

Final Report

Intake Project Summary Report

Commissioned by Department of Social Services (DSS)



DANA Disability Advocacy
Network Australia

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About DANA

DANA is the national representative body for a member network of over 70 independent disability advocacy organisations throughout Australia. In this role, DANA has consulted and liaised routinely with the sector over the last decade and is familiar with the breadth and depth of the work performed by disability advocacy organisations around Australia.

Glossary

Terms	Definition
AAT	Administrative Appeals Tribunal
Case management	A disability service under the previous block funding model that included a holistic approach to assessment, planning, facilitation and advocacy for options and services to meet an individual's needs.
Co-design	The collaborative exploration of both problems and solutions between stakeholders to design new products, services and policies. It is a participatory approach.
DANA	Disability Advocacy Network Australia
DEX	The Data Exchange, a computer system used to share data and information managed by DSS. It is used by disability advocacy organisations that receive DSS funding to record and report client data.
DEX requirement – 5% unidentified	The DEX protocols allow for only 5% of clients or less to be recorded as unidentified clients in any reporting period.
DRC	Disability Royal Commission
DSS	Department of Social Services
NCDA	National Centre for Disability Advocacy
NDIS	National Disability Insurance Scheme
Unmet demand	People who have enquired about advocacy services and are eligible to receive them but have not been able to access them.
Unmet need	People who are unaware that disability advocacy exists and have an issue advocacy could assist with.
Funding Streams	Explanation
Decision support	A pilot program funded under the NDAP providing decision-making support for people with disability with limited decision-making capacity who are seeking to engage with NDIS processes. The pilot ran from October 2018 to June 2023.
DRC advocacy	Disability Royal Commission individual advocacy services funded by DSS.
NDAP	The National Disability Advocacy Program (NDAP), individual advocacy services funded by DSS to disability advocacy organisations across Australia.
NDIS appeals	NDIS Appeals Program, advocacy and legal support for external reviews of NDIA decisions, funded by DSS.
Other funding	Other sources of funding received by disability advocacy organisations to provide individual advocacy, including from local government, or philanthropic funding.
State/ territory funding	Individual advocacy services funded by state or territory governments.
Measures in this research	Explanation
Eligible request	Request for advocacy that meets the disability advocacy organisation's eligibility criteria, and the person resides within the funded service area.
Ineligible request	Out of organisation's service area or out of the scope of the disability advocacy organisation, for example, needing a different service.

Executive Summary

Introduction and Purpose

Access to disability advocacy support is very important for people with disability, their families and carers to assist in upholding their human rights and accessing services and support needed for a good life. Independent disability advocacy is provided by a diverse range of organisations across Australia including 59 funded through the National Disability Advocacy Program (NDAP) and a range of other national, state and territory funded organisations. Extensive anecdotal reports indicate considerable unmet demand for advocacy resulting in people with disability missing out. This is largely due to limited resourcing and capacity constraints on disability advocacy organisations. Increased requests for disability advocacy support have been observed following the introduction of the National Disability Insurance Scheme (NDIS).

Disability Advocacy Network Australia (DANA) was funded by the Department of Social Services (DSS) in 2021-22 to undertake research to better understand the issue of unmet demand and the factors impacting the provision of advocacy support. This research will help to begin establishing a solid evidence base of the extent and nature of unmet demand in the disability advocacy sector, the intake and referral processes used by disability advocacy organisations and the barriers in meeting demand for support across the sector. It was also an opportunity to gather preliminary insights into sector capacity. As part of the project DANA was required to develop an *Intake Reference Guide* as a resource to assist disability advocacy organisations in managing demand.¹

Methodology

The project used a mixed methods approach to gather both quantitative and qualitative data over a 6-month period from September 2021 to February 2022. Quantitative data was gathered directly from the disability advocacy sector and informs the findings of this report. Quantitative and qualitative data was gathered from disability advocacy organisations across Australia as well as several other related sectors (such as community legal centres and financial counselling services). Whilst qualitative data from the disability advocacy sector has been discussed throughout this report, the qualitative data collected from related sectors was used to inform the development of the *Intake Reference Guide*.

The research explored issues related to demand for services, intake processes, advocacy issue prioritisation, and management of waitlists. DANA also conducted discussion forums with advocates to gather information about different intake and referral processes, to explore capacity issues and the range of challenges faced by disability advocacy organisations. These forums formed part of the co-design process for the *Intake Reference Guide*.

Quantitative and qualitative data were collected through:

- Monthly surveys sent to DANA member organisations known to be receiving disability advocacy funding across Australia (n=78) between September 2021 and February 2022. The survey was designed to collect quantitative and qualitative data from responding organisations.

¹ The *Intake Reference Guide* is now a resource of the National Centre for Disability Advocacy (NCDA).

- 29 individual interviews with advocacy organisations, advocacy clients and related stakeholders.
- 13 separate intake and referral stakeholder forums involving discussion with a total of 110 participating advocates representing 51 disability advocacy organisations.

There were high levels of participation in both the survey (39 participating organisations) and the series of stakeholder forums with each state and territory. A representative cross-section of disability advocacy organisations participated in the research including across jurisdictions and from a cross-section of types and sizes of organisations.

Key Findings

Requests for disability advocacy are dealt with in various ways depending on the nature of the request, the organisation's intake process and the capacity of the organisation. Whilst organisations receive enquiries for advocacy support, not all requests are eligible for disability advocacy assistance. This is due to a number of reasons discussed in the full report. For the purposes of this report, these requests are classified as **ineligible requests**.

Between September 2021 and February 2022, the organisations that participated in this project reported receiving 30,110 requests for advocacy. 12,572 were classed as ineligible for advocacy assistance, representing 42% of enquiries and 17,538 were deemed eligible for advocacy, representing 58% of enquiries. Of the 17,538 eligible requests for advocacy, 9,187 requests were provided advocacy, meaning on average, 52% of eligible requests received support during this 6-month period. It is noted that ineligible requests for advocacy require appropriate responses which utilise organisations time and resources. There are some limitations when analysing unmet demand as the data captured across the six months includes both eligible requests turned away, and eligible requests on a waiting list at the end of the month. Tracking individual people and waitlist turnover each month would provide a better picture of how waitlists are being managed, including unmet demand trends, but this type of data collection and analysis would require considerable time and resources from organisations to track.

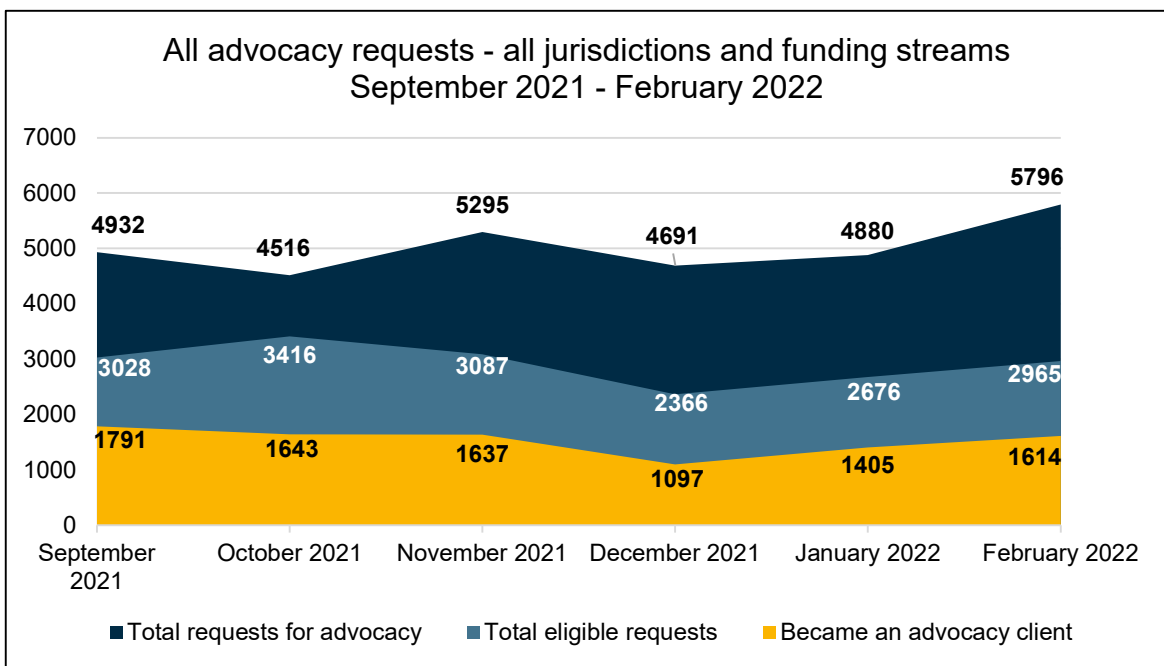
There were **five main findings** that emerged from the quantitative and qualitative data over the 6-month period:

1. An **upward trend in demand overall for disability advocacy** (Figure 1) from 4,932 requests in September 2021 to 5,796 requests in February 2022.
2. The existence of **unmet demand** in eligible requests (September 2021 – February 2022) for disability advocacy assistance **across all funding streams**. The reported data shows that while the total number of people requesting disability advocacy support over this period increased, the number of people becoming disability advocacy clients decreased from 1,791 in September 2021 to 1,614 in February 2022. The data indicated that **almost 50% of people with an eligible request** for advocacy did not receive support **when they requested it**. It is noted that some eligible requests for advocacy may be on more than one waitlist, increasing the total number of unmet demand.
3. The **NDIS Appeals Program had the highest proportion of unmet demand** in eligible requests (September 2021 – February 2022) with 58% of eligible requests not able to be met at the time of contact.

