

DISABILITY ADVOCACY BY THE NUMBERS

Data Integrity Supplementary Report

Statistics from July 2012 to June 2016

Victorian Office for Disability Advocacy Program

Quarterly Data Collection



Prepared by the Disability Advocacy
Resource Unit (DARU)

July 2017

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Acronyms

DARU: Disability Advocacy Resource Unit

DAV: Disability Advocacy Victoria

DHHS: Department of Health and Human Services

NDIS: National Disability Insurance Scheme

QDC: Quarterly Data Collection

VCOSS: Victorian Council of Social Service

About DARU

The Disability Advocacy Resource Unit (DARU) is unique in Australia as a dedicated resource unit funded to work with disability advocates to promote and protect the rights of people with disability. DARU is delivered by a partnership between the Victorian Council of Social Service (VCOSS) and Disability Advocacy Victoria (DAV).

We develop and distribute resources to keep disability advocates informed and up-to-date about issues affecting people with disability in Victoria. We organise forums to provide opportunities for a co-ordinated approach to issues of concern, and provide professional development opportunities and undertaking capacity building projects.

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DARU recognises the traditional owners of our land, and pays our respect to Elders past and present.

Executive summary

This supplementary report to *Disability Advocacy by the Numbers* outlines some of the data integrity issues DARU encountered in compiling the report. It should be read in conjunction with the main report.

We have provided this supplementary report specifically to inform the both administrators and funded agencies of the Victorian Disability Advocacy Program of the nature of these data integrity difficulties, and help suggest improvements to data collection that may avoid these problems in the future.

This report is published at a time when the Victorian Disability Advocacy Program has recently been reviewed,¹ and the Victorian government had made specific commitments² to improving the administration and management of the program, including:

- more effective measurement of demand and outcomes
- building stronger links with other safeguarding mechanisms, and
- simplifying administrative requirements for funded organisations.

DARU has identified a number of areas where data collection can be improved, including

- Clearly understanding the purpose of collecting data and what it will be used for
- Providing clearer data requests that reduce confusion and misinterpretation
- Avoiding asking for the same information multiple times
- Improving data integrity and consistency of reporting.

DARU looks forward to working with the Office for Disability and funded disability advocacy organisations to discuss these issues and help improve measurement and data collection in the future.

1 Victorian Disability Advocacy Program Review – Summary of Findings, <http://www.dhs.vic.gov.au/for-service-providers/disability/protecting-rights/disability-advocacy>

2 Victorian Government, *Government Response to the Inquiry into Abuse in Disability Services*, 2016, p.3

Options for consideration

Collecting useful data

Review and revise the Victorian Disability Advocacy Program quarterly data collection

Avoiding duplication errors

Ensure that people are only counted once, in the most relevant category, and are not counted again in subsequent reporting

Streamlining collection of personal characteristics

Only collect personal characteristics of people receiving individual disability advocacy support

Provide options for recording when personal characteristics are not present, or are not identified

Clarify whether the intention is to collect data on sex, gender identity, or sexuality and revise this question accordingly

Consider recording more evenly spaced age ranges

Consider asking clearer questions about cultural status, such as country of birth or language spoken at home

Change the method of recording geographic location to be less onerous and more consistent

Review the appropriateness and method of reporting types of disability

Consider submitting disaggregated data



Reporting advocacy issues

Review the categorisation of disability advocacy issues, and provide guidance on how to interpret them

Explore alternative options for collecting data on systemic, group and self-advocacy

Consider measuring the number of 'advocacy cases' undertaken by disability advocacy organisations

Consider ways to measure service intensity, such as the length of time taken to complete advocacy cases

Reporting organisational activities

Review the appropriateness and suitability of data collected on organisational activities

Consider whether data can be publicly reported in aggregated form

Consider whether useful measures of service demand can be reported, such as data on waiting lists or requests for service

Discuss options for measuring outcomes, recognising potential difficulties

Improving data integrity

Consider additional mechanisms for checking the integrity of data submitted

Consider electronic data submission

› The disability advocacy quarterly data collection

The main source of data for the *Disability Advocacy by the Numbers* report comes from the Victorian Disability Advocacy Program's Quarterly Data Collection (QDC) process.

QDC forms are given to funded agencies quarterly to complete and return to the Office for Disability for data collection purposes.

The QDC form contains 26 questions, in addition to providing basic organisational details and contact information.

Some fields in the form are set by the Victorian Government and used for official reporting within Government on the disability advocacy program, including to the Department of Treasury and Finance for budget purposes, and to the Australian Institute of Health and Welfare. These core data components are mandatory and likely to be very difficult to alter at program level.

Other fields have been designed by the Office for Disability in consultation with the disability advocacy sector with the intention to produce more detailed data, trends and case studies, which can be used by the sector to get a greater understanding of the sector, and as an evidence base for systemic advocacy.

Of the 26 questions, 22 questions request specific data items, while 4 allow for written, qualitative responses on diagnostic groups, systemic advocacy, case studies, and further comments.

If completed in full, the form requests up to 202 different pieces of information, collected four times a year.

The form requests up to 142 separate numerical data points. This includes up to:

- 79 separate data points for the number of people receiving service in each local government area in Victoria
- 14 numerical data points separately enumerating the number of referrals and complaints to six different agencies, plus those to 'other' agencies
- 14 different advocacy topics categories
- 12 different disability types.

