

Demand and Gap Analysis Project Summary

December 2020

Introduction

The Australian, state and territory governments all provide disability advocacy services and there is no mechanism to identify demand, unmet demand, service coverage, standards or funding levels across Australia. It is challenging to understand where there are gaps in supports from a national perspective. People with disability seeking advocacy services should be able to access quality, holistic advocacy support in relation to all service systems, regardless of where they live.

In December 2019, the Disability Reform Council agreed the Department of Social Services (DSS), in conjunction with the states and territories, would lead a demand and gap analysis of 'independent disability advocacy and decision-making supports'.¹This project was initiated to better understand the disability advocacy landscape since the implementation of the National Disability Insurance Scheme (NDIS), especially in response to reports of increased demand on disability advocacy services. It represents the first step towards governments beginning to work together to achieve an effective network of disability advocacy across Australia.

In March 2020, DSS engaged a consultancy firm, ASK Insight, to conduct this work. The project was finalised in December 2020 and this report provides a summary of the key findings. The findings demonstrate a point-in-time snapshot of demand on disability advocacy nationally and are not necessarily representative of the current landscape. The project did not address the impacts, outcomes or value of disability advocacy.

The project involved discussions with state and territory officials, interviews with eight Disability Representative Organisations (DROs) and the Disability Discrimination Commissioner, and surveying of disability advocacy providers. Seventy-eight disability advocacy organisations were invited to participate in the survey and 48 responded, which represents a 62% response rate. The survey included questions about changes in demand, the impact of current demand on their organisations and people with disability, their ability and capacity to meet demand, and the main gaps in disability advocacy service delivery.

Definitions

Disability advocacy supports range from the informal supports provided by friends and family, through to funded programs of support delivered by independent advocacy organisations. Definitions of types of disability advocacy and related services, including information services and decision-making supports, provides a foundation for a shared understanding of services, outcomes and responsibilities at a national level. A list of working definitions was developed as part of this project and is provided at Appendix 1.

¹ COAG Disability Reform Council Communiqué. December 2019.

Drivers of demand for disability advocacy

All disability advocacy services surveyed reported an increase in demand for advocacy services in the past three years with 70% indicating that this had been a 'major' increase in demand, or more than 20% growth.

Disability advocacy services identified the navigation of complex service systems as a key driver of demand for advocacy services. Complex cases take longer to resolve and typically require more resources and specialist skills.

Disability advocacy providers were asked to indicate what proportion of their advocacy was specifically related to the NDIS. The average response was 46% of all advocacy support provided, which represents the most common topic advocates assist with. Issues requiring advocacy support were primarily related to understanding, preparing for and navigating NDIS processes, including review processes and implementing NDIS plans. Disability advocacy services were additionally impacted by a lack of clarity around role and responsibilities, where disability advocacy services reported being engaged on issues which could be resolved by NDIS support coordinators or NDIA staff.

Resolving issues related to housing were also identified as complex and time consuming. Issues requiring advocacy support in this area were related to property maintenance or modification, appropriate, accessible housing, and availability of housing. These issues can also overlap with those related to the NDIS. Other complex issues were also identified including those related to legal assistance, criminal justice, government payments, education, transport, health and aged care.

The project also identified a lack of funding for supported decision-making models can result in increased demand for advocacy services in the absence of legal decision-making mechanisms.

Additionally, demand was impacted by delivering services in regional, rural and remote areas, COVID-19, and engaging with Government requests for input to policy.

To manage the increase in demand, the three most common strategies used by disability advocacy services were prioritisation, referral to other agencies and maintaining waitlists. Of the services who maintain a waitlist, half indicated a wait time of more than one month for people to receive support.

Disability advocacy services reported that their ability to meet requests for support that fall within their delivery responsibilities has been declining and, on average one in four people were not being assisted, based on data from the 2018-19 financial year. Disability advocacy services reported that the increased demand and wait times adds to people with disability's distress and frustration, in addition to missing out on services. From an organisational perspective, the increase in demand leads to a focus on crisis responses, higher workloads, increased staff stress, and higher staff turnover. Some advocacy services reported reluctance to promote their services and risk further increasing demand.

Gaps in the delivery of advocacy services

Disability advocacy services were also asked what they perceive to be current gaps in the delivery of advocacy services. The most common responses related to funding inadequacy and insecurity. Existing inadequacies of funding has meant disability advocacy services are limited in their ability to respond to increases in demand. Additionally, 87% of disability advocacy services surveyed reported that uncertainty about future funding impacted on their ability to plan ahead, recruit and retain staff. Other responses noted a lack of coordination between the available funding and existing programs, and reported competitive short-term funding is problematic as it sets organisations against each other and requires significant resources to prepare tenders.

Additionally, insufficient geographic coverage was raised as a gap in the delivery of advocacy services, particularly for regional and remote areas. There are a range of additional barriers to delivering advocacy in regional and remote areas, which require additional funding to overcome. With demand for disability advocacy currently outstripping supply, regional and remote service delivery is disproportionately impacted. Good service delivery also requires the leveraging of local knowledge, expertise and strong relationships, which is particularly important in remote, and Aboriginal and Torres Strait Islander communities.

Another gap in service delivery raised by disability advocacy services was insufficient training and professional development for advocates. There are limited formal training options available and large workloads leave less time for networking, skill sharing and formal training for staff. In particular, issues in complex systems require more specialised skills to resolve. Difficulties retaining staff further compound this gap.

