further Information Contact: Dr Kim Bulkeley,

Centre for Disability Research and Policy,

University of Sydney, kim.bulkeley@sydney.edu.au

APPENDIX D4: Disability Wellbeing Index (DWI) Young People

Draft (29 July 2022, amended 19 August 2022)

Life Aspects & Items

Overview

1. Relationships	2. Daily life	3. Community
4. Leisure	5. Health	6. Housing
7. Work	8. Learning	9. Respect & dignity
10. Choices	11. Safety	12. Finances
13. Support		

1. Relationships

Overall

I am satisfied with the people I talk to and do things with (for example, friends, family, carers, support workers)

Family

I am satisfied with my family life

Friends

I am satisfied with the friends I talk to and do things with

Intimate partners

I am satisfied with the intimate relationships, both romantic and non-romantic that I have in my life

Supporters

I get along with people who support me

2. Daily life

Personal care

I am satisfied with how I look after myself or get others to do personal care for me (for example, eating, washing, dressing)

Everyday activities

I am satisfied with how I do my day-to-day activities or get others to help me (for example, cooking, shopping, solving problems)

3. Community

Participating

I participate in the community as much as I want to (for example, sports, religious groups, cultural activities, connection to Country)

Contributing

I contribute to the community as much as I want to

Belonging

I feel accepted and included in all of my communities, in person and online

Meaning

I do things in my life that mean a lot to me

4. Leisure

I spend my leisure time doing things I enjoy (for example, hobbies, movies, Netflix, online TV streaming, gaming, holidays)

5. Health

I have good physical health

I have good mental health

6. Housing

I am satisfied with my living situation

I like where I live

I like who I live with

7. Work

Overall

I am satisfied with the work I do and I work as much as I want to (for example, paid employment, unpaid caring, volunteering)

Paid

I am satisfied with the paid work I do and I work as much as I want to

Unpaid

I am satisfied with what I do for others, and I do this as much as I want (for example, volunteering and unpaid caring, work experience

8. Learning

I learn new things as much as I want to

I am satisfied with my access to learning opportunities including education or training

9. Respect & dignity

I am satisfied with how people treat me at home

I am satisfied with how people treat me in the community

10. Choices

I control how I live my life (for example, where I go, what I do, what I eat, who I have as friends, who my services providers are)

11. Safety

I feel safe in my home

I feel safe in the community

I feel supported to speak out about my safety

***referrals to be added to support life area for 'not safe'**

000 Police

131114 Lifeline

1800 880 052 Disability Abuse and Neglect hotline https://www.jobaccess.gov.au/service-providers/making-complaint-and-reporting-abuse-and-neglect

12. Finances

I have enough money to do things that are important to me

if in financial difficulty contact 1800 007 007 Financial Counselling Australia https://www.financialcounsellingaustralia.org.au/

13. Support

Overall

I am satisfied with the overall support I get

Unpaid support

I am satisfied with the unpaid support I get when I need it

Services

I am satisfied with the services that I get when I need them (for example, education, employment and government services)

I am satisfied with the health services I get when I need them

Unpaid support

I am satisfied with the unpaid support I get when I need it

APPENDIX E: Copy of Online Surveys - Adult and Young People

Appendix E1: Copy of Adult Online Survey

Appendix E2: Copy of Young People Survey

APPENDIX E1: Adult Online Survey

The Disability Wellbeing Index (DWI): Qualitative Study

- Focus group online follow-up survey-

University of Sydney Human Research Ethics Committee: Project No. 2022/318

Contact details: Dr Kim Bulkeley
E-mail: kim.bulkeley@sydney.edu.au
Ph: 0430 431 292

Introduction to the survey

Thank you for being part of one of our focus groups in this research project.

In this follow-up survey we ask for your views about the

1. importance of the domains for the Disability Wellbeing Index and (Part A)
2. your preferred response options to use in the Disability Wellbeing Index (Part B)

At the end of the survey, you will be asked several questions about yourself. (Part C)

Your input will help us provide advice to the NDIS and DSS about the Disability Wellbeing Index.