4. **A sector that receives a significant number of enquiries including ineligible requests**, which utilises a significant amount of resources. On average during September 2021 – February 2022, 42% of requests for advocacy were ineligible to receive assistance. It is important to note that every request for advocacy needs to be responded to and this takes a specialist skillset.

5. **An overwhelmed disability advocacy sector** with an ever-increasing number of people seeking support and inadequate capacity to meet the demand. In particular, NDIS issues were reported to be complex, time consuming and frequently required support over an extended period. Advocacy organisations reported using risk assessment in their intake processes to prioritise people in crisis, stretching limited resources to those most in need. All enquiries must be handled and require prioritisation, including those that do not become active cases which is at a significant cost in time and resources. There was limited capacity to actively engage with systemic issues that contribute to the reasons for people with disability seeking support from advocacy organisations. Additionally, providing outreach to marginalised communities was constrained due to limited capacity.

Figure 1: Trends in demand across the country from survey respondents: September 2021 – February 2022



Discussion

The Intake Project data for the 6-month period (September 2021 – February 2022) confirms anecdotal reports of increased demand for disability advocacy and demonstrates significant unmet demand for support. Qualitative data complemented the quantitative data and provided contextual information about organisational processes, the factors contributing to unmet demand, and the pressures and challenges faced by the sector.

Of the 39 responding organisations, 33 provided full data sets for the 6-month period and there was missing data from six organisations for one month for Question 4.² The available data for these six respondents was averaged across the full 6-month period and applied to the missing months to avoid underreporting.

Wait list data was provided for the last day of the month and would not reflect fluctuations over the month; however, the data is unreliable because of the disparity in how organisations manage wait lists and the differences in intake and prioritisation processes. Some do not keep wait lists, they may be kept for varying lengths of time and people with disability may be on multiple wait lists. In summary, the reported wait list data possibly underrepresents the total unmet demand comprised by wait lists.

Despite these limitations, 77% of the raw data was complete. The high rate of participation and broadly complete data set lend confidence in the capture and processing steps.

Data collection and reporting systems in some organisations do not adequately capture the full extent of advocacy-related activity undertaken to support people seeking advocacy support. For example, DEX does not allow recording of all staff activity involved in responding to requests for advocacy support.³ The *Intake Reference Guide* will be a valuable resource for the sector to enhance organisational systems in meeting demand.

Due to constrained organisational capacity, only approximately half of all eligible clients were able to receive advocacy support. The NDIS Appeals Program was found to be experiencing the greatest stress as resolving NDIS issues involves considerable complexity and requires extensive time and resources in the provision of support. Clients at high risk were being prioritised with many organisations forced to act in a reactive, crisis-driven mode. Many people with disability were unable to access support in a timely manner which could also result in more people finding themselves in crisis situations rather than resolving issues early.

Staff in advocacy organisations reported they were stretched and stressed; greatly exacerbated by the COVID-19 pandemic period which created additional difficulties for people with disability and challenges in provision of advocacy support. Although advocates appreciate the importance of addressing problematic systemic issues there was scarce time and very limited funding to engage in systemic advocacy to address identified barriers for people with disability.

Conclusion

The Intake Project provided valuable national baseline data and a snapshot at a particular point in time of the increasing levels of disability advocacy demand and constrained service supply capacity. Although the participating organisations only represent approximately 50% of the sector, they did represent every jurisdiction in Australia.

² Question 4: “What is the total number of people that have contacted you inquiring for assistance in <month>, whether they became an advocacy client or not?”

³ Program Specific Guidance for Commonwealth Agencies in the Data Exchange February 2023 at page 201 – see <https://dex.dss.gov.au/sites/default/files/documents/2023-02/1851-program-specific-guidance.pdf> DEX protocols only allow 5 per cent of clients to be recorded as unidentified in any reporting period. Often organisations will not record personal details of enquires in order to build psychological safety with the person. Therefore, the actual volume of requests for advocacy is not accurately recorded through the DEX system.

Given the representativeness of the participating organisations, the findings are broadly illustrative of the impact of resource and capacity constraints and the concerning levels of unmet demand. People with disability were unable to access the advocacy support needed to uphold their rights and live a good life.

The findings clearly demonstrate the need for enhanced resourcing for disability advocacy and some areas for targeted support such as developing tailored outreach to access marginalised communities. It also highlighted areas that will benefit from further investigation and points to the need for ongoing monitoring to inform sector resourcing and capacity building to ensure adequate access to disability advocacy for people with disability nationally.

During the project, participating organisations reported an increase in demand and complexity of advocacy issues since the introduction of the NDIS. This is partly due to the abolition of case management services, which could provide wrap-around services to people with disability. Dealing with increased bureaucratic processes in the NDIS and Centrelink has added to the complexity of issues.

The National Disability Advocacy Framework 2023 – 2025 (the Framework) identifies that there is currently no mechanism to identify unmet demand for disability advocacy services. The Framework is a shared commitment from the Australian and state/ territories Disability Ministers to work towards developing consistent definitions to collect consistent data across the disability advocacy sector.

The National Centre for Disability Advocacy (NCDA) has been funded by the Australian Government (through DSS) to build capacity in the sector and address unmet demand and unmet need. A key function of the NCDA is to take a consistent approach to managing intake and referrals across the sector and to build on this report in collecting and analysing data on unmet demand.

DANA submissions to the Disability Royal Commission highlighted the value of independent disability advocacy and the need to significantly increase funding for the sector to meet the current and future demand for advocacy.

Introduction

Significant government reforms in the Australian disability sector over the past decade and the introduction of the National Disability Insurance Scheme (NDIS) in 2013 have brought major changes to funding and the roles of disability service organisations and peak bodies. These changes have improved the support available for many individuals with disability and their families, and provided greater opportunities for people to lead an ordinary life and participate in society. However, there remain considerable challenges for people with disability exercising their human rights and gaining the support they need.

Disability advocacy organisations play a significant role in working with individuals and organisations to support people with disability to uphold their rights, make their own decisions, and receive advice, support, and access to appropriate services. Organisations of various types, sizes, and capacity in jurisdictions across Australia receive funding from a range of national, state and other sources to provide disability advocacy support. 59 of these organisations are funded through the National Disability Advocacy Program (NDAP) funded through the Commonwealth Department of Social Services (DSS). Other targeted funding programs include or have included Disability Royal Commission (DRC) individual advocacy funding, Decision Support Pilot and the NDIS Appeals Program that was established by DSS for provision of advocacy and legal support for external reviews of NDIA decisions. The Disability Royal Commission and Decision Support Pilot individual advocacy programs ceased on 30 June 2023.

Organisations provide anecdotal reports of increasing levels of unmet demand for disability advocacy, particularly over the past decade. One unintended consequence of the introduction of the NDIS has been a significant increase in demand for advocacy. This level of unmet demand was reportedly due to the limited capacity and resourcing of disability advocacy organisations. However, unmet demand had not been formally investigated and no data was available on the scope and nature of the issue, the specific factors contributing to it or how to address it.

The Intake Project

In 2021, DSS commissioned DANA to conduct a 12-month project (the Intake Project) to explore current capacity and unmet demand for disability advocacy, and to investigate organisations' intake and referral processes and the barriers to meeting the demand. It provided an opportunity to gather insights into sector capacity. The project was also required to develop an *Intake Reference Guide* in conjunction with the disability advocacy sector using a participatory, co-design approach as a support resource for the sector.

