Review into Disability Advocacy in NSW

A report by the NSW Ageing and Disability Commissioner

19 December 2019

NSW GOVERNMENT

ageingdisabilitycommission.nsw.gov.au

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Acronyms and Definitions

Acronyms

		EXPLANATION
AAT	Administrative Appeals Tribunal	A Commonwealth agency
ABS	Australian Bureau of Statistics	A Commonwealth agency
ACNC	Australian Charities and not-for-profit Commission	A Commonwealth agency
ACTION	Action for People with Disabilities	A NSW advocacy organisation
ADACAS	ACT Disability, Aged and Carer Advocacy Service	A government department in ACT
ADC	Ageing and Disability Commission	NSW based commission, author of this report
ADD	Ageing and Disability Department	Previous name of a NSW government department
ADHC	Ageing, Disability and Home Care	Previous name of a NSW government department
AHRC	Australian Human Rights Commission	A Commonwealth agency
AIHW	Australian Institute of Health and Welfare	A Commonwealth agency
BCA	Blind Citizens Australia	A consumer peak body
CALD	Culturally and Linguistically Diverse	
CAPE	Citizen Advocacy Program Evaluation	
CAWS	Community Access Western Sydney	An outer Sydney advocacy service
CBA	Cost benefit analysis	
CDAD	Centre for Disability Advocacy Development	A key component of the DAFP
CJSN	Criminal Justice Support Network	A NSW program
CLSD	Cooperative Legal Services Delivery (program)	A NSW legal program
CLSP	Community Legal Services Program	Commonwealth/States funding program
COAG	Coalition of Australian Governments	
CoS	Continuity of Support	A Commonwealth Program
CSTDA	Commonwealth State and Territories Disability Agreement	Previous name of a multilateral government agreement
DADHC	Department of Ageing, Disability and Home Care	Previous name of a NSW government Department

DAFP	Disability Advocacy Futures Program	Key proposal of this Review, with a number of recommended components
DAISI	Disability and Aged Information Services	A regional NSW service
DAN	Disability Advocacy Network	A key component of the DAFP
DANA	Disability Advocacy Network Australia	National representative body for advocacy organisations
DARU	Disability Advocacy Resource Unit	A key component of disability advocacy Victoria
DAS	Disability Advocacy Services	A key component of the DAFP
DCJ	Department of Communities and Justice	NSW Government department
DIAP	Disability Inclusion Action Plan	Requirement under the NSW Disability Inclusion Act
DIP	Disability Inclusion Plan	Requirement under the NSW Disability Inclusion Act
DRC	Disability Reform Council	
DRO	Disabled Representative Organisation	A Commonwealth funded program
DSA	Disability Services Act	Commonwealth Legislation
DSP	Disability Services Program	A Commonwealth program
DSS	Department of Social Services	A Commonwealth government department
EOI	Expression of Interest	
FACS	Family and Community Services	Previous name of a NSW government Department
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs	Previous name of a Commonwealth government Department
FPDN	First People’s Disability Network	
IDRS	Intellectual Disability Rights Service	
IFP	Individually Funded Package	Funding received by individual participants in the NDIS
ILC	Information, Linkages and Capacity Building	Program funded under the NDIS
KPI	Key performance Indicators	
LAC	Local Area Coordination	Initiative funded under the NDIS
LGBTI	Lesbian, gay, bisexual, transgender, intersex	

LHD	Local Health Districts	Geographic areas of NSW Health
MDAA	Multicultural Disability Advocacy Association of NSW	
MHAS	Mental Health Advocacy Service	NSW specialist Legal Aid service
NCOSS	New South Wales Council of Social Services	
NDA	National Disability Agreement	A multilateral government agreement
NDAP	National Disability Advocacy Program	A Commonwealth funded program
NDIA	National Disability Insurance Agency	A Commonwealth Agency
NDIS	National Disability Insurance Scheme	A Commonwealth Program
NDS	National Disability Strategy	
NMDS	National Minimal Data set	
PHN	Primary Health Networks	Geographic areas under Commonwealth Health
PMC	Premier and Cabinet	NSW Department
PWDA	People with a Disability Australia	
RDAS	Regional Disability Advocacy Services	
RFP	Request for Proposal	
SARU	Self Advocacy Resource Unit	A key component of disability advocacy Victoria
SDAC	Survey Disability Ageing and Carers	
TAFS	Transitional Advocacy Funding Supplement	
TTP	Temporary Transformation Price loading	
UN CRPD	UN Convention on Rights of People with a Disability	International convention

Key Definitions

Advocacy	See expanded definition, roles and purpose of advocacy in Chapter 3
Carer	Person who provides care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail
Citizen Advocacy	Citizen advocacy seeks to support people with an intellectual disability by matching them with volunteer advocates on a one-to-one basis. Citizen advocates are encouraged to represent the interests of a person with a disability as if they were their own and be free from conflict of interest
Family Advocacy	Family Advocacy helps parents and family members advocate on behalf of the person with disability for a particular issue. Family advocates work with parents and family members on a short-term and issue specific basis.
Legal Advocacy	Legal Advocacy seeks to defend the rights and interests of people with disability on a one-to-one basis through the Australian legal system.
Individual Advocacy	Individual advocacy seeks to uphold the rights and interests of people with all types of disabilities on a one-to-one basis by addressing instances of discrimination, abuse and neglect. Individual advocates work with people with disability on a short-term and issue-specific basis.
Self Advocacy	Self Advocacy supports people with disability to advocate for themselves or as a group
Supported Decision-making	The process of assisting a person to make their own decisions in order that they can identify and pursue goals, make choices about their lives and exercise control over things that are important to them (MHCC)
Systemic Advocacy	Systemic advocacy seeks to influence or secure positive long-term changes that remove discriminatory barriers to ensure the rights and interests of groups of people with disability are upheld.

Commissioner's foreword

In NSW, approximately 1.4 million people have a disability, more than 18% of the state's population. Positively, people with disability are increasingly seeking to exercise their rights in order to participate equally within the community. Advocacy is critical to ensure the promotion, protection and security of their rights.

The NSW Government has been an important funder of advocacy, information and referral services over many years. However, the disability landscape, including for disability advocacy services, has changed dramatically with the introduction of the National Disability Insurance Scheme.

This Review was established as part of the legislation creating my new role as the Ageing and Disability Commissioner, which commenced on the 1st July 2019. The Review focuses on the funding and the nature and structure of advocacy, information, referral, and representational activities in NSW.

Ensuring everyone has access to high-quality, reliable services and supports is fundamental to an inclusive society – regardless of where you live, your disability or your cultural background.

This report provides the framework for a more sustainable, accountable and contemporary disability advocacy system underpinned by an enhanced, secure and better focused funding program. The reforms will deliver a more robust, responsive and equitable system of advocacy provision for people with disability in this State. They will deliver good value to the people of NSW.