In addition, there are 29 category data points, requiring organisations to answer yes/no or tick a category box.

There are also:

- 19 different fields for detailed written information, presuming an organisation details 3 different systemic advocacy topics, as is provided for on the form.
- 7 fields for specifying the nature of 'other' categories
- 5 fields for listing agency contact information.

Of the 26 questions in the QDC form, responses to 8 of the 26 questions have been provided to DARU to produce the *Disability Advocacy by the Numbers* report. This included 26 numerical data points and qualitative data from case studies. Data was aggregated and de-identified before being given to DARU.

A full list of fields in the QDC form can be found at Appendix 1.

› Collecting useful data

Option for consideration

Review and revise the Victorian Disability Advocacy Program quarterly data collection

The data reported through the Victorian Disability Advocacy Program is a potentially rich and powerful source of information about the problems experienced by people a disability, the characteristics of people with disability who seek assistance from disability advocates, and the work of disability advocacy organisations. Strong, high quality data can be used to inform systemic advocacy and demonstrate the value of disability advocacy.

In producing the *Disability Advocacy by the Numbers* report, DARU has observed a number of problems with the data available from the program. While we can draw tentative conclusions from it, these are undermined by under-reporting, misreporting and data gaps. The wording of some questions also makes the data difficult to report and interpret. It is impossible to determine how 'real' data trends are, when we cannot determine whether trends are due to data collection errors.

DARU believes the current format and process for data collection is resulting in errors and is generating inaccurate data. It is not maximising the use of the data to inform sector practice and systemic advocacy.

Only data that is consistently interpreted and reported can be used for strong analysis and conclusions. It is unclear in some instances whether the questions are collecting the most relevant information, and whether organisations are interpreting the questions in the same way.

Disability advocacy organisations report being aware the QDC represents a funding requirement and may be taken as a reflection of their work. They desire the QDC to collect information that fairly reflects the work they are conducting.

Disability advocacy organisations also report that data collection is often onerous, time consuming and repetitive due to the number of different auditing

processes undertaken by organisations funded by Victorian Disability Advocacy Program. Some of the auditing processes include:

- Human Services Standards Self-Assessment report and Quality Improvement Plan
- Staff, Volunteer and Carer file audit tool
- Client File audit tool
- ISO Quality Standards.

Some organisations have funding from several sources that also have other reporting and auditing processes that need to be completed. Smaller disability advocacy organisations struggle to keep on top of the administrative burden while providing advocacy services.

DARU believes it would be beneficial to review and revise the Victorian Disability Advocacy Program quarterly data collection, and this document provides the a number of suggestions for changing the QDC questions to allow them to be better analysed and produce more rigorous results. In doing so, priority should be given to collecting data that:

- Is simple and easy for organisations to report correctly
- Measures something important
- Has a clear purpose for being collected
- Is collected at the appropriate frequency
- Maximises the opportunities for analysis
- Is comparable with other data sources
- Can be made available for publication.

In particular, the data collected should be restricted to items that meet all or most of the above criteria. Every additional data-point represents an additional burden on organisations, and extraneous data collection should be avoided. DARU notes some data collected is used to report to the Victorian Government and the Australian Institute for Health and Wellbeing.

DARU believes any change should be subject to consultation with disability advocacy organisations.

› Avoiding duplication errors

Option for consideration

Ensure that people are only counted once, in the most relevant category, and are not counted again in subsequent reporting

The current way data is collected leads to the same thing being counted multiple times. This means that the data cannot be summated to give an overall total, making the data less useful. This can occur in different ways:

- Data for the same person being reported in multiple reporting periods, for example, a person receiving services over an extended period will have their gender, age, location, and disability type reported multiple times during a year
- People can be counted in several categories in the same report, for instance, they may experience a single problem which is reported multiple times in numerous advocacy categories.

If people appear multiple times in the same data set we cannot 'add up' the numbers to get a meaningful total for the year. For this reason, much of the data is reported as an 'average per quarter' figure in *Disability Advocacy by the Numbers*, as while the data is true for a single quarter, it is not true for a longer period. If these data were added together, some people would be counted more than once, meaning they would be represented more heavily in the data than other people.

Similarly, if some people are counted in multiple categories, they will appear multiple times in the totals, making their characteristics more prominent than other people.

In some cases, allowing multiple answers or repeat reporting may cause confusion for services, who may interpret questions differently. For example, some organisations may allocate each case to a single advocacy topic, while others may allocate a single case to multiple advocacy topics, creating inconsistencies in the approach to reporting. Multiple reporting requirements are likely to introduce more errors into the data.

Reporting people multiple times makes the administrative burden of reporting more onerous, as organisations have to report on more people in each report, requiring review of more case files or analysing larger samples from organisational databases.

To ensure people are only counted once, the questions can be changed so that people are only recorded once, such as when they first contact a service. Similarly, reporting could ask that people be allocated to the 'most relevant', 'primary' or 'main' category relating to their circumstances, rather than to any or all that apply.

Streamlining collection of personal characteristics

Most of the data provided to DARU for the *Disability Advocacy by the Numbers* report was drawn from the 'Individual Advocacy' part of the QDC. These questions provided information on the personal characteristics of people receiving advocacy services.