Methodology

The project methodology sought to investigate the extent and nature of disability advocacy demand, and in particular to quantify **unmet demand** and explore the factors contributing to capacity issues in disability advocacy organisations. Measurement of **unmet need** was beyond the scope of this project.

A mixed methods approach was utilised for collection of quantitative and qualitative data including the following methods:

- **An online survey** distributed each month for six months (September 2021 – February 2022) across the disability advocacy sector in Australia.
- **Stakeholder discussion forums** and **individual interviews** with disability advocacy organisations, advocacy service users, and other similar sectors such as financial counselling and community legal centres to gather a qualitative, multi-layered understanding of intake processes and to supplement the survey data.

An *Intake Reference Guide* was co-designed with the disability advocacy sector, as a resource to support sector organisations in managing service demand.

Online survey

The online survey (via Survey Monkey) was developed in consultation with the sector. It was designed with both quantitative and qualitative questions ([Attachment 1](#)) and circulated to 78 disability advocacy organisations nationally.

Quantitative data collected included:

- Number of people requesting advocacy assistance.
- Number of people with disability who became advocacy clients.
- Number of people who were provided information and did not become an advocacy client.
- Number of people on a wait list at the end of the month.
- Number of people with disability who couldn't become advocacy clients due to lack of capacity within the organisation.
- Number of advocacy hours provided, both individual client advocacy and systemic.⁴

Qualitative data via open ended questions regarding factors impacting waiting times and other comments on the reported quantitative data.

The survey aimed to optimise organisational input and to optimise representation of the disability advocacy sector to gather an accurate picture of unmet demand and capacity issues.

During the 6-month Intake Survey period (September 2021 – February 2022), 39 responding organisations (50% of the disability advocacy sector nationwide) provided monthly data captured retrospectively. The respondent sample provided a representative snapshot of the sector as it included multiple organisations from each state and territory, as well as different types of advocacy organisations (size, general or specialist service).

Forums

DANA facilitated a series of online discussion forums in each state and territory during the Intake Project with a two-fold purpose; to gather qualitative data to augment the survey findings; and to contribute to co-design of the *Intake Reference Guide*.

⁴ There is no DEX field for measurement of systemic data and this data may not be fully captured by organisations. Times given were estimates by organisations.

The forums were in two rounds—the first on intake prioritisation and demand management processes, and the second on referral processes.⁵

The forums were well attended, with 10-15 participants in each and involved a total of 110 advocates representing 51 disability advocacy organisations, reflecting strong sector interest in the discussions. It provided the opportunity for organisations to share ideas, current practice and to strengthen sector connections.

Interviews

Online semi-structured interviews were held with 29 stakeholders using an interview instrument that was consistent with the questions used in forum discussions. Interviewees included:

- Advocacy organisations that were unable to participate in the forums.
- Advocacy service users (to assist in understanding the client journey).
- Advocates from other related sectors with high demand for service—financial counselling sector, community legal centres and legal aid.

Interviews with other sectors in DANA networks were a way to assess comparable systems and tools used in the advocacy sector.

Analysis

Quantitative data

Three measures were used to assess unmet demand as a proportion of all enquiries/requests.

1. **All requests for advocacy** – all requests for advocacy received by disability advocacy organisations including for information alone and including eligible and ineligible requests. Ineligible requests may include the person requesting support not living with a disability; not living in the geographical area the organisation provides services; and/or requesting support for an issue the organisation does not assist with. This reflects the volume of requests that need to be responded to, sorted, managed, prioritised or referred elsewhere.
2. **Eligible requests for advocacy** – all requests for advocacy received by disability advocacy organisations that meet eligibility criteria to provide assistance.
3. **Eligible requests for advocacy that did not receive assistance**; or requests that were assigned to a wait list because the disability advocacy organisation did not have the capacity to take on more clients at the time support was requested.

Qualitative data

Thematic analysis was undertaken of the survey qualitative data and proceedings from the forum discussions and the interviews.

⁵ A specific referrals forum was deemed necessary as questions related to this were left out of the survey to keep it short and maximise engagement.

Caveats and limitations of the data

Some organisations experienced difficulty in extracting data for all survey questions due to the inadequacy of their reporting systems. There is inconsistency across disability advocacy organisations in how service contacts are recorded and processed. The personal details of many people seeking support may not be recorded so as to not jeopardise psychological safety, and people may be referred elsewhere or provided with information. Many contacts are not recorded in DEX due to the 5% unidentified rule.⁶ Nevertheless, these "invisible" numbers amount to substantial time and effort that is not captured through DEX reporting.

Of the 39 responding organisations, 33 provided full data sets for the 6-month period⁷ and there was missing data from six organisations for one month for Question 4.⁸ The available data for these six respondents was averaged across the full 6-month period and applied to the missing months to avoid underreporting.

Wait list data was provided for the last day of the month and would not reflect fluctuations over the month; however, the data is unreliable because of the disparity in how organisations manage wait lists. Some do not keep wait lists, they may be kept for varying lengths of time and people with disability may be on multiple wait lists. In summary, the reported wait list data possibly underrepresents the total unmet demand comprised by wait lists.

Despite these limitations, 77% of the raw data was complete. The high rate of participation and broadly complete data set lend confidence in the capture and processing steps.

Production of the Intake Reference Guide

The *Intake Reference Guide*⁹ was developed as a resource for the advocacy sector through a co-design process involving disability advocates and disability advocacy organisations from around Australia and across all funding streams. Input included sharing of organisational policies and procedures for intake and demand management, discussion at forums and feedback on draft Guide documents.

The *Intake Reference Guide* details examples of good practice intake processes and explores how demand can be managed through intake, prioritisation, wait lists and appropriate case load size. It highlights the fit-for-purpose operations of different sized organisations, as well as organisations that provide services for specific disability cohorts.

⁶ The DEX protocols only allow five per cent of clients to be recorded as unidentified in any reporting period. Therefore, the actual volume of requests for advocacy is not accurately recorded through the DEX system. Please see Program Specific Guidance for Commonwealth Agencies in the Data Exchange February 2023 at p 201 - see <https://dex.dss.gov.au/sites/default/files/documents/2023-02/1851-program-specific-guidance.pdf>

⁷ There was a downward trend in data for December for people taken on as advocacy clients that implies a possible seasonal variation, however a longer period of research would be required to test this assumption.

⁸ Question 4: "What is the total number of people that have contacted you inquiring for assistance in <month>, whether they became an advocacy client or not?"

⁹ The *Intake Reference Guide* is a resource for the sector written by DANA and now managed by the National Centre for Disability Advocacy (NCDA).

Disability advocacy intake process

Discussions with advocacy organisations demonstrate that the following intake process typically occurs following initial contact requesting advocacy support. The enquiry is assessed as **ineligible** or **eligible** for advocacy.¹⁰

Ineligible requests for advocacy are provided information and where possible, referred to appropriate organisations for assistance.

There are three main processes that occur for eligible advocacy requests:

- The person is provided with information and advice to resolve the issue without ongoing advocacy assistance.
- The person is placed on a waitlist until the organisation has the capacity to assist.
- The person is provided advocacy assistance.

It is important to note that an eligible advocacy request may go through one, two or all three of the above processes. An active client may still have to wait to be allocated an advocate, depending on the organisation's processes. The time it takes for an advocate to be allocated depends on the size of the organisation and its capacity at that point in time.

It is also important to note that some organisations reported not keeping waiting lists during this period due to the capacity of the organisation and as a strategy to manage demand.

Key Findings

The findings from the quantitative and qualitative data were complementary and provide valuable baseline information in relation to the national demand for disability advocacy, levels of unmet demand, the capacity of organisations to provide advocacy support and the factors impacting provision of advocacy. The quantitative survey data reported for the 6-month period (September 2021 – February 2022) confirms previous anecdotal reports of increasing demand for disability advocacy and demonstrate that there is significant unmet demand across all funding streams. The qualitative data provides insights into intake processes, the factors contributing to unmet demand and the key challenges facing the sector.

The five key findings from the Intake Project research were as follows:

1. An upward trend in demand for disability advocacy assistance nationally.
2. Significant unmet demand across all funding streams.
3. NDIS Appeals Program is under the most strain.
4. A sector that receives a significant number of enquiries including ineligible requests.
5. A sector overwhelmed by requests for advocacy and information.

¹⁰ For an in-depth breakdown and flowchart of the advocacy intake process, see: National Centre for Disability Advocacy, May 2023, *Intake Reference Guide*, version 1.0, page 12.

