



**Children and Young People  
with Disability Australia**

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15 November 2024

**Attention: Suraksha Maharaj, Director, Disability, Ageing, Carers and Mental Health Section Health, Disability and Vital Statistics Branch**

Please accept this letter as Children and Young People Australia (CYDA)'s submission to the Australian Bureau of Statistics' (ABS) consultation into collecting data about disability paper.

**Feedback on ABS "Collecting Data about Disability" Consultation Paper**

Thank you for the opportunity to provide written feedback on the consultation paper "Collecting data about disability". CYDA's Policy and Research Manager Dr Liz Hudson and Policy and Research Officer Dr Tess Altman attended a virtual meeting with ABS staff and other Disability Representative Organisations (DROs) on Thursday 17 October. In this meeting, we provided detail on CYDA's existing data collection measures along with our suggestions for improving nationally consistent data collection on disability in Australia. This letter further builds upon the suggestions we outlined in the meeting.

**Children and Young People with Disability Australia (CYDA)**

CYDA is the national representative organisation for children and young people with disability aged 0 to 25 years. Our vision is that children and young people with disability are valued and living empowered lives with equality of opportunity; and our purpose is to ensure governments, communities, and families are empowering children and young people with disability to fully exercise their rights and aspirations.

**CYDA's Recommendations to ABS**

- 1. Develop a nationally consistent and strengths-based approach to asking questions about disability in ABS surveys.** As part of this approach, ensure that sets of questions about disability are underpinned by the social model of disability, and are broad enough to capture the diversity and lived experiences of disability.
- 2. Pose consistent questions that identify people with disability directly, ensuring the opportunity to link and disaggregate data across multiple datasets.** This is especially important to address in datasets that do not already ask about disability directly, such as the Census.
- 3. Integrate data from multiple sources to improve understanding of how children and young people's wellbeing or service use differs among different population and geographic groups.**
- 4. Develop new datasets to gain a needed understanding of children and young people with disability as an equity priority group in the area of education.**

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5. **Give the option to group data at the level of LGA, to allow for capturing demographics of marginalised groups in regional and remote areas.**
6. **Ensure that data collection is accessible, to enable children and young people with disability to participate directly.** This process could involve Disability Representative Organisations, such as CYDA as trusted links to the community.
7. **Communicate ABS data summary and key output documents in accessible formats such as Easy Read.**

### **CYDA's Existing Data Collection Measures**

CYDA collects data on disability through surveys, consultations, and focus groups to inform our advocacy work and policy submissions. We ensure that questions are guided by a strengths-based approach to disability that always a) allows the respondent to identify as a person with disability, if they choose, and b) gives the option to provide further detail on disability through an open ended, non-mandatory question. This approach avoids the medical model of categorising disability into rigid or fixed types, and leaves room for the diversity within disability by enabling respondents to define their own identity.

### **Leading Best Practice through a Strengths-Based Approach to Disability**

CYDA notes that there is no nationally agreed framing of disability-specific questions in surveys. While we appreciate the need for flexibility in tailoring survey questions to specific groups and topics, we think it is crucial to instil best practice principles for framing questions about disability. Any question about disability should be guided by a strengths-based approach underpinned by the social model of disability which places the onus on societal barriers that prevent people with disability from participating fully in society and ensures that disability is framed in a positive light that centres identity. Questions must also be broad enough to capture the diversity and lived experiences of disability.

CYDA notes that ABS currently combines data from the Survey of Disability, Ageing and Carers (SDAC), the Census of Population and Housing, and the Short Disability Module to gain an understanding of disability in Australia<sup>1</sup>. While triangulating these sources provides a comprehensive overview of disability, we are concerned that not all these sources are underpinned by a strengths-based best practice approach to disability. In particular, the current phrasing of Census questions that focus on provision of care and supports, rather than directly asking about disability, perpetuate a deficit-based understanding of disability that is not centred on identity or strengths. While CYDA understands that the Census questions are designed to capture profound or severe disability as defined by the SDAC, we recommend that the Census questions be updated to ensure they are strengths-based, ask people directly about their disability in an open-ended way, and ask about the impacts of their disability on the supports they may require. This would also allow for a more accurate understanding of national demographics, and a consistent way of understanding disability across multiple datasets.