Organisations are significantly underreporting many of these characteristics. For example, organisations do not report:

- The gender of 47 per cent of their clients (figure 1)
- The age of 43 per cent of their clients (figure 2).

Similarly, the data does not allow us to identify the proportion of clients for whom Aboriginal or Torres Strait Islander status or cultural and linguistic diversity was not recorded. However, we expect there may be similar

or greater levels of under-reporting of cultural status. This means that the estimates we have provided of the proportion of people from Aboriginal or Torres Strait Islander background, or from culturally and linguistically diverse backgrounds may be too low.

From the data we have on age and gender, we can see that there had been an improvement in recording people's age and gender in the most recent financial year. However, around 30 per cent of people continue to have no gender recorded, along with 26 per cent for age.

Figure 1: Number of people with no gender recorded, quarterly, 2012–16

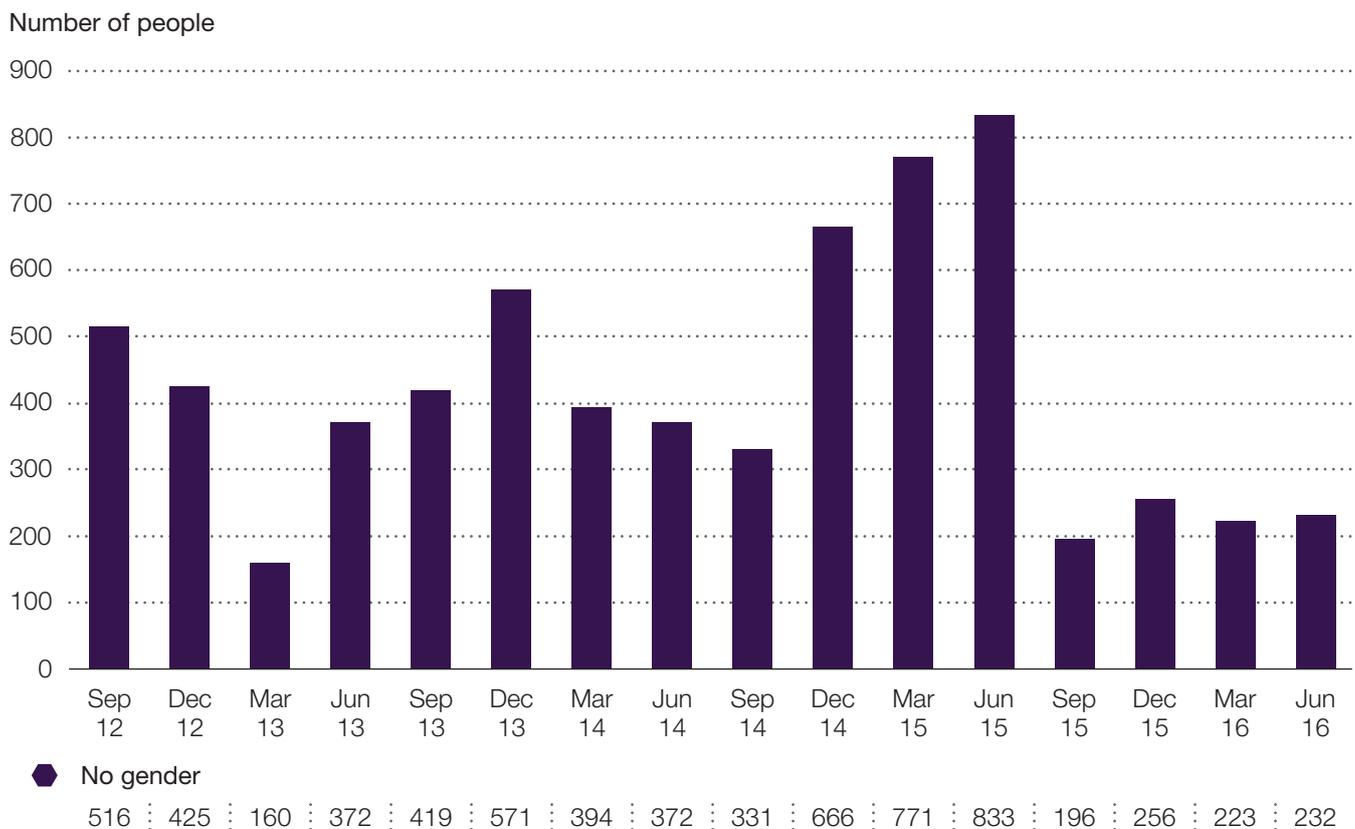
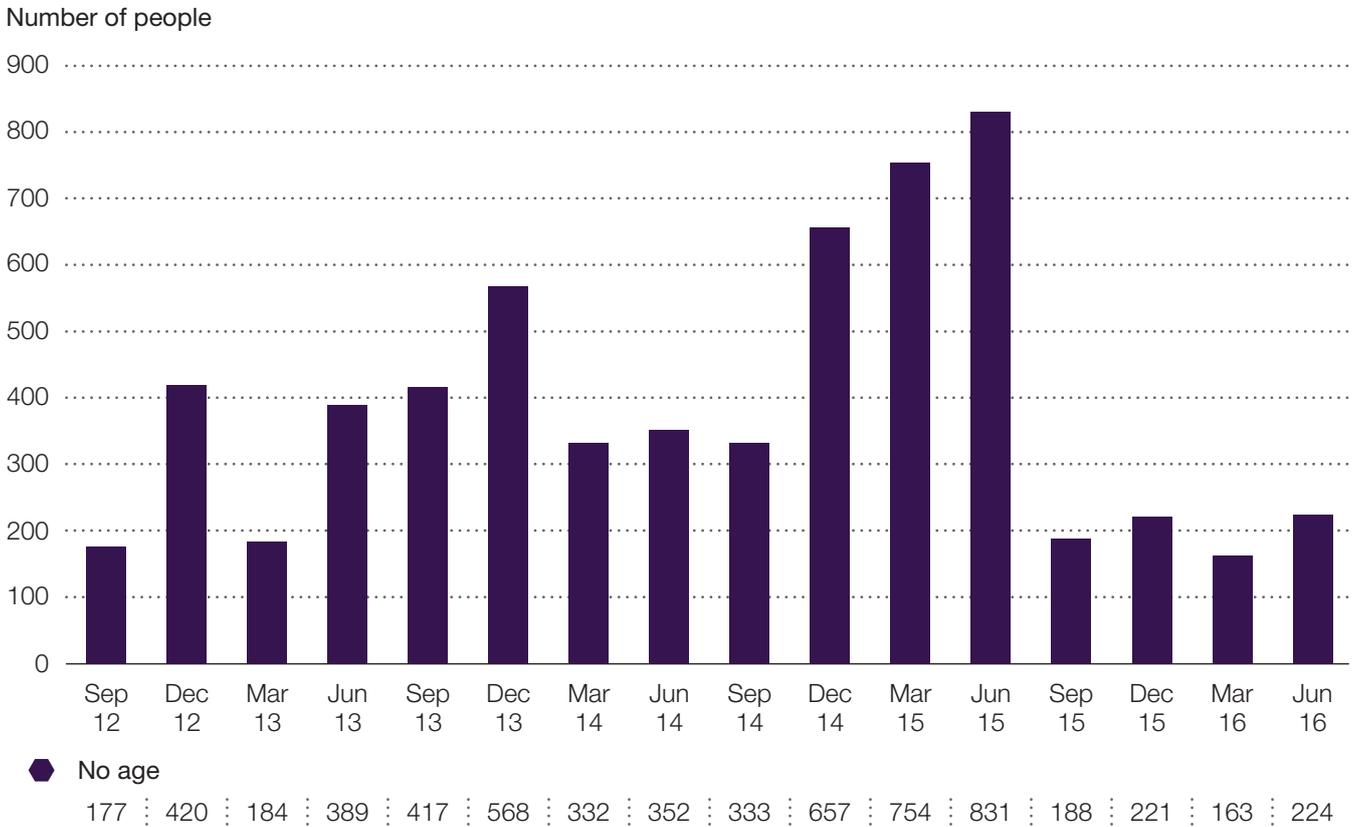