Declaration by Participant

I have previously consented to take part in the above research, and I consent to completing this 15-minute survey ☐

Part A: Domains

A1. Do you think the following domains should be included in the wellbeing index for people with disability?

Domains	Definitely Yes	Probably Yes	Unsure	Probably No
Choice & Control	○	○	○	○
Daily living activities	○	○	○	○
Relationships	○	○	○	○

Home	○	○	○	○
Health & Wellbeing	○	○	○	○
Lifelong learning	○	○	○	○
Productivity activities	○	○	○	○
Social connectedness, community & civic participation	○	○	○	○
Rights protection, Safety & Dignity	○	○	○	○
Financial security	○	○	○	○
Self-worth	○	○	○	○
Achieving in Life	○	○	○	○
_______________ (new domain proposed by stakeholder)	○	○	○	○
_______________ (new domain proposed by stakeholder)	○	○	○	○

A2. Are there any other life domain(s) missing from the table above? If so, please list them here:

(Free text)

A3. Are there any other items anywhere across the index that should be included, that are missing from the DWI survey?

(Free text)

A4. Anything else you would like to tell us?

(Free text)

Part B: This question is about response format using one item from the Choice and Control domain as an example (below).

B1. This question is about response format using one item from the Choice and Control domain as an example (below). Which one of the three formats do you prefer? Please tick one circle only.

- ○ (A, Never, Rarely, Sometimes, Usually, Always)
- ○ (B, Not at all, A little, Moderately, Mostly, Totally)
- ○ (C, Poor, Fair, Good, Very good, Excellent)
- ○ I don't have a preference

(A)	Never	Rarely	Sometimes	Usually	Always
I feel in control of my life.	○	○	○	○	○

(B)	Not at all	A little	Moderately	Mostly	Totally
I feel in control of my life.	○	○	○	○	○

(C)	Poor	Fair	Good	Very good	Excellent
To what extent do you feel in control of your life?	○	○	○	○	○

Part C: The next five questions are about you:

C1. About your disability:

1.1 In everyday life, do you have difficulty participating in any of the following, related to a long-term health condition or impairment or disability?	
• 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	○ Yes ○ No
• Activities of work, education and community living, such as: – Social and community life – Work, education or training	○ Yes ○ No

C2. 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 circle next to any that apply – you can tick more than one circle)

○ **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**

○ **Other**

C3. Gender:

- ○ Female
- ○ Male
- ○ Indeterminate/Intersex/Unspecified
- ○ Prefer not to say

C4. Age:

- ○ 15-24
- ○ 25-34
- ○ 35-44
- ○ 45-54
- ○ 55-59
- ○ 60-64
- ○ Prefer not to say

PART D: Comments to this project

Please feel free to add any comments related to this project below:

(Free text)

If you would like to provide any further comments on this project, please feel free to contact:

Dr Kim Bulkeley, kim.bulkeley@sydney.edu.au

Centre for Disability Research and Policy, University of Sydney

Thank you!

APPENDIX E2: Young People Online Survey

The Disability Wellbeing Index (DWI): Qualitative Study

- Focus group online follow-up survey-

University of Sydney Human Research Ethics Committee: Project No. 2022/318

Contact details: Dr Kim Bulkeley
E-mail: kim.bulkeley@sydney.edu.au
Ph: 0430 431 292

Introduction to the survey

Thank you for being part of one of our focus groups or interview in this research project.

In this follow-up survey we ask for your views on draft DWI life aspects and their statements (Part A) and several non-identifying questions about yourself (Part B).

Your input will help us provide advice to the NDIS and DSS about the Disability Wellbeing Index.