CYDA recommends that ABS work towards developing a nationally consistent and strengths-based approach to asking questions about disability in surveys. This approach should draw upon the existing work conducted by the Australian Institute of Health and

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<sup>1</sup> Australian Bureau of Statistics (2022) Understanding Disability Statistics in the Census and the Survey of Disability, Ageing and Carers. Available at: <https://www.abs.gov.au/statistics/detailed-methodology-information/information-papers/understanding-disability-statistics-census-and-survey-disability-ageing-and-carers>

Welfare (AIHW) on developing a disability data flag<sup>2</sup> (a set of questions to identify records of people with characteristics of interest within the data collection that enables key population groups, such as people with disability, to be identified), and continue to benchmark to international standards such as the World Health Organizations' International Classification of Functioning, Disability and Health as well as the Washington Group Set of Questions on Disability. The approach should also be informed by current Australian governmental guidelines such as the Attorney General's Department Data Standards Manual<sup>3</sup> and the Australian Disability Strategy's Good Practice Guidelines for Engaging with People with Disability<sup>4</sup>, as well as current best practice approaches to collecting diversity and inclusion data put forward by Diversity Council Australia<sup>5</sup>.

## Improving Intersectional Data through Linking Datasets and Disaggregation

Intersectional data is of vital importance for our understanding of the experiences of children and young people with disability in Australia. While incorporating the best practice principles detailed above and leaving room for the diversity within disability, questions on disability also need to be posed in a consistent way across multiple datasets that ensures the opportunity to link and disaggregate data.

We urge the government to endorse AIHW's Children with Disability Report<sup>6</sup> recommendation of integrating data from multiple sources to improve understanding of how children and young people's wellbeing or service use differs among different population and geographic groups, where data on a specific population group may only be available in one dataset. Such datasets include AIHW's Children with Disability and Australia's Children<sup>7</sup> Reports, and the Nationally Consistent Collection of Data on School Students with Disability (NCCD)<sup>8</sup>.

We also recommend prioritising a nationally consistent disability data collection to address the gap in data for students with disability, especially regarding year 12 attainment and school attendance. The absence of these metrics in the [Better and Fairer Schools Agreement](#), despite the identification of students with disability as a priority equity cohort, highlights the need for robust data to drive transparency and support systemic advocacy. Public access to this data will help track and improve educational outcomes for students with disability.

Additionally, CYDA notes that it is challenging to obtain reliable disaggregated data for children and young people with disability. While tools such as Census Table Builder allow for exploring data in more detail, the absence of disability-specific related questions in large-scale surveys like the Census limits the ability to effectively disaggregate data into subgroups, such as disability, age and other intersectional factors (e.g., gender, ethnicity),

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<sup>2</sup> Australian Institute of Health and Welfare (2023) Disability Links and Other Information: Standardised Disability Flag. Available at: [https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/disability/links-other-information#Standardised\\_disability\\_flag](https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/disability/links-other-information#Standardised_disability_flag)

<sup>3</sup> Attorney General's Department (2021) National Legal Assistance Data Standards Manual. Available at: <https://www.ag.gov.au/legal-system/publications/national-legal-assistance-data-standards-manual>

<sup>4</sup> Department of Social Services (2023) Good Practice Guidelines for Engaging with People with Disability. Available at: <https://www.disabilitygateway.gov.au/news/good-practice-guidelines>

<sup>5</sup> Diversity Council of Australia (2024) Your Diversity and Inclusion Data Questions Answered. Available at: <https://www.dca.org.au/news/blog/your-di-data-questions-answered>

<sup>6</sup> Australian Institute of Health and Welfare (2022) Children with Disability in Australia. Available at: <https://www.aihw.gov.au/reports/children-youth/australias-children/contents/data-gaps>

<sup>7</sup> Australian Institute of Health and Welfare, Australia's Children (2022). Available at: <https://www.aihw.gov.au/reports/children-youth/australias-children/contents/data-gaps>

<sup>8</sup> Australian Government and Education Services Australia (2024) Nationally Consistent Collection of Data on School Students with Disability. Available at: <https://www.nccd.edu.au/>

and compare them. To achieve meaningful disaggregation by disability, it is essential to identify people with disability in surveys like the SDAC does.