Figure 2: Number of people receiving disability advocacy services with no age group reported



Only request personal data for people receiving individual support

Option for discussion

Only collect personal characteristics of people receiving individual disability advocacy support

In recording the personal characteristics of people receiving advocacy support, it is currently unclear which people disability advocacy agencies are including in their reporting. In some cases it appears organisations may be reporting characteristics for more people than

they report providing individual advocacy services to. In other cases, organisations identify the personal characteristics of fewer people than they report providing individual advocacy services to.

While the questions on personal characteristics appear under the heading ‘Individual Advocacy’, it is unclear whether organisations are reporting only individual services, or including people participating in self-advocacy or group advocacy activities as well.

DARU is aware organisations can only report data they collect. We understand most advocacy organisations collect information on people’s personal characteristics during ‘intake’ processes, where people are asked or assisted to provide personal information when they begin receiving an individual disability advocacy service. This process may or may not occur for people participating in group activities or self-advocacy support.

By more clearly limiting questions to people receiving individual advocacy support, organisations may have greater clarity about the information they are to provide.

Collect information on non-responses

Option for discussion

Provide options for recording when personal characteristics are not present, or are not identified

A possible explanation for some under-reporting is that organisations are not recording the information in the first place. The data provided do not allow DARU to distinguish between instances where data is not recorded in the first place, as opposed to when data is not reported to the funding body. The distinction is important as it helps identify the causes of under-reporting.

For example, some agencies may not ask people whether they identify as an Aboriginal and/or Torres Strait Islander person. In other cases, people may choose not to disclose their status, and not wish to answer the question. In these circumstances, organisations may not report the number of people from an Aboriginal or Torres Strait Islander background because they have no data to report.

For example, an alternative set of questions could be:

- Number of people who identify as being Aboriginal and/or Torres Strait Islander
- Number of people who identify as not being Aboriginal and/or Torres Strait Islander
- Number of people whose Aboriginal and/or Torres Strait Islander status is unknown.

This would allow a more accurate estimate of the proportion of people who identify as Aboriginal and/or Torres Strait Islander, as those whose status is unknown could be excluded from the estimate.

Similar changes could be made to other questions about personal characteristics.