Quantitative data trends

All requests for advocacy support and unmet demand

Requests for disability advocacy ranged between 4,500 and 5,800 per month across the 39 responding disability advocacy organisations. A total of 30,110 enquiries was reported for the 6-month period across all funding streams (Table 1). Of these, 17,538 requests were eligible for advocacy (58%) and 12,572 requests were ineligible (42%).

There was an upward trend in monthly requests for advocacy assistance from 3,141 in September 2021 to 4,182 in February 2022 and an accompanying downward trend of fewer people becoming advocacy clients across the period with a total of 20,923 (or 70%) of all enquiries not becoming clients (Figure 2).¹¹ Figure 2 includes both eligible and ineligible requests for advocacy.

Of the total 30,110 enquiries for advocacy support, 17,538 were eligible to receive assistance, however only 9,187 became advocacy clients when they requested it (Figure 3).

All enquiries, including ineligible requests, need a level of assessment, often at a substantial cost in resources, regardless of whether they are accepted for advocacy, and this additional work is not reflected in activity reporting.

On average across the 39 participating disability advocacy organisations, 1,531 new advocacy clients were taken on collectively each month (Table 1 and Figure 2). On average, 30% of all enquiries for support were taken on each month as advocacy clients.¹²

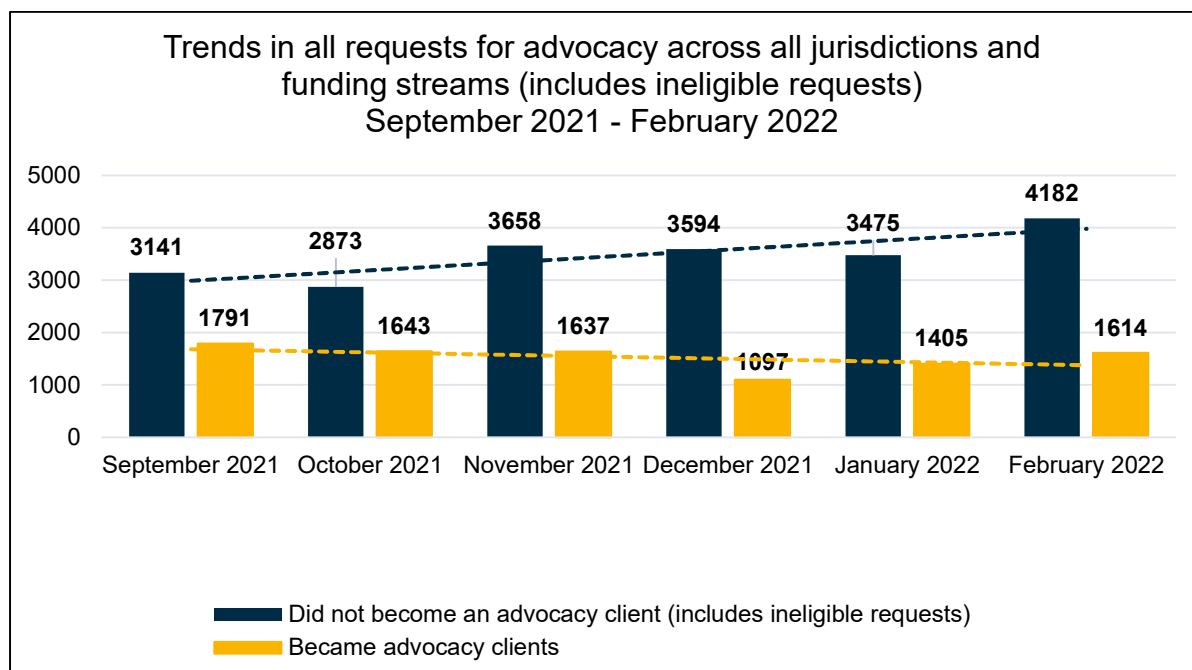
Table 1: Trends in demand – monthly requests for advocacy support: September 2021 – February 2022

Month	Became an advocacy client	Did not become an advocacy client (eligible)	Ineligible request	TOTAL requests
September 2021	1,791 (36%)	1,237 (25%)	1,904 (39%)	4,932
October 2021	1,643 (36%)	1,773 (39%)	1,100 (25%)	4,516
November 2021	1,637 (31%)	1,450 (27%)	2,208 (42%)	5,295
December 2021	1,097 (23%)	1,269 (27%)	2,325 (50%)	4,691
January 2022	1,405 (29%)	1,271 (26%)	2,204 (45%)	4,880
February 2022	1,614 (28%)	1,351 (23%)	2,831 (49%)	5,796
TOTAL	9,187 (30%)	8,351 (28%)	12,572 (42%)	30,110

¹¹ A person with disability who did not become an advocacy client may also have presented to another organisation to request advocacy assistance. Repeat contacts with multiple organisations is not captured in this data and was out of scope of this project.

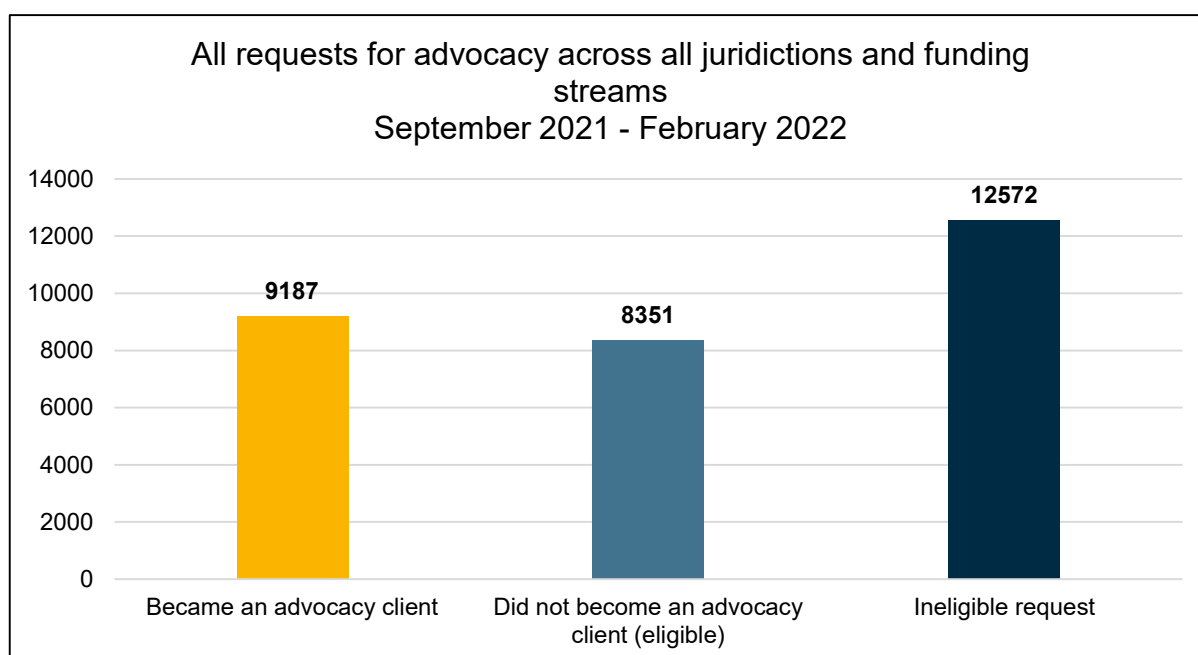
¹² The lowest numbers were for December 2021, which may reflect possible seasonal variation in requests for advocacy, however a longer period of research would be required to test this assumption.

Figure 2: Trends across all jurisdictions and funding streams (includes ineligible requests) – all requests for advocacy assistance: September 2021 – February 2022



All enquiries need handling, often at substantial expenditure of time and effort by intake teams in advocacy organisations and regardless of whether they are accepted for advocacy. This additional work is not reflected in activity reporting. There are various reasons for people not becoming an advocacy client at the time of request including not meeting the eligibility criteria of the organisation, constrained capacity, being put on a wait list or other reasons (information is adequate, referral is more appropriate).