Importantly, this report was informed by significant consultations and conversations with the sector, people with various disability, service providers, government agencies, and individual disability advocates. As part of this consultation I and members of the Review team visited numerous communities and organisations across NSW to hear about their experiences.

I acknowledge and thank all those who contributed to this Review. I especially acknowledge our consultants Westwood Spice, the Department of Communities and Justice and my staff for undertaking this Review within a very constrained timeframe.

This is the first report I have produced as the NSW Ageing and Disability Commissioner. I hope it delivers a clear way forward for disability advocacy in NSW, because effective advocacy matters in the lives of people with disability.

Robert Fitzgerald AM
NSW Ageing and Disability Commissioner

Executive summary

By 2030, it is expected that 1.8 million people in NSW will have a disability. Of this, there will be approximately 590,000 people residing and seeking services within the State who have a profound or severe limitation affecting their day to day activities.

The disability landscape and role of advocacy will also evolve over this time, especially with the continued rollout and increasing maturity of the NDIS. The need for advocacy will continue to be an important part of the lives of people with disability to ensure the continued promotion, protection and security of their rights, and enable their genuine participation in the community. We note that the NSW Government is committed to an inclusive community for all people with disability.

NSW has a long and strong history of community based disability advocacy and the NSW Government has been an important funder of advocacy, information and referral services. Many deliver great results for their clients. However the disability service environment, including the provision of advocacy services, has radically changed especially with the development of the NDIS. Additionally, the responsibility for and the level of funding of advocacy and related services has been uncertain.

> “Every advocacy issue is a different advocacy issue. Every story is different”
>
> Workshop participant

This Review into disability advocacy funding arrangements in NSW has explored the purpose, functions and funding arrangements for independent specialist advocacy, including information and representative organisations for people with disability across NSW. The Review has also looked at how advocacy funding and services should be delivered in the future.

The Review methodology is outlined on page 15.

What we found

The provisions of advocacy are diverse, as are the needs and circumstances by which advocacy is sought. Citizens, families, carers, peers, peak bodies and representative organisations often provide a level of advocacy alongside organisations that are funded to deliver individual advocacy. Many advocates provide an effective and high-quality service to their clients. However, because these provisions do not coherently operate together, the result is a fragmented, inequitable and often confusing disability advocacy ‘system.

Key challenges identified in relation to disability advocacy in NSW include:

- a significant impact of no **long-term, sustainable funding** on the capacity of advocacy services, and ability for organisations to retain or upskill staff, evaluate programs and develop long-term working relationships.
- no consistent means to measure performance.
- a **shift in work** for advocates assisting people with disability **to access the NDIS**.
- the **increasing demand from government** departments seeking the views and opinions of advocacy organisations in relation to various consultations, which albeit valuable, impacts on time.
- **a general low awareness of what disability advocacy is**, and the role it plays for people with disability.
- a **lack of sector support and capacity-building** that could grow the advocacy workforce and entice new talent.

Yet, these challenges can be met. There are many aspects of the disability advocacy sector that create considerable optimism.

- Many advocacy organisations not only represent people with disability, but have engaged them in their governance arrangements.
- Organisations have developed very committed, loyal membership and supporters over time.
- Organisations have highly knowledgeable and committed staff and volunteers who understand the needs and preferences of their clients and can access local solutions.
- Many organisations have navigated the changed funding environment by accessing different sources of funding, and optimised themselves by developing creative integrated service offerings.
- Many are well respected by government agencies for their insights, experiences and knowledge, as well as their capacity to inform consultation through the bringing together of those most affected.

> “Advocacy hasn’t invented itself. It has developed responsibly in response to people with a disability”
>
> Workshop participant

What should there be?

The Review found there is currently no overarching framework that facilitates a clear understanding of the role of advocacy for people with disability, the role for the NSW Government in supporting advocacy, or principles by which funding can be applied.

While there are many highly skilled and committed advocates and services, the current system is not likely to meet future challenges and demands. There is an evident need for further development of organisations and personnel, and improved coordination within the disability advocacy sector that builds capacity, encourages innovation and provides value for money for the Government, community and people with disability.

There needs to be an improved understanding of, and accounting for, the outcomes of the services provided and an enhanced evidence gathering process to inform sector and practice improvement.

Finally, service delivery needs to be more equitably available.

Of course, this needs to be based on an equitable, secure and sustainable funding model and at a level of funding that can facilitate a ‘fit for purpose’ system able to meet anticipated demand.

What is the funding context?

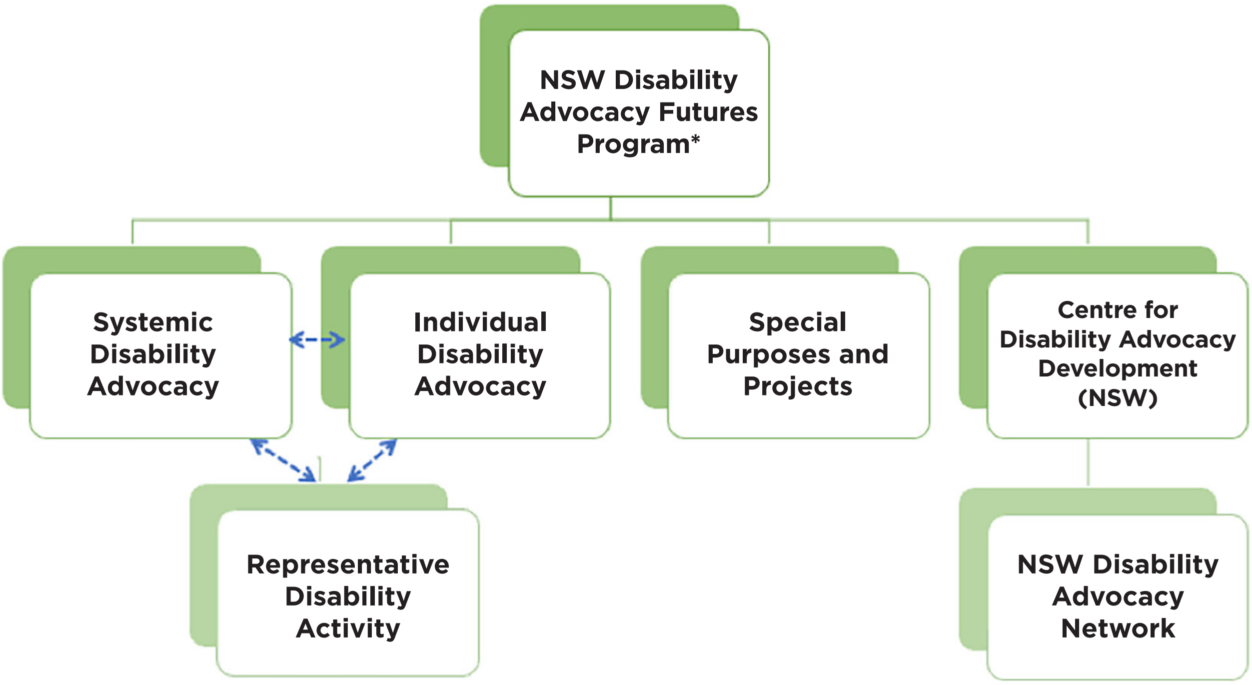
A focus of this Review has been to identify the current and future role and responsibility of the NSW Government in the funding of disability advocacy and related services, in a significantly changed context. To this end, the Review examined other funding sources that are provided to NSW disability advocacy and representative organisations – in particular, the Commonwealth Government through its National Disability Advocacy Program (NDAP), and the NDIS through its Information, Linkages and Capacity Building (ILC) program. We have sought to clarify the aims and contributions of these programs. As was expected, the NSW Government’s direct funding contribution to advocacy reduced after alternative funds under the NDIS came into the sector.