Clarify gender and sexuality data

Option for discussion

Clarify whether the intention is to collect data on sex, gender identity, or sexuality, and revise this question accordingly

Currently, the QDC form requests data on whether people's gender is "male", "female" or "other (e.g. transgender)". It is unclear whether this is a person's self-identified gender or the gender ascribed by an advocate.

Many transgender people clearly identify as male or female, even if this gender identity is different from their sex at birth. Some may object to the suggestion that transgender people belong in a gender category of 'other'. Other people, who may or may not be transgender, may choose not to identify as male or female.

It is unclear whether the question is attempting to identify a person's gender identity, or whether it is attempting to identify whether a person is cis-gendered or trans-gendered, or if they are intersex.² The intention of the question should be clarified, and amended accordingly.

A related question is whether a person's sexuality is an appropriate personal characteristic to record. While the current question appears to attempt to identify transgender people, it does not ask for reports of a person's sexuality. It should be considered whether or not this is an appropriate variable for reporting.

² Cis-Gender: a person whose gender identity corresponds with that person's biological sex assigned at birth.
Trans-Gender: a person whose gender identity does not correspond to that person's biological sex assigned at birth.
Intersex: an individual having reproductive organs or external sexual characteristics that are not exclusively male and female.

Consider appropriate age categories

Option for discussion

Consider recording more evenly spaced age ranges

The QDC form requests age ranges of varying lengths: from as small as a five year age span from 0–5, to a 40 year age span from 25–64, to the open-ended 65+ category. This makes detecting differences in the age compositions of clients over time more difficult, as significant changes in people’s ages can be masked by very wide age categories.

As *Disability Advocacy by the Numbers* reports, the majority of people are reported to fall into the 25–64 age category, which is unsurprising given its wide span. Consideration could be given to whether smaller age spans could be considered, which would provide greater analytical value.

Revise questions about cultural status

Option for discussion

Consider asking clearer questions about cultural status, such as country of birth or language spoken at home

The current QDC form requests organisations to report the number of people who “were from a culturally or linguistically diverse background”. No further information is given on how this criterion should be assessed. It is possible organisations may interpret this question in different ways.

The concept of “cultural and linguistic diversity” is generally applied to a group of people. For example, if residents of a particular suburb come from many different countries, speak different languages and have different faiths, the community can be said to be culturally and linguistically diverse.

It is less clear that the concept can be applied to an individual. A person has their own individual cultural heritage, language and faith. An individual person does not have a ‘diverse’ background. It is also unclear how an organisation should assess this feature. It is not clear whether people are asked about their cultural identity, or whether advocates determine whether they believe people fall into this category.

This question also does not have clear benchmark for comparison. *Disability Advocacy by the Numbers* reports 10.2 per cent of people receiving advocacy services were reported to be from culturally and linguistically diverse backgrounds. However, we cannot say whether this is ‘high’ or ‘low’, as there is no established measure for this criterion for the general population, or for people with a disability.

Consideration can be given to requesting different information that can be more easily compared to available benchmarks. For example, the number of people born outside Australia, or the number of people who speak a language other than English at home.

Change the way geographic location is recorded

Option for discussion

Change the method of recording geographic location to be less onerous and more consistent

The QDC form requires organisations to identify both the DHHS region and the local government area of people receiving advocacy services. This requires working out which of the 79 local government areas the person resides in, and further determine their



DHHS region. The example given in the QDC form shows both the DHHS division and local area (there are currently 4 divisions and 17 local areas). Data for this question were not provided to DARU for inclusion in *Disability Advocacy by the Numbers*.

This method of reporting is very onerous. It requires an organisation to undertake a great deal of investigation to ensure they are correctly reporting a person's location. It is possible that this may result in organisations underreporting or not completing location data in the QDC. Consideration should be given to finding an easier way to report a person's geographic location.

One simple method could simply be to provide a list of people's postcodes, not linked to any other identifying information. Using this, more detailed work could be during data analysis to present geographic information, rather than requiring organisations to undertake this work.

Review the appropriateness of disability type categories

Option for discussion

Review the appropriateness and method of reporting types of disability

The current QDC form collects two different sets of information about disability types. It asks organisations to list any specific diagnostic groups they provide advocacy for. It also asks organisations to specify the number of people in each of the following disability categories:

- Acquired Brain Injury
- Autism Spectrum Disorder
- Deafblind
- Deaf/hearing impaired
- Intellectual disability
- Neurological disability
- Physical Disability
- Psychiatric Disability
- Speech Impairment
- Vision Impairment
- Undisclosed
- Other

DARU has not been provided with the responses to either question. We observe that there is some overlap between the two questions. We also note that the disability categories substantially overlap. For example, a deafblind person obviously also experiences both hearing and vision impairments, and may also be impaired in their speech. A person with an acquired brain injury may experience many different impairments, including to vision, hearing, intellect, neurology, speech and behaviour.

It is unclear whether placement in these categories is self-reported by people receiving disability advocacy, or whether they are assigned to categories by disability advocates.

It is also not clear that every person receiving a service has a disability, or identifies as having a disability. It is possible some services provide advocacy services for parents, relatives, companions, families or carers of people with disability, or to people who require assistance, but do not consider themselves as having a disability.

