



## **People with Disability Australia (PWDA)**

---

### **Productivity Commission Issues Paper: Data Availability and Use**

---

**Submission  
August 2016**

Contact details:

**Dr Jessica Cadwallader**

Advocacy Project Manager, Violence Prevention  
People with Disability Australia Incorporated  
PO Box 666 Strawberry Hills NSW 2012  
Tel: 02 9370 3100  
Fax: 02 9318 1372

## **About People with Disability Australia**

People with Disability Australia (PWDA) is a NSW and national peak disability rights and advocacy organisation. Our primary membership is made up of people with disability and organisations primarily constituted by people with disability. We also have a large associate membership of other individuals and organisations committed to the disability rights movement. Founded in 1981, The International Year of Disabled Persons, PWDA seeks to provide people with disability with a voice of their own. We are a cross disability organisation representing the interests of people with all kinds of disability. We have a vision of a socially just, accessible, and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are recognised, respected and celebrated.

## **Expertise in the Area**

People with Disability Australia are uniquely situated to respond to this Issues paper. We are a national and NSW peak body representing people with disability, who are rarely well-represented or considered in data collection approaches. PWDA in this role undertakes systemic advocacy and provides expert policy advice, so we are frequently confronted by the inadequacy of current data collection in relation to people with disability. Additionally, we provide disability advocacy, funded under the National Disability Advocacy Program, amongst others, meaning that we collect administrative data in accordance with a variety of Government mechanisms.

We appreciate the opportunity to provide the Productivity Commission with our experiences and expertise in relation to these issues.

## **Human Rights Obligations**

Data collection in relation to people with disability is an ongoing problem in Australia, despite being a party to the Convention on the Rights of Persons with Disabilities (CRPD), which states at Article 31:

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:
  - Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
  - Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.
2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Additionally, in the most recent Review of Australia's performance in relation to the CRPD, the following recommendations were made:

The Committee recommends that the State party develops nationally consistent measures for data collection and public reporting of disaggregated data across the full range of obligations contained in the Convention, and that all data be disaggregated by age, gender, type of disability, place of residence and cultural background. It further recommends that the State party commissions and funds a comprehensive assessment of the situation of girls and women with disability, in order to establish a baseline of disaggregated data against which future progress towards the Convention can be measured

The Committee recommends that the State party systematically collect, analyse and disseminate data, disaggregated by gender, age and disability, on the status of children including any form of abuse and violence against children. It further recommends that the State party commissions and funds a comprehensive assessment of the situation of children with disabilities, in order to establish a baseline of disaggregated data against which future progress is made towards the implementation of the Convention.<sup>1</sup>

**PWDA highly recommends that the Productivity Commission take due account of guidance from the United Nations regarding our fulfilment of our international obligations, especially in relation to the CRPD.**

In addition to the highlighted topics above – namely, violence against women and girls with disability, and children with disability – Article 31 refers to the rest of the Convention to define what kinds of data should be collected. The rest of the Convention covers diverse topics, including:

- Accessibility
- Situations of risk and humanitarian emergencies
- Equal recognition before the law
- Access to justice
- Liberty and security of the person
- Freedom from torture or cruel, inhuman or degrading treatment or punishment
- Freedom from exploitation, violence and abuse
- Protecting the integrity of the person
- Liberty of movement and nationality
- Living independently and being included in the community
- Freedom of expression and opinion, and access to information
- Respect for privacy
- Education
- Health
- Habilitation and rehabilitation
- Work and employment
- Adequate standard of living and social protection
- Participation in political and public life
- Participation in cultural life, recreation, leisure and sport

Few of these topics are subject to adequate data collection in Australia, and they are rarely disaggregated by disability even where the data collections do exist.

---

<sup>1</sup> CRPD/C/AUS/CO/1 found here:

[http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/AUS/CO/1&Lang=En](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/AUS/CO/1&Lang=En)

## **Definitions of Disability used in Data Collections**

Where data is disaggregated by disability, it usually deploys problematic definitions of disability which are focused on condition, impairment type and 'functioning'. This maintains a focus on the medical model of disability, rather than the internationally accepted standard of the social model reflected in the work of the UN CRPD and the World Health Organisation. Despite acceding to the International Classification of Functioning, Disability and Health, Australia continues to not use this system in the majority of its data collections.