Nevertheless, there is an important, indeed necessary, ongoing role for the NSW Government to directly support disability advocacy. This can be achieved through a more clearly focused, outcomes-driven funding program based on a set of principles as recommended in this report. Underpinned by a transparent, adequate and secure funding base, the sector should be better able to respond to the needs of people with disability, and government should be better able to identify what is being achieved as a result of its contribution.

The way ahead

To deliver effective and meaningful change, a new long term disability advocacy funding program – the NSW Disability Advocacy Futures Program (DAFP) – is being proposed that will also enhance the components of advocacy that are working well. This new program will be strategically targeted to maximise value for people with disability, the community and funded organisations, and be the principal means by which the NSW Government will fund the provision of advocacy in NSW. Above all other goals, it must deliver an improved disability advocacy system that will uphold and promote the rights of people with disability irrespective of the nature of the disability, gender, sexual orientation, age, culture or background, or location.

A basic structure of the DAFP is outlined in the below figure, and further detail of each stream is provided in Chapter 4.



*oversight of the establishment and performance of this Program by the NSW Ageing and Disability Commission

Each stream will have a clearly defined purpose that meets the needs of the sector, the Government and people with disability. The program will also include a new centre that will drive better practices across the advocacy sector, and strengthen links between advocacy agencies, the Government and the broader NSW community.

> "Advocates need to network as a significant part of their role… Attending interagency meetings, conferences helps advocates build their networks"
>
> Workshop participant

- **NSW Centre for Disability Advocacy Development (NSW) CDAD**
    - The Centre will enhance and improve the development of high quality, sustainable disability advocacy services by fostering collaboration and innovation amongst disability advocacy service providers; provide community information about access to disability advocacy; and support self-advocacy initiatives.
- **NSW Disability Advocacy Network (DAN)**
    - The Network is a membership-based advocacy network of providers who receive funding from the DAFP. The purpose is to drive quality improvement, collaboration and innovation among advocacy organisations, and build stronger networks and learning opportunities.

Regarding streams of advocacy:

- **Systemic disability advocacy**
    - Designed to provide high quality evidence-based advice to inform the resolution of systemic issues, and be particularly informed by the views and lived experience of people with disability.
- **Individual disability advocacy**
    - Deliver supported advocacy activities to address specific issues for individual people with disability. A priority will be on issues related to the upholding rights, accessing services and resolving disputes and complaints.
- **Representative disability advocacy**
    - Primarily focused on a defined cohort of people with specific disabilities, their families or carers. It seeks to promote and represent the views and interests of its members and other people with similar disabilities.
- **Special purposes and projects**
    - Designed to support community operated initiatives to assist people with disability to actively engage in their communities in a more informed and empowered way for which alternative funding sources are not available.

The DAFP will need to operate within some constraints, and some services will need to be prioritised, depending on variable demand. This is also only a part of the broader disability support and advocacy environment, which involves variously funded and non-funded activities and a diverse range of models of advocacy, organisations and community groups, all of which may continue to sit alongside the proposed DAFP.

Yet, the proposed reformed program will have an impact on the nature and supply of advocacy services in this State. The number of funded contracts will be streamlined. Nevertheless, many existing organisations will inevitably be able to successfully apply for the new funding contracts and will be the backbone of the reformed service system.

Others, however, may not be directly funded. Some may enter into arrangements with those funded agencies, and the commissioning process should be flexible to enable subcontracting, consortia and partnerships to emerge.

What about implementation?

The report recognises that timely implementation of the proposed reforms is vital. In order to do this effectively, the Government should establish an implementation taskforce or working group of government and sector experts to guide the establishment of the DAFP and broader reforms. It is recommended that the DAFP be fully implemented by 2022/23.

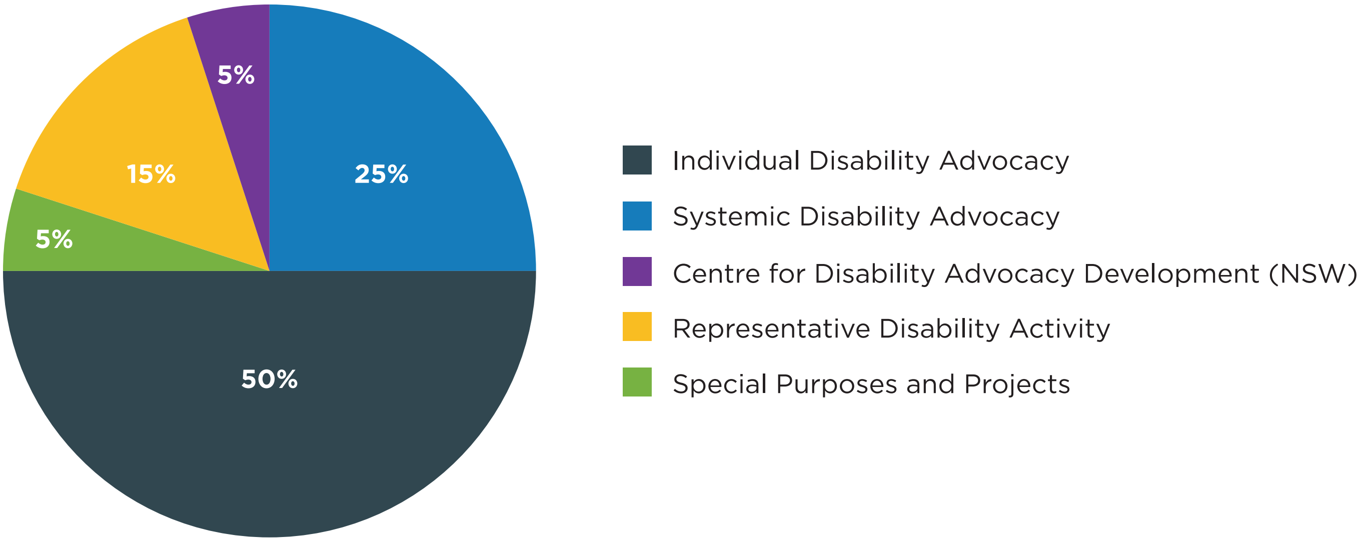
Additionally, certainty of funding will ensure stability in the sector and continued delivery of some advocacy services until full implementation is achieved.