The purpose of documenting the number of people with different impairments is unclear. One possibility is to determine whether people with particular kinds of impairments are less likely to receive support from disability advocacy organisations. If this is the case, then some benchmark is required to determine an appropriate level of access. It is unclear whether the current set of categories matches to any available set of benchmarks.

Consideration could be given to whether it is appropriate to collect information on the types of disabilities people have. If so, the categorisation of impairments should be comparable to an established benchmark.

Consider submitting disaggregated data

Option for discussion

Consider submitting disaggregated rather than aggregated data

The current method collects data in aggregate from each organisation. This means organisations provide the number of people they assist and the type of issues presented, but does not allow them to be cross-referenced. This means, for example, that the data cannot be disaggregated to determine whether men and women approach organisations for different advocacy issues.

It would be possible for organisations to report disaggregated data, which would allow for a richer and more meaningful examination of the experiences of different groups. However, this type of reporting would likely be significantly more onerous for organisations to complete. While the information would be de-identified, and not include personal details like names and addresses, the privacy implications for people and organisations should also be considered.

Reporting advocacy issues

Clarify advocacy categories

Option for discussion

Review the categorisation of disability advocacy issues, and provide guidance on how to interpret them

The current QDC form asks organisations to count the number of people provided with advocacy support on the following topics:

- Abuse and Neglect
- Accommodation
- Built Environment
- Disability Services
- Education
- Employment
- Family
- Gender
- Health
- Legal
- Leisure and Recreation
- Transport
- NDIS
- Other

No further information is provided about what these categories mean, or how to determine which category a particular advocacy case may belong. For instance, assisting a woman with disability escaping family violence could conceivably be categorised as abuse and neglect, accommodation, family, gender or legal. It is unclear whether organisations are interpreting these categories in the same way, or if some organisations are selecting only the most relevant categories, while others select all and any that could conceivably apply.

This means the data on advocacy issues may not provide a good reflection of the proportions of people experiencing particular advocacy issues.

DARU observes a number of specific topics have particular problems with interpretation:

- **NDIS:** the NDIS was added as an advocacy topic in the 2015–16 financial year. In *Disability Advocacy by the Numbers*, DARU combined this topic with ‘disability services’ for continuity of reporting over a four-year period. However, it is unclear how ‘NDIS’ differs from ‘disability services’, particularly as in the future, most disability services will be funded by the NDIS.

- **Legal:** This area is unclear as to its categorisation, as many problems may involve the law or require legal advocacy. It is unclear whether this category is intended to apply to issues involving the justice system, such as criminal charges or dealing with fines, compared with any case that may require a court appearance or legal advice, such as family law, child protection, tenancy law, or guardianship proceedings.
- **Family:** This reporting item may be unclear as to the scope of issues covered. Issues relating to family could include family conflict, family violence, child protection, guardianship, inheritance matters or relationship breakdowns, including divorce. These issues may overlap with other categories.
- **Built environment:** There may be some overlap between this category and that of ‘accommodation’ and ‘transport’ which both also pertain to the built environment.
- **Gender:** This category is very rarely used by disability advocacy organisations to record advocacy issues. It is unclear what is meant by a ‘gender issue’ for the purposes of reporting, and advocacy organisations may be reporting advocacy issues where the person’s gender is pertinent in other categories.
- **Financial:** DARU observes there is no category to cover issues relating to a person’s income, financial management, or control over their finances. Disability advocacy organisations report these are heavily represented in their advocacy work.

It is not clear whether the categories intend to capture the cause of the advocacy issue or the type of service or organisation the advocacy is engaged with. For example, if a person requires a transport service to access health appointments, the underlying reason for advocacy is to maintain a person’s health. However, the service they require is a transport service, which an advocate may assist with securing. It is unclear how organisations should categorise this issue.

One way to help maintain consistency would be to provide advocacy organisations with guidance and examples of how to categorise advocacy issues, so they are making consistent interpretations.

Review data collection for systemic, group and self-advocacy

Option for discussion

Explore alternative options for collecting data on systemic, group and self-advocacy

It is unclear whether organisations are including people other than those receiving individual advocacy services when completing the QDC form.

There are several instances where the data for individual advocacy issues is heavily influenced by the data from a single organisation. There are examples where organisations report assisting more people with a particular advocacy topic than they have clients. It is possible that some organisations are reporting people assisted through systemic, group or self-advocacy when reporting on advocacy topics.

These instances may influence the data reported in *Disability Advocacy by the Numbers*. For example, there is a noticeable spike in the December 2015 quarter for the number of people assistance with transport issues. This is heavily influenced by data from a single organisation.

The QDC form provides an opportunity for written, qualitative data on systemic advocacy. DARU was not provided with this information. The QDC form does not collect any information on group or self-advocacy activities.

Consideration could be given as to whether it is appropriate to collect more information on systemic, group and self-advocacy activities, and the most appropriate form in which to do so.

Measure intensity of advocacy

Options for discussion

Consider measuring the number of 'advocacy cases' undertaken by disability advocacy organisations

Consider ways to measure service intensity, such as the length of time taken to complete advocacy cases

Currently, the Victorian Disability Advocacy Program only collects data on the numbers of people accessing advocacy services.