Figure 3: Trends across all jurisdictions and funding streams – all requests for advocacy assistance: September 2021 – February 2022



Eligible requests for advocacy – all funding streams

Of the total 17,538 eligible requests for advocacy across all funding streams only 9,187 or 52% became advocacy clients (Figure 4, Table 2 and Figure 5). The remaining 8,351 or 48% of eligible requests (Figure 5) did not become advocacy clients or were placed on waiting lists due to organisational capacity issues.¹³

Figure 4: Unmet demand and waitlist trends across all jurisdictions and funding streams: September 2021 – February 2022

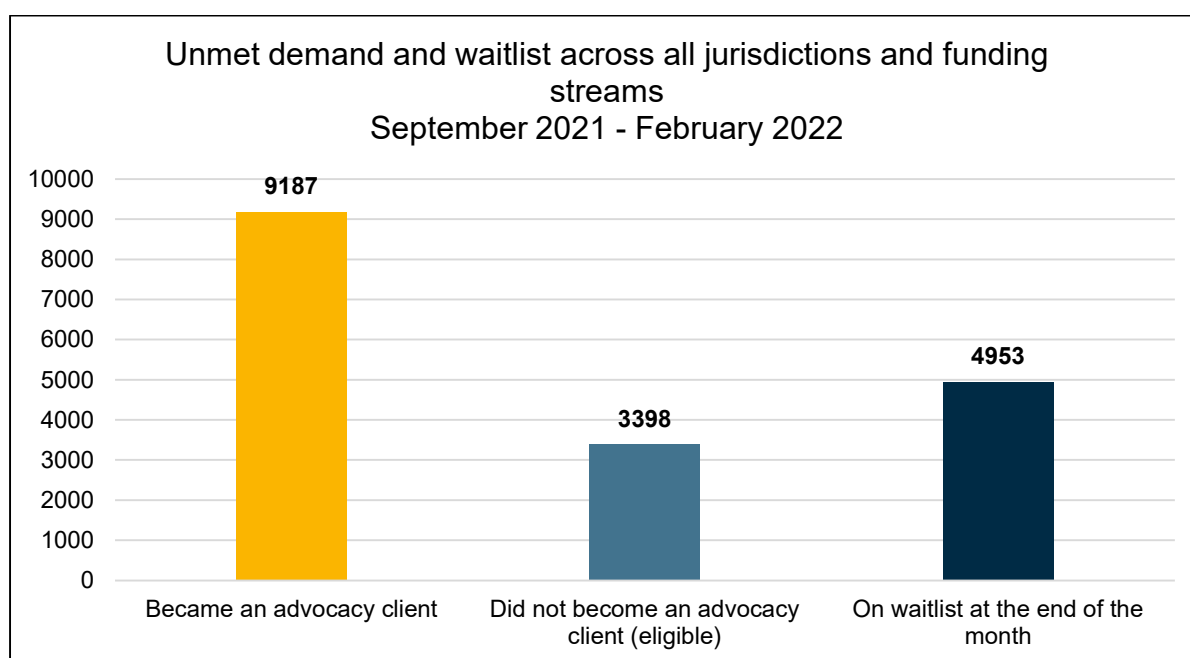
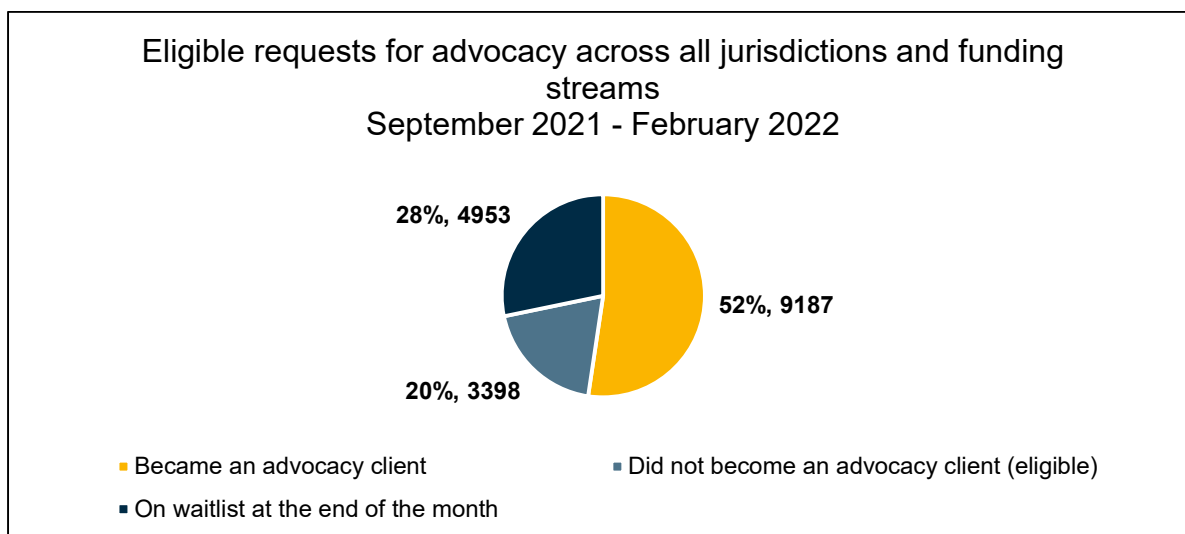


Table 2: Unmet demand and waitlist trends across all jurisdictions and funding streams: September 2021 – February 2022

Month	Became an advocacy client	Did not become an advocacy client (eligible)	On waitlist at end of month	TOTAL eligible requests
September 2021	1,791 (59%)	453 (15%)	784 (26%)	3,028
October 2021	1,643 (48%)	858 (25%)	915 (27%)	3,416
November 2021	1,637 (53%)	549 (18%)	901 (29%)	3,087
December 2021	1,097 (46%)	538 (23%)	731 (31%)	2,366
January 2022	1,405 (53%)	484 (18%)	787 (29%)	2,676
February 2022	1,614 (54%)	516 (18%)	835 (28%)	2,965
TOTAL	9,187 (52%)	3,398 (20%)	4,953 (28%)	17,538

¹³ There was great disparity at this time in the ways in which organisations keep waiting lists, some did not keep waiting lists. There is now a requirement for NDAP funded organisations to keep waiting lists.

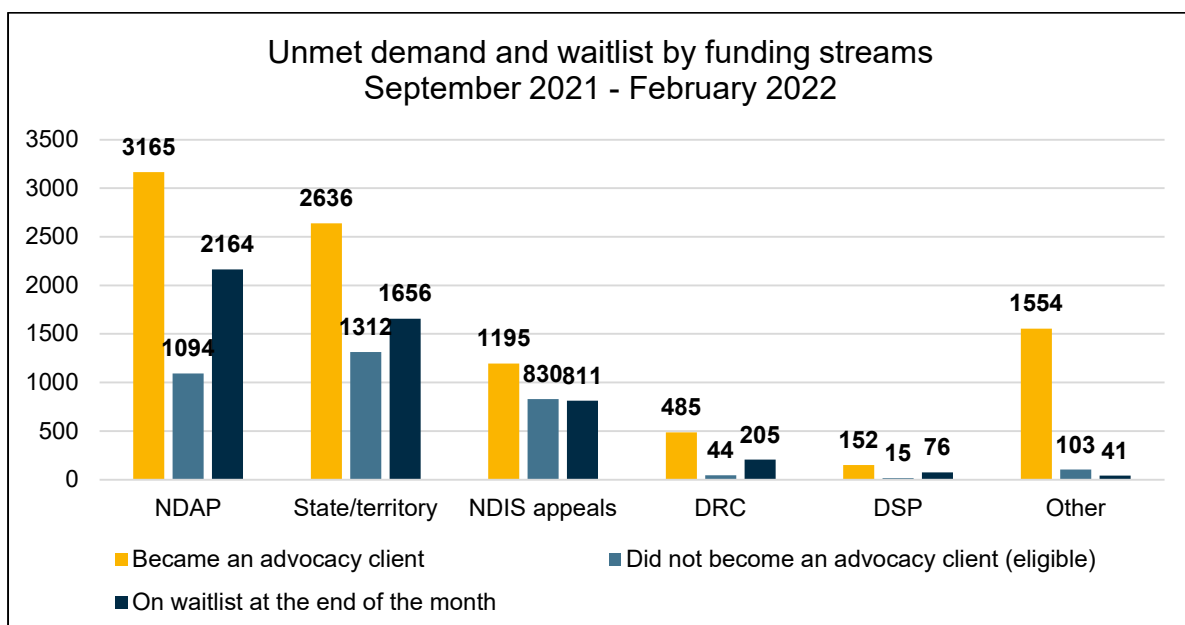
Figure 5: Unmet demand and waitlist trends across all jurisdictions and funding streams: September 2021 – February 2022¹⁴



Unmet demand in eligible requests – by funding stream

Survey respondents provided data for the number of eligible requests in each funding stream that the organisation could not assist due to insufficient capacity (Question 7) (Figure 6). The highest volume of advocacy requests fell into the NDAP funding stream which covers the broadest range of advocacy issues. Over the 6-month period, 3,258 eligible NDAP requests did not receive advocacy when requested representing 51% of total eligible requests in this funding stream (Table 3).