Therefore, we recommend that the Government should provide a budget allocation of $13 million for FY 2020/21, and $14 million for FY 2021/22.

The funding allocation for the first full year of the DAFP program should be $15 million for F/Y 2022/23. This level of direct funding to disability advocacy organisations under the DAFP would be the new minimum funding baseline.

A breakdown of the funding allocation is provided below:

First Full Year Funding



What are the benefits?

For a **person with disability**, the benefits should be that they can better access advocacy services or support as they need it and where they need it; have a service that responds in a timely, skilled and competent way – one that understands their issues and respects their will and preferences.

For **funded services**, it will afford a much more certain funding environment, clearer outcome measures and accountability, opportunities to collaborated in a community of practice and to enhance skills, capabilities and capacity over time.

For the **community**, a confidence that people with disability are being better supported, through a system that is delivering good value for the limited resources applied.

For the **Government**, a strengthened partnership with the advocacy sector, providing **evidence-based** solutions and quality **advice**, delivering better outcomes for people with disability.

We conclude that disability advocacy is, when delivered effectively, a valuable and rewarding process. Among other things, it enables people with disability to navigate services, systems and environments to ensure they have access to necessary services that are right for them.

The role of advocacy will continue as the population evolves. It is not a matter of no longer needing advocacy; rather, developing a clear and strategic system that threads purposeful advocacy throughout funded service delivery.

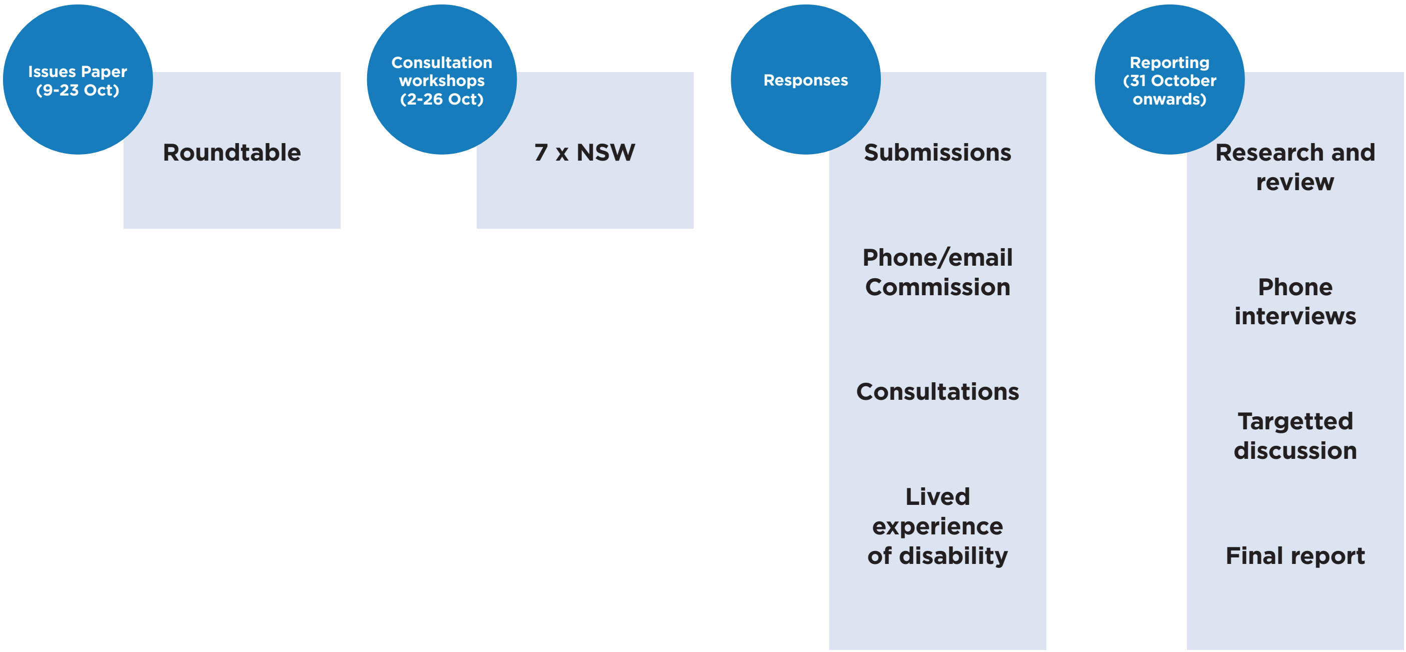
Advocacy matters for people with disability, their families and their carers. Advocacy matters for the quality of our governments, the policies they make, and the services they deliver. Advocacy matters to our community to ensure we create a genuinely inclusive society.

> Advocacy plays an important role in safeguarding and prevention and it should not just be viewed as a mechanism to manage crises by responding to complaints.
>
> Submission to the Review

Methodology

The Review methodology is shown below at Figure 1. Consultation was widespread, with participants having varied backgrounds and experience across advocacy and other related sectors. There were over 70 participants in the face-to-face consultations, 44 submissions, 75 emails as well as other meetings, workshops and interviews.

Figure 1: Methodology of the consultation process



Recommendations

We have outlined 11 sets of recommendations from the Review. These recommendations take into account key parts of the Review, with deep consideration of the future needs of people with disability.

1. Align the definitions of disability advocacy

To promote a nationally consistent approach, the NSW Government, for the purposes of the new disability advocacy framework and funding program, should adopt the definitions in the National Disability Advocacy Program (NDAP) for the terms - advocacy, individual advocacy and systemic advocacy.

2. Develop a strategic advocacy framework that is fit for purpose

To better promote, protect and secure the rights of people with disability, the NSW Government should develop a new, long term, sustainable framework for disability advocacy provision in NSW that underpins a reformed, fit for purpose funding program. At a minimum, the framework should cover the purposes and roles of advocacy, principles of funding, services to be delivered and performance measurement.

3. Funding will be based on key principles that supports effective advocacy

Future long term funding of disability advocacy in NSW should be based on the following principles by which resourcing will:

- demonstrate value for money to people with disability, the government and the people of NSW.
- be managed in a way that is transparent and provides a secure foundation for service operations, including through longer term funding commitments.
- achieve equity of access to disability advocacy across NSW, regardless of location.
- be cognisant that there are no eligibility criteria for accessing funded disability advocacy in NSW.
- support delivery of timely, competent advocacy activities regardless of culture, gender and nature of disability.
- recognise the interdependent nature of different forms of advocacy in supporting an effective advocacy system.
- support the capacity of funded organisations and the sector as a whole to adapt to meet the demands of a dynamic service and system environment.