However, this may not be the best unit to measure the amount of service being provided. A person may contact a disability advocacy service with multiple advocacy issues, or a person may return to the advocacy service with a different concern for resolution. In other words, a single person may seek assistance from an organisation for multiple 'advocacy cases'. The current process does not collect data on multiple services provided to the same person.

Consideration could be given to collecting data on the number of 'advocacy cases' an organisation undertakes. For instance, organisations could report the number of advocacy cases commenced or completed during a reporting period. This would allow organisations to record instances where they had assisted an existing client with an additional advocacy issue.



This would also allow a better method of collecting information on advocacy issues. By identifying the advocacy issue attached to each case, the data would more clearly be able to determine the prevalence of different categories of issues.

The QDC currently asks organisations to report how much time was spent providing individual advocacy per person in the quarter. It provides the options of:

- One-off assistance
- Short-term (a month or so)
- Medium-term (a few months)
- Long-term (more than six months)

DARU was not provided with data for this question.

This method of collecting data has a number of shortcomings. The answer options are vague, without clear delineation between categories. They are also awkward, as technically an advocacy service cannot provide long-term support *during* a quarter. Finally, the question could provide inaccurate data, as organisations are asked to respond for all people receiving individual advocacy, including people whose advocacy case is not complete. In this case, organisations can only report how long a person has been supported up until the time of reporting, which may not indicate how long the case actually takes.

An alternative suggestion is to collect data on the length of time an advocacy case takes on completion. By recording the actual length of advocacy cases, a more reliable indicator of service intensity can be produced.

› Reporting organisational activities

Review organisational data collection

Options for discussion

Review the appropriateness and suitability of data collected on organisational activities

Consider whether data can be publicly reported in aggregated form

Many of the items on the QDC form relate to organisational activities. These data were not provided to DARU for reporting in *Disability Advocacy by the Numbers*.

DARU observe some aspects of these data could be re-considered.

DARU observes that many fields in the QDC survey ask organisations about their usual activities, practices or clients groups, rather than what they actually were during the reporting period. Collecting information on what organisations actually did, rather than usually do, may more accurately detect changes in organisational practice or client groups, if that is the intended purpose.

Some of the questions go to items detailed in organisations' funding agreements, and it is unclear why organisations are required to report on them. Many of the answers are unlikely to change from quarter to quarter, and it is also unclear whether it is useful for them to be reported every 3 months.

For example, DARU is funded to provide a resource unit. Every 3 months, we report that we describe our organisation as a Resource Unit. It is unclear of what benefit collecting this information is.

Disability advocacy organisations are also asked to provide the number of both complaints and referrals to a number of different government complaints bodies. DARU was not provided with this data for *Disability Advocacy by the Numbers*. It is unclear what the intended purpose of recording this information is.

Consideration should be given to the purpose of collecting data on organisational activities is, whether the appropriate data is being collected for that purpose, and whether the information can be published.

Measuring demand and outcomes

Options for discussion

Consider whether useful measures of service demand can be reported, such as data on waiting lists or requests for service

Discuss options for measuring outcomes, recognising potential difficulties

The Victorian Government, in its response to the *Victorian Parliamentary Inquiry into Abuse in Disability Services*, has announced its intention to improve measurement of demand and outcomes for disability advocacy.

This is no easy task.

It is very difficult to generate population-wide estimates of the demand for disability advocacy services. In part, this is because there remains low levels of awareness of disability advocacy services, or strong understanding of the nature of disability advocacy. As a result, many people may be unaware of the existence of disability advocacy services, or may not understand that disability advocacy might enable them to resolve an advocacy issue.



However, organisations may be able to provide data on *expressed* demand for disability advocacy. In other words, organisations may be able to provide data on the number of times people request a disability advocacy service. Alternatively, organisations may be able to report the number of people on their waiting list, where they maintain them.

These will underestimate the total level of demand for disability advocacy, but may provide an improved understanding of the level of demand.

Similarly, measuring the outcomes of disability advocacy is not simple. People present to disability advocacy organisations with many different individual advocacy issues, which cannot be translated into simple outcome measures. Complicating analysis is that people's expectations of outcomes may be different, and those expectations may differ from what is achievable from a disability advocacy service. Greater discussion is required about what useful outcome measures for disability advocacy can be generated.

➤ Improving data integrity

Options for discussion

Consider additional mechanisms for checking the integrity of data submitted

Consider electronic data submission

Many organisations are not completing the QDC accurately. In examining the quarterly data over the four year period of this report, it is clear that the reported data is not complete.

Some organisations will complete fields for some of their service users, but not others, leaving gaps in the data recorded. For example, an organisation may report the gender of some of their clients, but not record the gender of others.

DARU believes that additional mechanisms should be considered to ensure the data submitted for reporting is accurate and complete. Data is much less valuable to identify trends and inform systemic advocacy if errors are including in reporting.

It is unclear whether organisations are entering data for new clients, total clients, or including clients not recorded elsewhere, for example, including group advocacy clients in some fields.

QDC forms are currently sent out by email as Word documents. This limits how many data integrity checks can be incorporated into the process before submission. The option of electronic submission, for instance through a secure online form, could enhance the accuracy of information provided by including additional prompts and simple consistency checks.