Declaration by Participant

I have previously consented to take part in the above research, and I consent to completing this 15-minute survey ☐

Part A: DWI life aspects and their statements

The current list of life aspects includes:

Relationships, Daily Life, Community, Leisure, Health, Housing, Work, Learning, Respect & Dignity, Choices, Safety, Finances, and Support

We would like to know from your perspective

(1) whether the statements for life aspects are clear,
(2) whether there is any other statement you think should be included under each life aspect,
(3) which response option is better for each life aspect, and
(4) whether the life aspects should be included in the wellbeing index for people with disability.

A1. Life aspect: Relationships

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	Is clear	Is unclear	Explain why it is unclear
A1.1 Overall relationship I am satisfied with the people I talk to and do things with (for example, friends, family, carers, support workers)	○	○	
A1.2 Family I am satisfied with my family life	○	○	
A1.3 Friends I am satisfied with the friends I talk to and do things with	○	○	
A1.4 Supporters I am satisfied with the way I get along with my supporters (please select clear or unclear)	○	○	

A1.5 Is there any other statement you think should be included under the Relationships life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A1.6 Which response option do you prefer for Relationships life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A1.7 Do you think Relationships life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A2. Life aspect: Daily life

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	**Is clear**	**Is unclear**	**Explain why it is unclear**
A2.1 Personal care I am satisfied with how I look after myself or get others to do personal care for me (for example, eating, washing, dressing)	○	○	
A2.2 Everyday activities I am satisfied with how I do everyday activities or get others to help me (for example, cooking, shopping, solving problems)	○	○	

A2.3 Is there any other statement you think should be included under the Daily life life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A2.4 Which response option do you prefer for Daily life life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A2.5 Do you think Daily life life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A3 Life aspect: Community

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	**Is clear**	**Is unclear**	**Explain why it is unclear**
A3.1 Participating I participate in the community as I want (for example, sports, religious groups, cultural activities, connection to Country)	○	○	
A3.2 Contributing I contribute to others in the community as much as I want to	○	○	
A3.3 Belonging I feel accepted and included in all of my communities, in person and online	○	○	
A3.4 Meaning I do things in my life that mean a lot to me	○	○	

A3.5 Is there any other statement you think should be included under the Community life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A3.6 Which response option do you prefer for Community life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A3.7 Do you think Community life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A4 Life aspect: Leisure

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	**Is clear**	**Is unclear**	**Explain why it is unclear**
A4.1 I spend my *leisure* time doing things I enjoy (for example, hobbies, movies, holidays)	○	○	

A4.2 Is there any other statement you think should be included under the Leisure life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A4.3 Which response option do you prefer for Leisure life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A4.4 Do you think Leisure life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A5 Life aspect: Health

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	**Is clear**	**Is unclear**	**Explain why it is unclear**
A5.1 Physical health I am satisfied with my physical health	○	○	
A5.2 Mental health I am satisfied with my mental health (for example, happy and content, not anxious or depressed)	○	○	

A5.3 Is there any other statement you think should be included under the Health life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A5.4 Which response option do you prefer for Health life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A5.5 Do you think Health life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A6 Life aspect: Housing

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	**Is clear**	**Is unclear**	**Explain why it is unclear**
A6.1 I like where I live and who I live with	○	○	

A6.2 Is there any other statement you think should be included under the Housing life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A6.3 Which response option do you prefer for Housing life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A6.4 Do you think Housing life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A7 Life aspect: Work

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	**Is clear**	**Is unclear**	**Explain why it is unclear**
A7.1 Overall I am satisfied with the work I do and I work as much as I want to (for example, paid employment, unpaid caring, volunteering)	○	○	
A7.2 Paid I am satisfied with the paid work I do and I work as much as I want to	○	○	

A7.3 Unpaid I am satisfied with what I do for others and I do this as much as I want (for example, volunteering and unpaid caring)	○	○	

A7.4 Is there any other statement you think should be included under the Work life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A7.5 Which response option do you prefer for Work life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A7.6 Do you think Work life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A8 Life aspect: Learning