This makes them inaccurate, and means that Australia's performance in relation to people with disability not fully comparable with that of other countries. It can also mean that there are people with disability who are not identified as such. We have seen a recent example of the problems arising from this, with the estimation of the need for the NDIS underestimated in the Northern Territory due to inaccuracy in ABS data collection and problems with the identification of foetal alcohol syndrome disorders as disability.<sup>2</sup>

**PWDA recommends the adoption of the International Classification of Functioning, Disability and Health as the basis for data collection regarding disability within Australia.**

## **Problems with current public data collection**

Very very few data collection mechanisms and methodologies within Australia are disability inclusive. People with disability are routinely excluded because of their disability from some of our most important data collections, including those created by the most trusted source of statistical data in Australia, the Australian Bureau of Statistics.

For example, despite a key aim of the Survey on Disability and Aged Care being to identify the number of people with disability in Australia, people with disability who do not access services are excluded. In most circumstances, the Survey is additionally filled out by support workers rather than by people with disability themselves; indeed much of the focus is on support workers themselves. There are zero questions regarding human rights.

Similarly, people with disability living in institutional or residential settings, or those requiring communication support, are routinely excluded from the Personal Safety Survey. The design of the survey focuses on intimate partner violence, not reflecting the breadth of perpetrators of personal violence experienced by people with disability – for example, support workers. It also fails to clarify whether the disability resulted from or pre-existed the violence that occurred, which has been used to dismiss the data that does arise from it.

These exclusions of people with disability are not only discriminatory, but also mean that contemporary data collection does not fulfil article 31 of the CRPD. It also makes it exceedingly difficult for Government, civil society and others to assess, for example, our fulfilment of the CRPD and the success of strategies developed to fulfil the CRPD (including, for example, the National Disability Strategy and the National Disability Insurance Scheme). In many arenas, Australia does not even have a baseline regarding the representation of people with disability within a particular cohort (e.g. child protection).

**PWDA recommends that all development of data gathering mechanisms – whether administrative or statistical – occur in consultation with people with disability, their representative organisations (Disabled People's Organisations) and experts in inclusive research design.**

---

<sup>2</sup> Rick Morton, "Thousands Missed in Northern Territory Disability Study" *The Australian*, 24 Aug 2016

## **Problems with the collection of administrative data**

Few administrative data sets include the collection of disability data, unless the service collecting information is routinely focussed on people with disability. This means that so-called mainstream or generic services – including government-funded services – have no way to address any over or under representation of people with disability in receipt of their services. This includes, for example, crime data, data regarding the representation of disability amongst family and domestic violence services users and so on; without this information, it is difficult to develop evidence-based policy responding to actual need. Given that the data collection matrix is provided by government as part of contract, this lack should be addressed.

There is no national agreement regarding the definition of disability, meaning that key state-based administrative data sets are routinely accurate or nationally comparable. National reports such as the annual Child Protection support continues to fail to report on the overrepresentation of children with disability in these systems, despite being required to do so by the National Framework for Protecting Australia's Children. The Australian Institute of Health and Welfare has suggested that this was because each state functioned with a different definition of disability, and so the data was not commensurate.

This fact could easily be footnoted in any report instead, which would enable analysis of the impact that different definitions have on the representation of children with disability in child protection. This is particularly important given that other analyses of, for example, out of home care, find a much much higher percentage of children with disability in these settings (over 60%<sup>3</sup>). The official government numbers are likely to measure the rate of access to support services, meaning that lower numbers could provide evidence that in turn could have substantial and significant impacts on policy in this space. In other words, even administrative data which does not easily reach the threshold of robustness for statistical data is extremely important in measuring how the category of disability functions in relation to funding and support provision.

**People with Disability Australia recommend that all administrative data collection frameworks reflect the ICF wherever possible, and that where this is not possible, administrative data still be made available in anonymised, disaggregated form, with details regarding the definitions of disability in use in various jurisdictions.**

## **Problems with access to administrative data**

One of the biggest problems with administrative data sets is that they are locked away by government. PWDA used to run the Disability Abuse and Neglect Hotline, providing substantial data to government regarding situations of often quite serious abuse and neglect against people with disability. The information provided to government was quite detailed, including demographic information such as gender, age, location, form of violence and so on.

This information could easily be disaggregated, anonymised and publicly released, enabling not only potential recognition of the scope of the problem of violence, but also an assessment of whether the service provided successfully achieved the purpose. A summary of this data has only recently been made public following the request of the Senate Inquiry into Violence, Abuse and Neglect last year

---

<sup>3</sup> Anglicare Victoria, 2014. 'Children in Care Report Card', Report No. 2, p. 3 Available at: <http://www.aph.gov.au/DocumentStore.ashx?id=222758a7-181f-42e5-a02f-6daf8e787241&subId=30420020>; N Milburn, Royal Children's Hospital Mental Health Service (2005), 'Protected and respected: Addressing the needs of the child in out of home care: the Stargate early intervention program for children and young people in out of home care', Royal Children's Hospital Mental Health Service.