4. Reignite the system with a new NSW Disability Advocacy Futures Program

The NSW Government should establish a new funding program to be known as the NSW Disability Advocacy Futures Program (DAFP). It should be strategically targeted to maximise the value of such funding for people with disability, the community and funded organisations in NSW.

Importantly, the DAFP will be the principal means by which the NSW Government will fund the provision of advocacy for people with disability in NSW.

The DAFP should:

- be based on a clear set of funding principles as recommended, and key assumptions
- be designed to have a more targeted focus on systemic and individual advocacy while recognising support for representative activity
- recognise the particular or distinctive needs of certain cohorts of people with disability including of people with disability from culturally and linguistically diverse (CALD) backgrounds and Indigenous communities
- while recognising the need for flexibility in the provision of advocacy services and supports, require proportionate, comparable and meaningful accountability in relation to all funded organisations
- recognise the need for the will and preferences of people with disability to be respected within a better designed and more focused funded disability advocacy system

5. The NSW Government has a targeted focus when establishing the DAFP

The NSW Government should target the Disability Advocacy Futures Program:

- to support the engagement of people with disability with NSW Government and non-government services, to promote their social inclusion, enable them to uphold their rights, and provide for the voice of people with disability to influence NSW Government policies, practices and outcomes including under its commitments to the National Disability Strategy
- to support sector development, systemic and individual advocacy, and representative activities
- to support information and referral as an ancillary component of all advocacy work, with funding for specific information and referral services remaining primarily the responsibility of the Commonwealth/NDIS.

In respect of the funding of advocacy, information and referral and related activities, the NSW Government should seek to have the respective roles and responsibilities of the Commonwealth, NDIS and the State agreed and set out in the new National Disability Agreement due in 2020.

6. Guiding principles will enhance the operations and outputs of funded organisations

The NSW Government, through its funding contracts and guidelines, should support the following principles for the conduct of disability advocacy organisations in NSW and their staff. In respect of DAFP funded disability advocacy services, organisations should:

- have regard to the will and preferences of each person with disability
- operate in a way that is free from conflicts of interest
- operate in a way that recognises the importance of local advocates with local knowledge
- support choice of advocate where practical
- demonstrate skills and competencies to build the capacity of the people they support
- use a transparent and fair process to prioritise their advocacy activities
- demonstrate, and are accountable for, the outcomes, impacts and quality of their service delivery practice and approach
- be prepared to work in collaboration to further develop the sector's capacities, promote innovation and optimise outcomes for people with disability.

7. NSW Disability Advocacy Futures Program offers clearer funding streams

Under the NSW Disability Advocacy Futures Program, clear funding streams should be established to fund the following:

- **NSW Centre for Disability Advocacy Development** – designed to enhance and improve the development of high quality, sustainable disability advocacy services, provide community information about access to disability advocacy, foster collaboration and innovation among disability advocacy service providers and support self-advocacy initiatives. The Centre would also provide the secretariat and resourcing for a new collaborative of disability advocacy providers, known as the NSW Disability Advocacy Network.
- **Disability Advocacy Network** – a membership-based collaborative network of disability advocacy providers with the purpose of enhancing quality improvement, collaboration and innovation among Network members and other disability advocacy service providers; enhancing networking and learning between advocacy providers and advocates more broadly; and creating a community of practice that is committed to a code of conduct. The Network will also work with the Department of Communities and Justice to develop a relevant performance and outcomes reporting framework.
- **Systemic disability advocacy** – designed to provide high quality evidence-based advice to inform the resolution of systemic issues. Systemic advocacy should aim to inform government and service systems owners of ways to uphold the rights of people with disability and improve the quality of life of people with a disability through their access to services. It shall be delivered through a number of statewide contracts for specifically identified cohorts and one cross-disability service.

- **Individual disability advocacy** – designed to provide supported advocacy activities to address specific issues for individual people with disability and to encourage self-advocacy where needed. It shall be delivered through a number of contracts, including for a statewide legal advocacy service, regionally defined services, and two statewide services, one for people from CALD and one for Indigenous communities.
- **Representative disability activity** – designed to support representative activities primarily conducted by an organisations focused on a defined cohort of people with specific disabilities, their families or carers. They should seek to promote and represent the views and interests of its members and other people with similar disabilities.
- **Special purposes and projects** – designed to support community-operated initiatives to assist people with disability to actively engage in their communities in a more informed and empowered way, for which alternative funding sources are not available.

8. The timely implementation of the proposed reforms is vital

The NSW Government should establish an implementation taskforce or working group of government and sector experts to guide the establishment and implementation of the proposed reforms.

The implementation of the proposed reforms and the establishment of the DAFP should be completed by the commencement of the 2022/23 financial year at the latest, and the NSW Government should establish a clear implementation timetable at the earliest opportunity.

An independent body, such as the NSW Ageing and Disability Commission, should oversight the implementation of the Review's recommendations and the ongoing performance of the DAFP and the disability advocacy sector.

9. Certainty of funding will stabilise the sector and underpin effective reform implementation

Assuming that implementation of the proposed reforms will occur over two years, the NSW Government should provide a budget allocation of $13 million for 2020/21 and $14 million for 2021/22, with a full allocation of $15 million for the first full year of implementation by 2022/23. This would be adjusted depending on the timetable for full implementation.

The individual advocacy funding stream should account for not less than 50% of the total allocation.

10. Sustainability in the sector will be enabled through longer term contracts

Under the DAFP, longer term contracts should be established:

- The Centre for Disability Advocacy Development, systemic disability advocacy and individual disability advocacy should have an initial contract term of three years. Subsequent contracts should be for five years' duration.
- Representative disability activities should have a contract term of three years.
- Special purposes and projects should have individually determined contract terms, having regard to the specific proposal.

11. Performance and outcomes are measured through a purposeful reporting framework

The NSW Government should develop a new DAFP Performance and Outcomes Reporting Framework based on the following principles:

- outcome and other reporting should serve the interests of clients, services and the community, and hence, as far as possible, should be conducted collaboratively and constructively
- data collection and reporting should be kept to an absolute minimum, consistent with meeting the needs and purposes described above, particularly where smaller services are involved
- the resources required to collect and report data for these purposes should be factored into relevant budgets and funding.

All DAFP funded programs should have explicit performance and outcomes measures. Such measures should be primarily based on the Commonwealth NDAP reporting framework, adjusted to meet the individual funding stream proposed outcomes. It should be further developed over time in consultation with the Disability Advocacy Network.