Appendix: Items in the QDC form

Operating patterns

1. **Has this advocacy service operated for the full quarter?** Answer: Please answer Yes or No
2. **How many weeks per quarter does the advocacy service usually operate?** Answer: Please write the number of weeks per quarter or no regular pattern
3. **How many days per week does the advocacy service usually operate?** Answer: Please write the number of days per week or no regular pattern
4. **How many hours per day does the advocacy service usually operate?** Answer: Please write the number of hours per day or no regular pattern

Staffing

5. **What were the hours worked by paid staff (including contracted staff) on behalf of this advocacy service in the 7-day reference week for the quarter?** Answer: Please write the number of paid hours per week
6. **What were the total hours worked by unpaid staff (including volunteers) on behalf of this advocacy service in the 7-day reference week for the quarter?** Answer: Please write the number of unpaid hours per week

Amount of service

7. **How many new service users received advocacy support from your service during the quarter?** Answer: Number of new service users
8. **How many services users have received ongoing support from the previous quarter?** Answer: Number of ongoing service users

Type of organisation

9. **How would you describe your organisation?** Answer: Choose from the following (multiple responses accepted)
 - Advocacy only
 - Advocacy and Disability Service
 - Advocacy and Information Service
 - Metropolitan Service
 - Resource Unit

- Rural Service
- Statewide service
- Other (please specify)

10. **Which model(s) of advocacy does your organisation provide?** Answer: Choose from the following (multiple responses accepted)

- Individual advocacy
- Systemic advocacy
- Self-advocacy
- Other (please specify)

11. **Does your organisation provide advocacy for a specific diagnostic group e.g. Acquired Brain Injury (ABI), Intellectual Disability?** Answer: Please list diagnostic groups

12. **What type of funding has your organisation received for advocacy provision in this quarter?** Answer: Choose from the following (multiple responses accepted)

- Ongoing state government funding
- Ongoing federal government funding
- Philanthropic trust funding
- Time limited project funding
- Membership fees and donations
- Other (please specify)

Formal complaints/referrals

13. **How many formal complaints or referrals did your organisation lodge in this quarter?** Answer: Separately write the numbers of complaints and referrals for each of:
 - Victorian Equal Opportunity and Human Rights Commission (VEOHRC)
 - Disability Services Commission (DSC)
 - Health Services Commissioner
 - Australian Human Rights Commission
 - Victorian Civil and Administrative Tribunal (VCAT)
 - Victorian Ombudsman
 - Other

Individual Advocacy

14. What was the gender of people receiving advocacy support from your service during the quarter? Answer: Write number of people for each of:

- Male
- Female
- Other (e.g. transgender)

15. What was the age of people receiving advocacy support from your service during the quarter?

Answer: Write number of people for each of:

- 0–4 years
- 5–14 years
- 15–24 years
- 25–64 years
- 65+ years

16. How many people receiving advocacy support from your service during the quarter identified themselves as from an Aboriginal or Torres Strait Islander background? Answer: Write the number of people

17. How many people receiving advocacy support from your service during the quarter were from a culturally or linguistically diverse (CALD) background? Answer: Write the number of people

18. What was the geographic location of people receiving advocacy support from your service during the quarter? Answer: Write the number of people, categorised by local government area and DHHS region

19. Which issues did you provide advocacy support for during the quarter? Answer: Write numbers of people for each of:

- Abuse and Neglect
- Gender
- Accommodation
- Health
- Built Environment
- Legal
- Disability Services
- Leisure and Recreation
- Education
- Transport
- Employment
- NDIS
- Family
- Other

20. What disability types were represented by people receiving advocacy support from your organisation during the quarter (if known)?

Answer: Write numbers for each of the following (an individual can be listed multiple times)

- Acquired Brain Injury
- Physical Disability
- Autism Spectrum Disorder
- Psychiatric Disability
- Deafblind
- Speech Impairment
- Deaf/hearing impaired
- Vision Impairment
- Intellectual disability
- Undisclosed
- Neurological disability
- Other

21. How much time was spent providing individual advocacy per person in this quarter?

Answer: Write number of people for each of:

- One-off assistance
- Short-term (a month or so)
- Medium-term (a few months)
- Long-term (more than six months)

Systemic Advocacy

22. In this quarter, which of the following systemic issues did your organisations choose to address and what activities supported this?

Answer: Provide written details of activities and outcomes, in the categories of:

- Abuse and Neglect
- Gender
- Accommodation
- Health
- Built Environment
- Legal
- Disability Services
- Leisure and Recreation
- Education
- Transport
- Employment
- NDIS
- Family
- Other

Membership Development

23. What did your organisations do to support new and existing members in this quarter?

Answer: Indicate activities from the following list:

- Advertising
- Social event
- Group session

- Social media (e.g. facebook)
- Information session
- Training provided
- Newsletter
- Workshop
- Recruitment of members
- Other

Qualitative Data – Case Study

24. This information may be used to provide qualitative information regarding advocacy practice. Answer: Write details using case study template, comprising:

- Statement of the advocacy issue: what was the situation/problem?
- Key factors/key players: who/what was involved?
- Description of the process: what did you do?
- Outcomes and impacts: what worked well/what didn't work?
- Evaluation: what have you learned? What would you do differently?
- Hours spent on this case.

Further comments

25. Do you have any other comments or suggestion you would like to make? Answer: Write details.

26. Please indicate how long it took you to complete this form Answer: Amount of time.



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