The issue of disaggregation is also compounded in regional or remote areas. Currently available data is disaggregated to the level of postcode, yet numbers are not reported if they amount to less than 10 people in a postcode. This can mean that data is missing in areas with less critical mass – which particularly applies for marginalised groups already at risk of under reporting. We point to the vital need for accurate data on disabled and marginalised groups in regional and remote areas to provide an evidence base for purposes such as directing important resources, e.g. housing or services. We suggest that there continues to be an option to group data at the level of LGA as per ABS Community Profiles, to allow for capturing demographics of marginalised groups in regional and remote areas.

### **Making Data Collection and Outputs Accessible**

CYDA is concerned that both data collection and data outputs are inaccessible for children and young people with disability. Children and young people with disability and DROs such as CYDA should be involved as active participants and decisionmakers at every stage of the data process. As highlighted in AIHW's Australia's Children Report, there are limited instances of gathering children's opinions or experiences as evidence. While national-level monitoring exists, it mainly involves administrative data from service delivery and surveys targeting adults, exclusively. Similarly, data output communication is also not specifically targeted towards children and young people with disability.

CYDA advocates for the improvement of data accessibility to strengthen the evidence base and improve outcomes, as “...*society cannot be equitable unless all children are included, disabilities cannot be included unless sound data collection and analysis render them visible*<sup>9</sup>.”

Creating project consultative or advisory committees (or other similar processes) with young people with disability could be one mechanism to support this. Another approach could be to ensure that data forms such as digital or paper copies are directly sent both to families and caregivers as well as to children and young people themselves. This gives the option for children and young people to decide whether to participate independently or to seek assistance from their parent or caregiver and enables them to define their own identities.

Regarding data outputs, CYDA have been unable to find any easy read, or otherwise accessibility focused communication exploring key ABS outputs, including the Census. CYDA recommends that ABS data summary and key output documents going forward should be communicated in accessible formats. A best practice example of data output accessibility is the Australian Disability Strategy's Disability Gateway, which makes Easy Read copies of all Strategy documents available, including accessible analysis of survey and data outputs<sup>10</sup>.

Young people with disability are often not given the opportunities to access information which would support their individual and systemic advocacy efforts or high-level analytical skills, unnecessarily limiting their opportunities and potential. CYDA also notes, following the National Medical and Health Research Council's Statement of Ethical Conduct<sup>11</sup>, that

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<sup>9</sup> United Nations Children's Fund 2013, *State of the World's Children 2013: Children with Disabilities*, United Nations: New York, p. 63.

<sup>10</sup> Department of Social Services (2024) Easy Read Copies of the Australian Disability Strategy Documents. Available at: <https://www.disabilitygateway.gov.au/ads/easy-read-strategy>

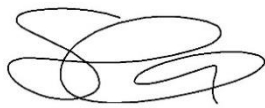
<sup>11</sup> National Health and Medical Research Council (2023) National Statement of Ethical Conduct in Human Research. Available at: <https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2023>

good research practice across any program is to ensure that all participants benefit from the knowledge their participation in the research helps produce. Accessibility of this information would validate the efforts of young people with disability who participate by enabling them to engage with the outputs of their contribution.

Thank you again for this opportunity to contribute to improving nationally consistent data collection on disability in Australia.

If you have any questions about this letter or you would like to know more about CYDA's policy and research work please do not hesitate to contact Liz Hudson, Policy and Research Manager on 03 9417 1025 or [lizhudson@cyda.org.au](mailto:lizhudson@cyda.org.au), or Tess Altman, Policy and Research Officer [tessaltman@cyda.org.au](mailto:tessaltman@cyda.org.au).

Kind regards,



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