The NSW Government should provide de-identified aggregated data and information, provided by DAFP funded organisations, to the Centre for Disability Advocacy Development to help in analysis, evaluation, sector and practice improvements.

Chapter 1: Context of the Review

Introduction

This report is the first delivered by the newly created office of the NSW Ageing and Disability Commissioner.

Under section 26 of the *Ageing and Disability Commissioner Act 2019*, by 31 December 2019 the Ageing and Disability Commissioner must:

- Prepare a report in relation to the funding arrangements for independent specialist advocacy, information and representative organisations for people with disability in NSW. In preparing this report, the Commissioner must take into account any funding provided by the Commonwealth, under the National Disability Insurance Scheme Act 2013 to independent specialist advocacy, information and representative organisations for people with disability in NSW.
- Consult with independent specialist advocacy, information and representative organisations for people with a disability NSW in relation to the report,
- Provide the report to Parliament.

The Review Methodology is outlined in the Executive Summary. A broad range of people and organisations participated in the Review – joining consultation meetings, providing submissions to the issues paper or suggesting further reading for the literature review. Participants included representatives from funded disability advocacy organisations as well as other government and non-government parties who have intersecting or parallel interests in the advocacy sector[1].

This chapter sets the scene for the Review by, firstly, providing key information about people with disability in NSW. It then describes the current international, national and NSW operating context. This is followed by a history of advocacy in NSW before more detailed description of current advocacy provision and funding.

Subsequent chapters provide more detail arising from the Review activities and the way forward for the proposed Disability Advocacy Futures Program.

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[1] In particular, see Appendices 2, 3 and 4.

Review focus

This Review acknowledges that the landscape of disability advocacy is multi-faceted. Provision of disability advocacy is not confined to disability advocacy organisations; nor is it always funded. In practice, citizens, family, carers, peers, peak bodies and representative organisations may all provide or assist with advocacy activities alongside those organisations specifically funded to provide disability advocacy.

The current disability advocacy sector in NSW comprises a large number of organisations; some receive direct funding from the Commonwealth, including the National Disability Insurance Agency (NDIA)[2], and some from the NSW Government. The sector is historical in nature and includes both statewide and regionalised bodies. The current arrangements for disability advocacy in NSW reflect the state of change in broader disability service provision particularly over the last five years, the history of disability advocacy over many decades and the emergence of directions in NSW Government service provision.

For the purpose of this Review, the focus is on funded disability advocacy services in NSW.

The Review acknowledges the broad landscape of disability advocacy provision; for the purposes of this Review, the focus is on funded disability advocacy services.

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[2] While the NDIA does fund information services, it is explicit that it does not fund individual advocacy – see National Disability Insurance Scheme. 2019: A Framework for Information, Linkages and Capacity Building. https://www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc/ilc-policy-framework.

People with disability in NSW

In any review, there is value in understanding the broad population picture before considering specific matters.

The NSW Department of Communities and Justice (DCJ) is establishing baseline demographics of people with disability in NSW, using data from the Survey of Disability, Ageing and Carers (SDAC). The full DCJ report is at Appendix 7 with highlights noted here. In summary, SDAC 2015 and DCJ's analysis shows:

- **There are 1.4 million people in NSW with a disability**[3]. This represents 18.1% of the NSW population and is very similar to the national estimates. Of the 1.4 million people in NSW:
  - The data is similar between males and females (680,000 vs 693,000 respectively).
  - Approximately 105,000 (or 7.6%) were aged 14 and under, with approximately 600,000 (or 43.8%) aged 65 and over.
  - The number of people with a disability varies by gender for certain age groups with younger males reporting disability (particularly 5-14 years) and more females aged 35 to 54 reporting disability. These features are similar between the NSW and overall Australian population.
  - The proportion of people with disability increases by age band for both genders because older Australians are more likely to have a 'long term health condition' that limits activities (this wording is the basis of the definition of 'disability' in SDAC, see commentary below).
  - The data shows 440,000 people with profound or severe core activity limitation.
- **The population of people with disability is growing,** expected to be 1.8 million by 2030 (compared with 1.4 million in 2015). All 1.8 million should receive supports through mainstream service systems such as health, education and transport. NSW has identified some additional demographics for attention. In 2030 in NSW there will be (in very rounded terms) 590,000 people with profound or severe core activity limitation (compared with 440,000 in 2015):
  - 330,000 will be over the age of 65 (compared with 220,000 in 2015).
  - 260,000 will be under the age of 65 (compared with 224,000 in 2015), of whom 170,000 (65%) are expected to be supported by the National Disability Insurance Scheme (NDIS) (compared with 140,000 in 2015[4]) and 90,000 (35%) who are not (84,000 in 2015).

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[3] The 2018 SDAC has the estimation slightly less at 1.3 million people.

[4] COAG Disability Reform Council Quarterly Report for 2018-2019 Q4.

General commentary about a profile of people with disability in NSW

A broad understanding of people with disability in NSW is helpful to DCJ for its own planning purposes, particularly planning for people with disability who are not eligible for the NDIS. A baseline profile can help NSW departments and agencies better scope activities to meet their obligations under the NSW *Disability Inclusion Act 2014*, noting that all people with disability should be able to access supports through mainstream service systems such as health, education and transport.

The DCJ report notes some limitations to the data in Appendix 7, and we add the following commentary:

- We agree with DCJ that it is likely that the SDAC sampling methodology may not capture transient populations who may experience a higher prevalence of disability[5].
- The SDAC definition of disability focuses on self-reported **health conditions and its impact as the source of disability**[6]; we believe this may lead to under-reporting of disability.
- The SDAC data on **'assistance needed and received'** excludes data from the sample subset in 'Cared For'[7] accommodation settings. This subset includes residents of group homes and we believe their exclusion distorts overall estimates of levels of 'assistance needed and received'.
- We agree with DCJ that the figures are estimates, useful as a guide for broad strategic planning purposes.
- We believe that NDIS participants are likely to be from a number of the SDAC need groups, not just the profound/severe need group.

Specific commentary about any estimate of need for disability advocacy in NSW

In relation to **any estimate of the need for disability advocacy in NSW**, the Review is clear that this is not related to levels of disability. Rather, need for advocacy is related to the urgency and importance of the presenting issue along with the capacity of the individual to address the issue taking into account the other networks and support around the person.

> The need for advocacy for people with disability is **not** related to levels of disability. Rather, need for advocacy is related to the urgency and importance of the presenting issue along with the capacity of the individual to address the issue taking into account the other networks and support around the person.