Other gaps raised by disability advocacy services include lacks in national data capture, clarity around definitions of advocacy and related services, and appropriate services for specific cohorts including culturally and linguistically diverse people, Aboriginal and Torres Strait Islander people and people with psychosocial disability.

Conclusion

Disability advocacy has been acknowledged as a shared responsibility by the Commonwealth, state and territory governments. However, there is need for clarity around how this should work in practice. The aim should be to ensure a ‘no wrong door’ approach for people seeking advocacy support. Individuals may have multiple issues to resolve, some relating to state or territory responsibilities and others to Commonwealth responsibilities. Establishing consistent working definitions provides a basis to establish the scope of a national approach to advocacy services. The understanding of drivers of demand and service delivery gaps will underpin a shared approach to addressing these.

There are existing mechanisms Commonwealth, state and territory governments can use to guide this work. This project highlighted the need to update the National Disability Strategy 2010-2020 (NDS).² The NDS can be used to align and coordinate governments’ shared commitment to disability advocacy, which should lead to clearly articulated roles within the funded independent advocacy sector. Additionally the National Disability Advocacy Framework (NDAF), which was endorsed by Commonwealth, state and territory governments in 2012, is also due for updating. Designing a new national framework for disability advocacy to take account of an agreed objective, principles and outcomes alongside the NDS will be important to achieve alignment and improve outcomes for people with disability.³

² The NDS was updated and launched in December 2021 as [Australia’s Disability Strategy 2021-2031](#). Disability advocacy is an important element of the Strategy and falls under the outcome area Safety Rights and Justice, under Policy Priority 4 – “the rights of people with disability are promoted, upheld and protected”.

³ The NDAF has been revised and can be found on the [DSS website](#). A report on the public consultation on the NDAF conducted in 2022 can be found on the [DSS Engage](#) website.

Appendices

Appendix 1: Definitions

Decision making	The process of making choices among possible alternatives.
Decision-making capability	Decision-making capability can be defined as: understanding information relevant to the decision or action being able to weigh up the options understanding the possible consequences of taking or not taking a particular decision or course of action. It requires that a person is capable of freely and voluntarily making decisions about the matter and is able to communicate their decision in some way.
Disability advocacy	Acting, speaking or writing to promote, protect, uphold and defend the human rights of people with disability.
Disabled People's Organisation (DPO)	A DPO is an organisation that is controlled by people with disability (at least 51% people with disability at the board and membership levels). A DPO is different to other disability sector organisations because it is 'for us, by us' (PWD).
Independent disability advocacy programs	Take action to promote, protect, uphold and defend the human rights of people with disability who face complex challenges and are unable to advocate for themselves. Advocates act on the expressed wishes of the person they represent and are free from any conflict of interest. *Types are listed separately in the table below
Individual capacity building	Activities that build the capacity of people with disability by ensuring that they have the knowledge, skills and confidence they need to participate and contribute to community, and speak up for themselves.
Informal advocacy	Someone, such as a carer, family member or friend, provides assistance to explain to others what a person with disability needs or wants as a natural extension of their role in the person's life.
Information service	An information service is characterised by high volumes of enquiries and short interactions with help seekers.
Natural support	The support and assistance that naturally flows from the relationships that occur in everyday life. Examples of these relationships are family members, friends, co-workers, neighbours and acquaintances.
Nominee under the NDIS	A nominee is a person who is appointed to act on behalf of, or make decisions on behalf of an NDIS participant.

Self-advocacy	Acting, speaking or writing to represent your own rights, needs or interests.
Self-advocacy groups/programs	Self-advocacy groups are run by people with disability and can offer peer support and skills development as well as campaigning for change and disability equity
Substitute decision maker	<p>A legally appointed administrator or guardian who makes decisions on behalf of another person. These decisions may be about financial, lifestyle, personal or medical issues.</p> <p>Each state and territory has legislation to cover the appointment and role of substitute decision makes (such as Power of Attorney Acts and Guardianship arrangements).</p>
Supported decision making	Enabling a person with disability to make their own decisions and choices or express their will or preferences.
Systemic advocacy	Seeks to address and remove barriers and discrimination to ensure the rights of people with disability are upheld.

Types of independent advocacy

Individual advocacy	<p>Upholds the rights of individual people with disability by working on issues relating to discrimination, abuse and neglect.</p> <p>The typical issues (using NDAP records) are:</p> <table border="0"> <tr> <td>abuse/neglect/violence</td> <td>education</td> </tr> <tr> <td>access to supports</td> <td>employment</td> </tr> <tr> <td>child protection</td> <td>equipment/aids</td> </tr> <tr> <td>community inclusion</td> <td>finances</td> </tr> <tr> <td>disability services complaints</td> <td>government payments</td> </tr> <tr> <td>discrimination/rights</td> <td></td> </tr> </table>	abuse/neglect/violence	education	access to supports	employment	child protection	equipment/aids	community inclusion	finances	disability services complaints	government payments	discrimination/rights	
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Citizen advocacy	Matches people with disability with volunteer advocates.												
Family advocacy	Assists parents and family members to advocate on behalf of the person with disability for a particular issue.												
Legal advocacy	Upholds the rights and interests of individual people with disability by addressing the legal aspects of discrimination, abuse and neglect.												