Figure 6: Unmet demand and waitlist trends by funding streams: September 2021 – February 2022



¹⁴ The amount of time a person spends on a waitlist varies between organisations and funding streams, with some waitlists being up to 16 weeks. Waitlisting is a process to assist in managing unmet demand.

The data shows that proportionately the NDIS Appeals Program is under the greatest pressure with 58% of eligible requests for advocacy unmet (Table 3, Figure 7 and Figure 8). Advocates reported that NDIS appeals cases are often very complex and time consuming and can continue over many months (or years).

Table 3: Unmet demand and waitlist trends by funding streams: September 2021 – February 2022

Funding stream	Became an advocacy client	Did not become an advocacy client (eligible)	On waitlist at end of month	TOTAL eligible requests
NDAP	3,165 (49%)	1,094 (17%)	2,164 (34%)	6,423
State/ Territory	2,636 (47%)	1,312 (23%)	1,656 (30%)	5,604
NDIS Appeals	1,195 (42%)	830 (29%)	811 (29%)	2,836
DRC	485 (66%)	44 (6%)	205 (28%)	734
Decision Support	152 (63%)	15 (6%)	76 (31%)	243
Other	1,554 (92%)	103 (6%)	41 (2%)	1,698
TOTAL				17,538

Figure 7: Unmet demand and waitlist trends – NDIS appeals: September 2021 – February 2022

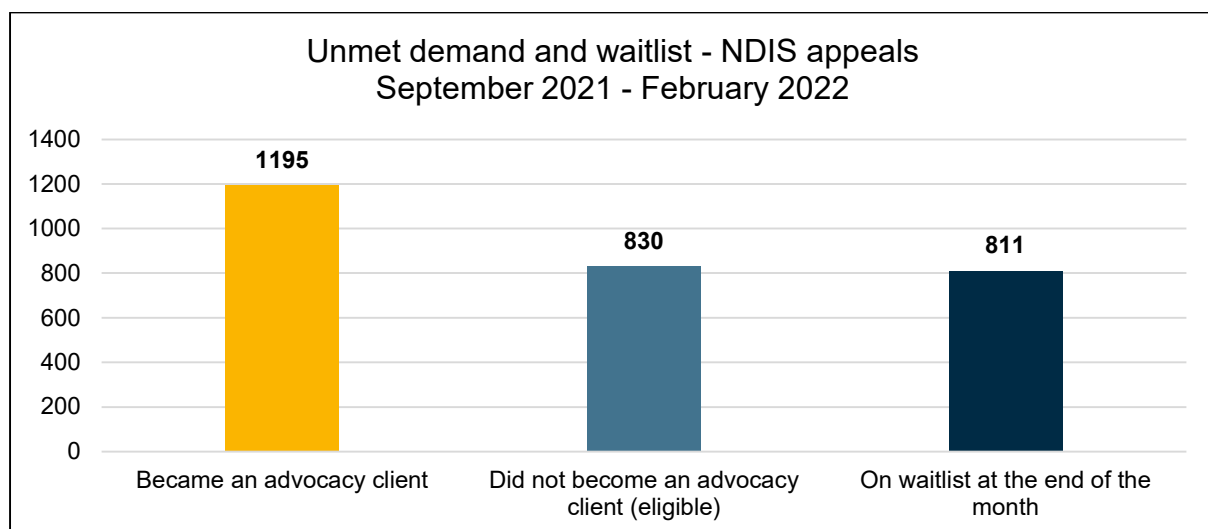
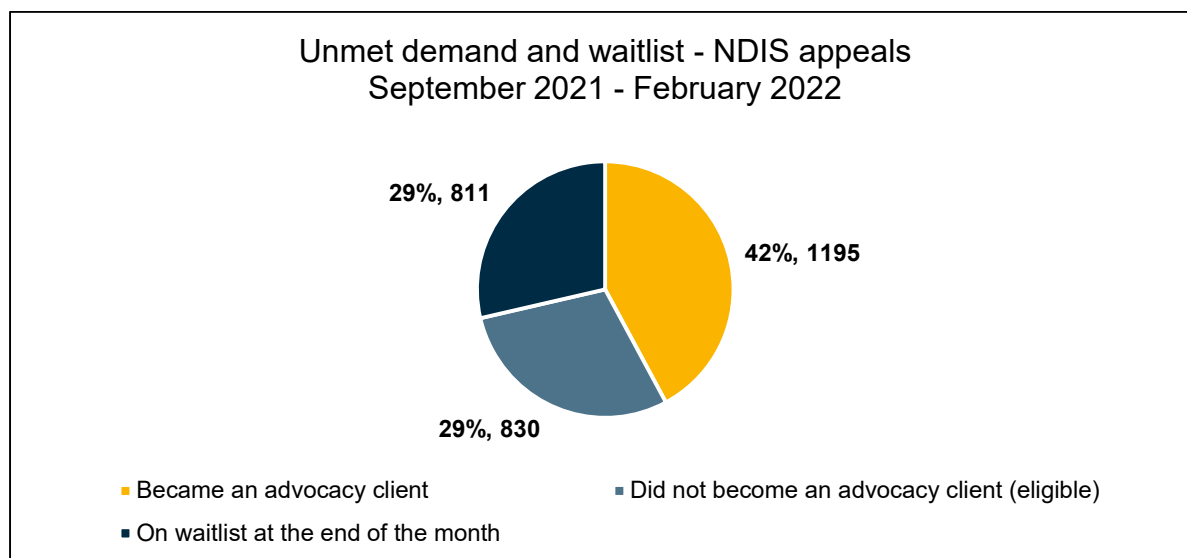


Figure 8: Unmet demand and waitlist trends - NDIS appeals: September 2021 – February 2022¹⁵



Books closed

One of the ways advocacy organisations manage demand is to close their books. This means no additional issues were accepted for advocacy during the period of closure.¹⁶

Table 4: Total days books closed and organisations that closed their books by month: September 2021 – February 2022

Month	Total days with books closed	Total organisations closed ¹⁷
September 2021	203	5
October 2021	275	8
November 2021	447	10
December 2021	587	9
January 2021	471	8
February 2021	374	7
TOTAL	2,357	

¹⁵ The amount of time a person spends on a waitlist varies between organisations and funding streams, with some waitlists being up to 16 weeks. Waitlisting is a process to assist in managing unmet demand.

¹⁶ The data does not differentiate how the number of days books were closed were calculated. Some include weekends, public holidays and shut down periods, while others do not.

¹⁷ 78 organisations were provided the survey 39 organisations responded.

Figure 9: Total days books closed by month: September 2021 – February 2022

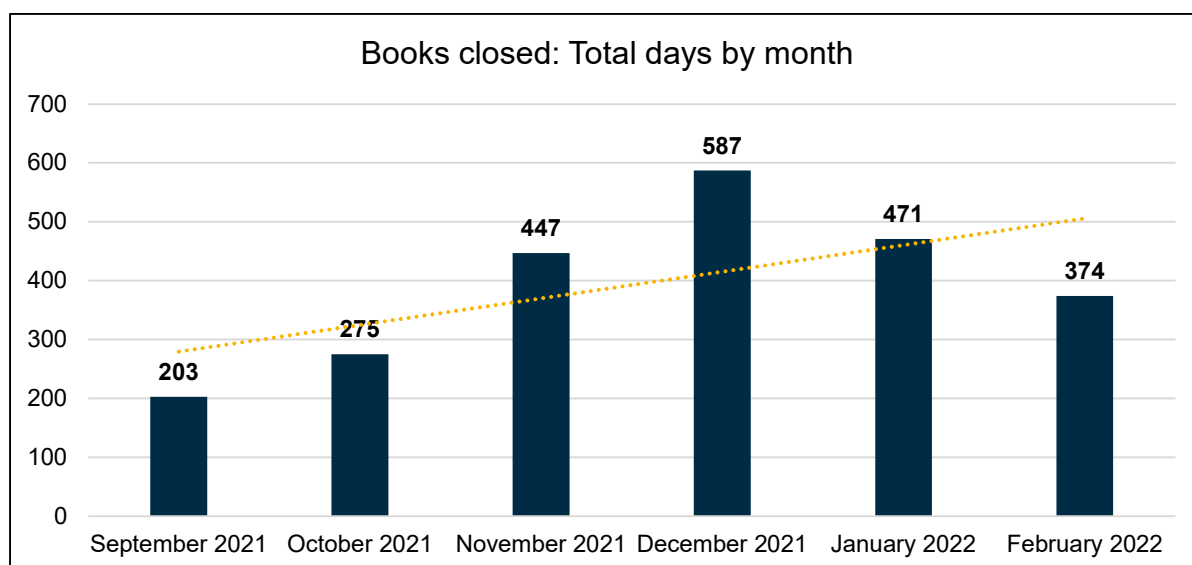


Table 4 above shows that during the survey period, advocacy organisations closed their books and were unable to accept new advocacy clients for 2,357 days over the 6-month period.