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[5] The SDAC methodology excluded people living in boarding houses, caravan parks and hostels for the homeless – in About the survey of disability, ageing and carers, 4430.0 Disability, Ageing and Carers, Australia: Summary of Findings, 2015, Australian Bureau of Statistics. Released 18/10/16. EXPLANATORY NOTES Released 18/10/16. NOTE #5

[6] The SDAC differentiates between those who have long-term health conditions that limit their activities (that is, those with disability) and those who have long-term health conditions without restrictions and limitations: 'A person has a disability if they report they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities' – taken from About the survey of disability, ageing and carers, 4430.0 Disability, Ageing and Carers, Australia: Summary of Findings, 2015, Australian Bureau of Statistics. GLOSSARY Released 18/10/16.

[7] About the survey of disability, ageing and carers, 4430.0 Disability, Ageing and Carers, Australia: Summary of Findings, 2015, Australian Bureau of Statistics. Released 18/10/16. EXPLANATORY NOTES Released 18/10/16.

Operating environment of disability advocacy in NSW

There are a number of matters in the international, national and NSW environments that affect the current operation of disability advocacy in NSW and needed to be considered by this Review in finding a way forward. Major matters are listed below; where they specifically relate to funding of advocacy, they are also expanded later in this Chapter under *Current Disability Advocacy Service Provision and Funding in NSW.*

The United Nations Convention on the Rights of Persons with Disabilities

Australia ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008. Its purpose is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity. The National Disability Strategy (see below) is the main mechanism for the implementation of the UNCRPD in Australia. The UNCRPD principles are also reflected in the Australian Human Rights Commission Act 1986[9] and in the mechanisms for the delivery of services to people with disability, such as the National Disability Agreement (NDA) and the NDIS.

> Advocacy and representation is a critical, interconnected component of progressing the human rights of people with disability and supporting Australia's international human rights obligations.
>
> Submission to the Review

National Disability Strategy 2010 - 2020

The National Disability Strategy (NDS) 2010–2020 is the mechanism under which the principles underpinning the UNCRPD are incorporated into policies and programs in Australia. This strategy was endorsed in 2011 by all state and territory governments and the Australian Local Government Association.

The NDS covers all people with disability, irrespective of whether they need or use specialist disability services. In particular, the strategy is intended to drive improvements in access to mainstream services, to promote a more inclusive approach to the design of policies and programs, and to ensure that all people with disability can participate and fulfil their potential as equal citizens.

A new NDS for 2020 – 2030 is being developed in consultation with stakeholders[10] and is anticipated to include new goals and targets.

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[9] https://www.humanrights.gov.au/our-work/legal/legislation

[10] https://www.dss.gov.au/our-responsibilities/disability-and-carers/shaping-the-future-of-disability-policy-for-2020-and-beyond

National Disability Agreement

The National Disability Agreement (NDA) was first agreed by all states and territories and the Australian Government in 2008. It replaced earlier iterations of Australian Government and state and territory agreements for providing disability services.

The NDA sets out the roles and responsibilities for funding and providing specialist disability services. It is one of a series of agreements between the Australian and state and territory governments covering major areas like health, education and housing. These agreements provide a framework and measurement approach for tracking progress of agreed performance indicators.

The NDA is due for renewal in 2020. In 2018, the Productivity Commission conducted a review of the NDA, releasing a study report in early 2019[11] with recommendations to address shortcomings in the current NDA, including matters relevant to advocacy – see the NDIS section of this chapter.

The National Disability Insurance Scheme

In 2010, the Australian Government asked the Productivity Commission to carry out a public inquiry into a long-term disability care and support scheme. In July 2012, in response to the Productivity Commission's final report, the Australian Government introduced the NDIS.

The NDIS fundamentally changes the way specialist disability supports have historically been provided in Australia and is widely regarded as a once-in-a-generation reform. Its key principles focus on improved outcomes for people with disability, their families and carers, driven by participant choice and control.

The NDIS provides 'reasonable and necessary supports' to help people with 'significant and permanent' disability. It is based on an insurance model, and each individual seeking access is assessed against common criteria. Eligible individuals receive an Individual Funding Package (IFP) to buy the supports identified in their 'individualised plan'.

The NDIS has been progressively implemented by the National Disability Insurance Agency (NDIA) since 2013. At full implementation, it is expected to provide services to about 460,000 Australians aged under 65 years[12]. In NSW, the NDIS commenced in 2013/14 in the Hunter region and statewide rollout was achieved in 2018/19. By the end of June 2019, there were almost 102,000 people with IFPs[13]; full take-up is expected to be 140,000 people in NSW.

This major shift in specialist disability service provision has influenced both the need for disability advocacy and how advocacy services are delivered as people navigate the new arrangements. Two particular elements of the NDIS landscape are noted below.

[11] https://www.pc.gov.au/inquiries/completed/disability-agreement/report

[12] Productivity Commission. 2019 *Review of the National Disability Agreement.* Australian Government, 2019.

[13] COAG Disability Reform Council Quarterly Report for 2018-2019 Q4.

NDIS Information, Linkages and Capacity Building

The Council of Australian Governments (COAG) Disability Reform Council (DRC) endorsed the Policy Framework for the **Information, Linkages and Capacity Building** (ILC) component of the NDIS in August 2015. The ILC component[14] is intended to provide information, linkages and referrals to efficiently and effectively connect people with disability, their families and carers, with appropriate disability, community and mainstream supports. ILC also seeks to facilitate capacity building supports for people with disability, their families, and carers that are **not** directly tied to a person through an IFP.

The Department of Social Services Community Grants Hub (the Hub), in partnership with the NDIA, determines ILC Grants. ILC is an important component of the NDIS, implemented through the Community Inclusion and Capacity Development Program. The objective of the Program is to build innovative ways to increase the independence, social and community participation of people with disability. ILC focuses on inclusion of people with disability, and creating connections between people with disability and their communities.

The ILC component of the NDIS is targeted at activities that provide people with disability and their families and carers with access to up-to-date, relevant and quality information and/or towards activities that make sure they are linked into services and supports in the community that meet their needs.

The objective of ILC is to increase social and community participation for people with disability by:

1. Building the capacity of people with disability to participate in their community; and
2. Creating opportunities for people with disability to participate by creating more inclusive services and communities.

There are four specific, complementary programs outlined in the ILC Investment Strategy:

1) Individual Capacity Building Program.
2) National Information Program.
3) Economic and Community Participation Program.
4) Mainstream Capacity Building Program.

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[14] Adapted from the ILC Investment Strategy at https://www.ndis.gov.au/media/1665/download.

The ILC Framework (2015) states that "Systemic advocacy and legal review and representation will be funded outside of the NDIS. ILC will support people with disability to act for themselves and each other, and support families, carers and community members to act for or with people with disability[15]".

To date, all ILC funding has been project funding of either one or two years rather than longer term or ongoing.

Individual Funding Packages of NDIS participants – advocacy excluded

People who are eligible to receive IFPs under the NDIS may have identified 'Support Coordination' as an NDIS support that is reasonable and necessary to achieve the goals in their NDIS plan. This coordination may include ancillary decision-making support activities like those below; however, **advocacy itself is explicitly excluded**[16].