(following through on a letter coordinated by PWDA signed by over 30 academics in the area (attached)). The publication of this data revealed that the Disability Abuse and Neglect Hotline was not an accurate reflection of prevalence, and highlighted that other strategies were required to ensure the reporting of violence against people with disability. This was only possible to identify with provision of the data from DSS.

Similarly, the National Disability Advocacy Program is a national program delivered by over 50 organisations across Australia. PWDA led the development of a human rights based client data collection database which recognised which articles under the convention had been breached in a particular case. While some other disability advocacy organisations adopted the same database, enabling national comparisons to be made, the information submitted to the government has never been made public. This has meant that systemic problems have not been identified or responded to, in line with the requirements of the CRPD. It has also obscured the importance of advocacy, and in a recent review of the program, peak bodies have been unable to use these administrative data sets to support government in its assessment of the program.

There are ongoing problems with the covering up of violence, abuse and neglect in disability services, or their concealing within administrative processes only. With the development of the NDIS, one of the much-touted safeguards has been the ability of a person with disability to exercise choice in relation to which service provider they use under the scheme. However, there is limited information available about service providers. There is the development of 'Trip Advisor' style tools for disability service providers, but in many respects this, as with Trip Advisor, may be subject to interference by disability service providers themselves. This may be through paying for recommendations, or through clients facing repercussions for honest reviews.

At the same time, an extraordinary amount of data regarding the quality of various services, remain locked up in complaint, audit, registration and accreditation procedures. The availability of this information would assist people with disability in making an informed choice of service provider. It would also enhance the safeguard potential of the 'choice and control' element of the NDIS, by ensuring that people with disability knew of complaints made against the service provider they may be accessing.

After all, every individual should be able to take account of various matters – like quality measures, abuse allegations (both resolves and otherwise), adherence to contracts (for example where a woman requests only women support workers to reduce the risk of sexual assault) or adequacy of policies – in deciding who should provide them with often quite intimate support.

**People with Disability Australia recommends that data regarding audits, quality assessments and accreditation be made freely available to the public to support the selection of appropriate services for example through programs like the NDIS.**

## **Privacy and Personal Information**

People with disability routinely have their privacy breached, especially with regard to their disability, with a wide. PWDA is concerned about the way that data linking may enable the identification of people with disability, depriving of their rights to decision-making and choice. Examples include where their accessing more than one service is understood as problematic.

Additionally, we have serious concerns regarding the development of new databases and associated metrics within the Department of Social Services. An example is the Data Exchange system. The Data Exchange requests people's actual private data, although thus far DSS has assured stakeholders that

clients remain anonymous. PWDA, along with other support services, has raised questions about how this data is being used, and why it must be provided. We are very much aware that if we did not opt to anonymise data before entering it into the system, many of our clients who have experienced extremely poor responses from government and from support services, would decline our services rather than give away their information. This factor ought to be better recognised in relation to administrative data collection.

It should also be acknowledged that no administrative data set need provide detailed personal information in order to be useful. Although broadly in Australia there is an increasing focus on the significance of enabling data linkages, the priority ought to be on ensuring the release of data from the many currently closed administrative data sources. Data linkage should only occur with the approval of the individual concerns. The provision of personal information should never become a requirements for the access of services.

**People with Disability Australia recommends that in order to ensure equitable access to services, no contract should require service providers to provide personal details of clients to government.**

Additionally, administrative data set collection should be carefully designed with thorough consultation. Currently optional in the Data Exchange is a wellbeing assessment that is designed to be taken of a client on entry into the service and on their exit out of the service. It is focussed on client capacity, and is intended to demonstrate where a person acquires new strategies or skills for dealing with recurrent problems.

However, it fails to provide any categories where a person seeking to access services is not themselves the problem being addressed. In individual advocacy, people with disability are usually not the problem being addressed; the failures of service systems, violence perpetrated by others against a person with disability, and difficulty in accessing housing are examples that have little if anything to do with a client's personal capacity.

The approach taken by the Data Exchange in seeking to assess individual capacity also undermines the usefulness of the data collected in identifying systemic issues. Wherever possible, such data collection should focus on systemic issues rather than assuming individual problems, in order to provide adequate data to support changes to service provision as needed.

**PWDA recommends that administrative data set frameworks be developed in consultation with clients of a particular service, any relevant peak bodies and the organisations providing the services, to ensure that the collection reflects the needs of the community.**

## **Conclusion**

People with Disability Australia thanks the Productivity Commission for the opportunity to provide its advice, expertise and experience in relation to data use and data collection. We would be pleased to provide further advice as required.