During September, five organisations (across 6 funding streams) closed their books for a total of 203 days. November was the month when ten organisations closed their books, the highest number of organisations closed during the survey period. This resulted in books being closed for a total 447 days.

This is across all (six) funding streams. For example, one organisation may have books closed for 30 days for NDIS Appeals, and ten days for NDAP. This demonstrates that organisations are under pressure, given that they needed to close the books for more than one funding stream.

December had the highest number of days for books being closed – 587, and the second highest number of organisations with their books closed.

Figure 9 demonstrates a strong upward trend in the number of days advocacy organisations had to close their books, indicating increasing demand for advocacy. A period longer than six months to gather data on this is required to confirm the trend in this data.

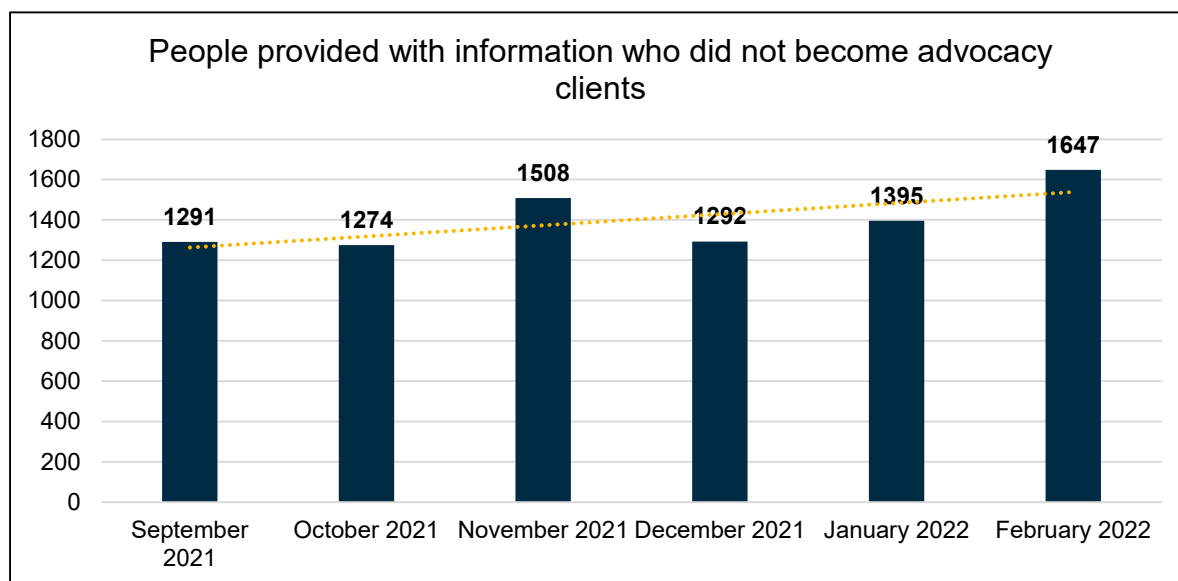
Information provision

There was a significant upward trend in numbers of people provided with information, who did not become advocacy clients;¹⁸ over the six months, disability advocacy organisations provided information to an average of 28% of advocacy requests (Figure 10).

The data does not clearly indicate whether the limited capacity of the organisation to take on new clients or the adequacy of the information provided was the reason for the request for advocacy not becoming an ongoing client.

¹⁸ Generally, these people will not be counted in the DEX system due to the 5% unidentified rule.

Figure 10: People provided with information who did not become advocacy clients



Advocacy agencies have various approaches to capturing data regarding enquiries where information is provided—some do not record it, others use an intake ‘logbook’ but do not transfer the data to a spreadsheet or other software, some use software systems such as IVO or Community Data Solutions to collect data required by their funding agencies.

“Some of the data ... has not been systematically recorded. There are a lot of enquiries where we simply provide the information and advice without recording any client details unless it is going to be put onto the waiting list.”¹⁹

Information provision is an important aspect of the work of advocacy organisations; this may be the provision of a phone number or website, or it may involve more detailed explanation of a system or a process and the best way to navigate it. Information may also be provided when an organisation has no capacity to take the person on as a client. Sourcing and providing information can be time consuming, however this activity is frequently not captured in organisational records. Requesting details of the inquiring person may be inappropriate and organisations often provide information without recording details of the person. Third party enquiries e.g. those from Centrelink, hospital social workers, and health professionals are excluded from DEX reporting. The above factors lead to an underestimation of the total work of advocates.

Qualitative data themes

Analysis of the project’s qualitative data (survey qualitative comments, discussion forums and interviews) revealed a number of themes that centred around overloaded service systems and can be summarised as follows:

- Complexity of advocacy issues and dealing with NDIS matters.
- Overwhelmed disability advocacy services increasingly operating in crisis mode.
- Importance of systemic advocacy in addressing barriers.
- Need for fit-for-purpose intake processes to provide greater access to advocacy.

¹⁹ DANA Intake Survey response.

Complexity of advocacy issues and dealing with NDIS matters

In response to the survey question, “*What do you think is impacting wait times?*” advocates repeatedly commented on the increasing complexity of advocacy issues and navigating the NDIS system:

“Wait times are increased due to demand, increasingly complex matters, NDIS bureaucracy, and a severe lack of funding to service client needs. Overwhelmed service systems lead to waiting times for reports and evidence.”²⁰

Advocates also observed the increasing trend in complexity of advocacy cases correlated with the rollout of the NDIS and confirmed that disability advocacy organisations were significantly impacted by increasing requests for support with NDIS appeals. NDIS Appeals Program funding has been provided to some advocacy organisations, but the level of funding is not sufficient to meet demand for appeals due to the increased case complexity meaning cases took longer to close and therefore impacted the resources available for other cases. Organisations report that they needed to dip into their generalist advocacy funding for their NDIS appeals work to keep up with demand.

“NDIS Appeals support being sought ... all state-wide orgs appear to be at full capacity leaving people with nowhere to go for help.”²¹

NDIS-related issues can be a matter of urgency for people seeking to become participants or to access additional supports or equipment through their NDIS plan. Advocates commented that only some people with disability have support coordination in their plan, and this support is fee-for-service. The role of an advocate was being strained with external pressure to provide a broader scope of service beyond advocacy. However, if issues were not addressed quickly the situation may become an advocacy issue later. This occurred often with access to NDIS and internal reviews:

“We continue to have a number of enquiries requesting advocacy support for people at NDIS plan reviews and accessing NDIS or internal reviews. We refer access to NDIS to LACs, and we prioritise [consumers seeking assistance with] plan review and internal review to [those] most at risk and [with] no informal support.”²²

The NDIS Appeals Program funding appears to have not kept pace with the significant increased demand for advocacy support for people taking appeals to the Administrative Appeals Tribunal (AAT). This trend reached crisis levels with overwhelming numbers of NDIS participants appealing Agency decisions. The increase to AAT appeals has been documented by advocacy organisations, including an in-depth analysis by Queensland Advocacy for Inclusion which shows there was a significant increase to new AAT applications from September 2021.²³

²⁰ DANA Intake Survey response.

²¹ DANA Intake Survey response.

²² DANA Intake Survey response.

²³ Queensland Advocacy for Inclusion, 30 June 2022, *Analysis of NDIS Appeals*, Prepared for the Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships, https://qai.org.au/wp-content/uploads/2022/08/20220804_QAI-Report-for-DATSIP_NDIS-Appeals-AAT_Final-for-Publication.pdf page 10.