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	Is clear	Is unclear	Explain why it is unclear
A8.1 I *learn* new things as much as I want to	○	○	

A8.2 Is there any other statement you think should be included under the Learning life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A8.3 Which response option do you prefer for Learning life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A8.4 Do you think Learning life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A9 Life aspect: Respect & Dignity

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	Is clear	Is unclear	Explain why it is unclear
A9.1 I am satisfied with how people treat me	○	○	

A9.2 Is there any other statement you think should be included under the Respect & Dignity life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A9.3 Which response option do you prefer for Respect & Dignity life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A9.4 Do you think Respect & Dignity life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A10 Life aspect: Choices

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	Is clear	Is unclear	Explain why it is unclear
A10.1 I *control* how I live my life (for example, where I go, what I do, what I eat, who I have as friends, who my services providers are)	○	○	

A10.2 Is there any other statement you think should be included under the Choices life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A10.3 Which response option do you prefer for Choices life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A10.4 Do you think Choices life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A11 Life aspect: Safety

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	Is clear	Is unclear	Explain why it is unclear
A11.1 I feel *safe* in my life	○	○	

A11.2 Is there any other statement you think should be included under the Safety life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A11.3 Which response option do you prefer for Safety life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A11.4 Do you think Safety life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A12 Life aspect: Finances

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	Is clear	Is unclear	Explain why it is unclear
A12.1 I have enough money to do things that are important to me	○	○	

A12.2 Is there any other statement you think should be included under the Finances life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A12.3 Which response option do you prefer for Finances life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A12.4 Do you think Finances life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A13 Life aspect: Support

Do do you think the description of each statement is clear?

If it is unclear, could you let us know the reason or suggest a new statement?

Statement	Is clear	Is unclear	Explain why it is unclear
A13.1 Overall support I am satisfied with the overall support I get)	○	○	
A13.2 Unpaid support I am satisfied with the unpaid support I get when I need it	○	○	
A13.3 Services I am satisfied with the services that I get when I need them (for example, health, education, employment and government services)	○	○	
A13.4 Health Services I am satisfied with the health services that I get when I need	○	○	

A13.5 Is there any other statement you think should be included under the Support life aspect? If so, please explain and add additional statement(s) here:

(Free text)

A13.6 Which response option do you prefer for Support life aspect?

○ **Option 1:** Never, Rarely, Sometimes, Mostly, Always,
○ **Option 2:** Not at all, A little bit, Sometimes, Most of the time, All the time
○ **Option 3:** Not at all, A little, Moderately, Mostly, Completely
○ None of the above (*please explain why*):

(Free text)

A13.7 Do you think Support life aspect should be included in the wellbeing index for people with disability?

Yes	Probably yes	Unsure	No	If No, please explain
○	○	○	○	

A14 If you think there is any other important life aspect(s) that matter to the wellbeing of people with disability that are missing from this current draft please list them here:

(Free text)

Part B: The next five questions are about you:

B1. About your disability:

1.1 In everyday life, do you have difficulty participating in any of the following, related to a long-term health condition or impairment or disability?	
• 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	○ Yes ○ No
• Activities of work, education and community living, such as: – Social and community life – Work, education or training	○ Yes ○ No

B2. 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 circle next to any that apply – you can tick more than one circle)

○ **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**

○ **Other**

B3. Gender:

○ Female
○ Male
○ Indeterminate/Intersex/Unspecified
○ Prefer not to say

B4. Age:

○ Under 15
○ 15-17
○ 18-24
○ 25-34
○ Over 34
○ Prefer not to say

PART C: Comments to this project

C.1 Please feel free to add any comments related to this project below:

(Free text)

If you would like to provide any further comments on this project, please feel free to contact:

Dr Kim Bulkeley, kim.bulkeley@sydney.edu.au

Centre for Disability Research and Policy, University of Sydney

Thank you!