Overwhelmed disability advocacy services increasingly operating in crisis mode

Participating organisations commented on working at full capacity and needing to make intake decisions based on ‘risk’ or ‘most in need’ or measurement of the ‘crisis’. This reflected a reactive, crisis-driven model of advocacy provision with many people who qualify for advocacy not receiving support due to limited capacity as demonstrated by the quantitative data:

“Increased complexity of advocacy requirements - due to gaps and wait times for advocacy and other services and supports those requesting advocacy are more frequently presenting already in crisis which requires more sophisticated and time-consuming advocacy response. This then has flow on effects for others waiting for advocacy and contributes to a negative feedback loop.”²⁴

Consistently dealing with people in crisis as a priority meant that advocates did not have the capacity to undertake timely prevention and early intervention support for people to avert potential subsequent crises.

The importance of systemic advocacy

Advocates emphasised the importance of addressing the systemic issues causing people to seek advocacy – and the importance of moving advocacy to a more preventative model. However, organisations cannot allocate time to systemic issues at the expense of individual advocacy. They stressed the need for increased funding for systemic advocacy. Concerns were expressed that without sufficient attention to systemic failures, individual advocacy issues will continue to grow, and many will remain unresolved.

Fit-for-purpose intake processes provide greater access to advocacy

Participants commented on the need for flexibility and that variation to intake processes is key to providing equitable access to advocacy. Tailored advocacy approaches are needed to increase access and support for identified high-risk population groups to address their specific needs. This includes outreach to marginalised communities, to provide education and information about rights, information to self-advocate (enabling a systemic solution to addressing demand – if people know where they can go for information, they may be able to self-advocate). While acknowledging that outreach generates demand, it also provides tools and information to communities to self-advocate.

Advocacy organisations need to be able to remain flexible and responsive so they can adapt to changes on the ground, including impacts from government systemic and policy changes and also respond to local issues such as bushfire or flood disasters.

Discussion

The Intake Project findings drew on data from half of the disability advocacy sector nationally including a broadly representative sample of participating organisations across all states and territories. Trends in the quantitative data for the period September 2021 to February 2022 confirmed the anecdotal reports of significantly increased demand for advocacy support and concerning levels of unmet demand across all funding streams.

²⁴ DANA Intake Survey response.

The project also found that due to DEX and other reporting system limitations there was likely to be considerable under-estimation of the level of demand for advocacy. For instance, there was highly variable maintenance of waiting list data by different organisations. Also, the sheer volume of work that advocacy organisations do in striving to serve the requests for support they receive is not adequately captured in current data reporting systems.

The constant increase in demand was observed by advocates to have occurred since the introduction of the NDIS, which has also reportedly resulted in increased complexity of advocacy issues, and particular strains on the NDIS Appeals Program. It was observed that the move away from case management that existed in the previous block-funded system was a major contributing factor together with limited support coordination in NDIS plans.

With constrained capacity and additional strains created by COVID-19, high demand on the NDIS Appeals Program and other emergencies (including local natural disasters), organisations adopted risk assessment processes to ensure that those people in crisis or at highest risk were being prioritised. The high levels of unmet demand for eligible clients due to insufficient capacity means that many people with disability were missing out on the support they need to uphold their rights. Constrained capacity was also at the expense of preventative and developmental work of rights education and awareness raising, capacity building, early stage problem-solving, and dispute resolution to resolve issues early and avoid escalation into crises.

Qualitative data confirmed that staff in disability advocacy organisations were overwhelmed by the challenges of meeting the increased demand and dealing with the impact of increased complexity of cases – resulting in staff burnout. Undertaking the necessary work to respond to a spectrum of requests (information provision, referrals, third party enquiries) without funded capacity and inability to address identified systemic issues created additional strains.

At current funding levels across all funding streams, organisations simply do not have the staffing capacity to address the unmet demand that people with disability have for advocacy support.

The *Intake Reference Guide* will be a welcomed resource for disability advocacy organisations and benefited greatly from the co-design process used in its development. Participating organisations reported on the value of being given the time and space to engage with colleagues from other organisations during the project discussion forums to discuss the processes they use, and their effectiveness.

Conclusion

The Intake Project provides valuable baseline data regarding national demand for disability advocacy support and confirms increasing rates of unmet demand over time in a sector struggling to meet the need with existing funding and organisational capacity. Without additional and targeted funding to support NDIS related issues, people with disability will continue to be excluded from the very system designed to ensure they are included and able to participate socially and economically. Designated funds are needed to ensure equitable access and support for high-risk groups - their specific needs will not be achieved without this.

The project found an adaptable and agile sector open to changes and improvements in advocacy services so that the sector can provide advocacy to more people with disability. The sector would benefit from government support to investigate and support

implementation of different methods to manage increasing demand. One suggestion by advocates is that NDIS appeals become a specialised area as experience is needed to support appeals and other NDIS issues. Additionally, the role of the National Centre for Disability Advocacy (NCDA) is well placed to provide ongoing monitoring of unmet demand and support to the sector through resources and guides, the first being the *Intake Reference Guide*.

This project was undertaken at a particular period (September 2021 - February 2022) where the ongoing impacts of the COVID-19 pandemic, the Disability Royal Commission and possible seasonal fluctuations were likely influencing factors. The findings provide valuable baseline data for further investigation, longitudinal research, and ongoing monitoring and review to inform decision-making regarding resource allocation.

During the course of the project, participating organisations reported an increase in demand and complexity of advocacy issues since the introduction of the NDIS. This is partly due to the abolition of state-funded and Centrelink case management which could provide wrap-around services. Dealing with increased bureaucratic processes in the NDIS and Centrelink has added to the complexity of issues. The current review into the NDIS may identify a way to streamline some of these processes particularly in the plan review and appeals space. The abolition of the Administrative Appeals Tribunal (AAT) and the trial of an Independent Expert Review process provided an opportunity to trial a more equitable and less time-consuming process for reviewing NDIS plans.

The National Disability Advocacy Framework 2023 - 2025 identifies that there is currently no mechanism to identify unmet demand for disability advocacy services. The Framework makes a shared commitment from the Australian and State/ Territories Disability Ministers to work towards developing consistent definitions to collect consistent data across the disability advocacy sector. Consistent data will build the evidence for the current capacity and demand for disability advocacy, and this is a key role for the NCDA.

DANA submissions to the Disability Royal Commission have also highlighted the value of independent disability advocacy and the need for a significant increase in funding for the sector to be able to meet current and future demands for advocacy.

Attachment 1: Monthly intake survey

Disability Advocacy Network Australia's (DANA) "Intake and Wait List Data" survey aims to capture a snapshot of unmet demand. DANA will send out one survey a month for six months to gather information as part of the DANA Intake Project.

This survey is only asking about disability advocacy, and all data in the questions below will refer to clients during September 2021. This survey will be open until Friday 29th October 2021.

We will provide the compiled data for each month back to all of you when we send the subsequent survey at the beginning of the next month.

The survey takes about 10 minutes to complete, only one response per organisation required.

1. In the provision of individual advocacy, how many advocacy hours were provided by your organisation in <month>? Please enter the number below.
 2. In the provision of systemic advocacy, how many advocacy hours were provided by your organisation in <month>? Please enter the number below.
 3. Which geographical areas do you cover?
 4. What is the total number of people that have contacted you inquiring for assistance in <month>, whether they became an advocacy client or not?
 - State/ territory
 - NDAP
 - DRC
 - NDIS Appeals
 - Decision support
 - Other
 5. How many people were accepted through your intake system and became an advocacy client in September? Please enter the total number for each applicable funding stream.
 6. What is the total number of people you helped by providing information* (and support to self-advocate) in <month>? (These people didn't become an individual advocacy client through your intake system).
 - State/ territory
 - NDAP
 - DRC
 - NDIS Appeals
 - Decision support
 - Other
- * For the purpose of this survey, 'information' means provision of material in a general way. It does not include contacting another service on behalf of the person.

6. Due to insufficient capacity, how many people couldn't you help in September? Please enter the total number beside each applicable funding stream.

- State/ territory
- NDAP
- DRC
- NDIS Appeals
- Decision support
- Other

8. How many people did you have on each of these waiting lists at the end of <month>, if applicable?

Did you 'close the books' in <month>?

- State/ territory
- NDAP
- DRC
- NDIS Appeals
- Decision support
- Other

10. If yes, for how many days have the books been closed for <month>? Please enter the number of days beside each relevant funding stream.

11. What factors, if any, do you believe are impacting wait times?

12. Anything else you want to tell us about any of the questions above?

13. What is the name of your organisation? (This information is kept strictly confidential. You or your organisation will not be identified).

Thank you for your input into this survey. Please do not hesitate to contact DANA if you have any further questions or input.