An IFP held by an NDIS participant may include funding for supports such as:

- Assistance to strengthen a person's ability to coordinate their supports and to participate in the community.
- Advice and assistance to develop resilience and resolve points of crisis
- Training in planning and plan management.
- Specialist support coordination.
- Developing life skills.
- Life transition planning, including mentoring, peer support and skill development.
- Assistance with decision making, including daily planning and budgeting.

Summary: NDIS and advocacy policy and implementation matters

There is an acknowledged lack of clarity about the role and funding of advocacy within the NDA, with the Productivity Commission noting the following:

- *...the exact supports to be provided through the National Disability Advocacy Program, ILC grants and NDIS plans at full scheme are yet to be fully clarified or established*
- *Roles and responsibilities in the NDA need to be updated to reflect contemporary policy settings, to reduce uncertainty and to address gaps in several areas — including in relation to advocacy, carers, and the interface between the NDIS and mainstream service systems.*
- *issues exist in the interface between specialist and mainstream services*
- *lack of clarity for advocacy services including systemic, individual, legal and self-advocacy*[18].

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[15] ILC Policy Framework page 6: https://www.ndis.gov.au/media/241/download

[16] National Disability Insurance Scheme. 2019: *A Framework for Information, Linkages and Capacity Building.* https://www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc/ilc-policy-framework.

[17] Productivity Commission Report into the National Disability Agreement, Commonwealth of Australia, 2018a, p11.

[18] Recommendation 3.4

Other documents note:

- *Systemic advocacy and legal review and representation will be funded outside of the NDIS. ILC will support people with disability to act for themselves and each other, and support families, carers and community members to act for or with people with disability*[19]*.*
- Coordination within an IFP may include ancillary decision-making support activities but advocacy is explicitly excluded[20]. We note that the DCJ report (Appendix 6) referred to mapping traditional advocacy and information activities against NDIS support categories in the early days of NDIS readiness – primarily against Capacity Building line items funded in NDIS IFPs. It has since become clear that IFPs are not an avenue to advocacy funding.

NDIS Quality and Safeguards Commission

The NDIS Quality and Safeguards Commission (NDIS Commission) is an independent agency established in July 2018 to improve the quality and safety of NDIS supports and services.

The NDIS Commission started operations in NSW and South Australia on 1 July 2018. Once fully operational nationally (July 2020), the NDIS Commission will be a single, national registration and regulatory system for NDIS providers that will set a consistent approach to quality.

The NDIS Commission has a role (among other matters) to manage the registration of disability service providers who are required to undergo external audits against the NDIS Practice Standards and Quality Indicators.

Relevant to disability advocacy, the NDIS Commission has practice standards[21] that requires registered NDIS disability service providers to demonstrate they facilitate access to advocates (including independent advocates) and other representatives of persons with disability who are affected by complaints or incidents, and who wish to be independently supported in that process by an advocate or other representative.

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[19] ILC Policy Framework p 6: https://www.ndis.gov.au/media/241/download

[20] National Disability Insurance Scheme. 2019: A Framework for Information, Linkages and Capacity Building. https://www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc/ilc-policy-framework.

[21] https://www.ndiscommission.gov.au/participants/disability-advocacy

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

On 5 April 2019, *the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (the Disability Royal Commission) was announced and is expected to last up to three years. Its terms of reference cover what should be done to:

- Prevent, and better protect, people with disability from experiencing violence, abuse, neglect and exploitation.
- Achieve best practice in reporting and investigating of, and responding to violence, abuse, neglect and exploitation.
- Promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

The Disability Royal Commission covers all forms of violence against, and abuse, neglect and exploitation of people with disability, in all settings and contexts.

The Commonwealth has provided advocacy for people who need extra support to engage with the Disability Royal Commission – see National Disability Advocacy Program (NDAP) below.

National Disability Advocacy Program

The Commonwealth-funded NDAP provides people with disability with access to disability advocacy that is aimed at promoting, protecting and ensuring their full and equal enjoyment of all human rights enabling community participation. NDAP agencies receive funding from the Commonwealth Department of Social Services under the Commonwealth *Disability Services Act 1986* (DSA). All disability advocacy agencies funded under the NDAP must comply with the DSA and the applicable standards[22].

The target group for advocacy support provided by NDAP agencies, as required under section 8 of the DSA, consists of people with a disability that:

- is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments
- is permanent or likely to be permanent, and
- results in a substantially reduced capacity of the person for communication, learning or mobility; and the need for ongoing support services.

Agencies are funded to provide disability advocacy support:

- delivered from specified locations
- covering a specified service area
- using the specified model or models of disability advocacy support.

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[22] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap

Agencies may also be funded to specialise in providing advocacy support to groups such as:

- people from Indigenous backgrounds
- people from diverse cultural and linguistic backgrounds
- people with a particular disability type, such as acquired brain injury.[23]

In relation to NDAP work generally, funded agencies work across a range of specific and mainstream situations requiring advocacy.

In relation to the NDIS generally, the NDAP provides decision support, safeguard supports and capacity building for participants, including support to approach and interact with disability supports and access mainstream services[24].

In relation to NDIS Appeals specifically, agencies receiving NDAP are also funded to provide disability advocates for the NDIS Appeal Support Program (NDIS Appeals). NDIS Appeals has been set up to ensure that all people with disability, and other people affected by reviewable decisions of the NDIA, have access to support when seeking review of those decisions by the Administrative Appeals Tribunal (AAT). There are two types of supports available via NDIS Appeals:

- access to a skilled disability advocate who acts as a support person, and
- access to funding for legal services, where a case raises complex or novel legal issues[25].

A support person can help by:

- explaining the review process, including what is involved in appealing to the AAT
- helping to prepare documents
- providing advice and skills so the applicant can better represent themselves
- attending AAT conferences and hearings to help the applicant put their case to the AAT.

In relation to the Disability Royal Commission, NDAP has been extended to include individual advocacy for people who need extra support to engage with the Disability Royal Commission. Advocacy support is for people with disability (or family members or carers acting on their behalf) who cannot advocate for themselves because they have difficulty in communicating or understanding how to engage with the Disability Royal Commission. An advocate will be able to help people with disability to understand how to tell their story to the Disability Royal Commission, how to work out problems or avoid discriminatory issues, find communication supports such as interpreters, and access other supports, such as legal or financial services[26].

A review of NDAP was undertaken in 2017; and we understand that a final proposal for a reformed NDAP is currently with Government.

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[23] https://www.dss.gov.au/sites/default/files/documents/03_2018/ndap_operational_guidelines_february_2018.pdf p3.

[24] 2019: *A Framework for Information, Linkages and Capacity Building*

[25] Legal services are provided by Legal Aid Commissions, which determine eligibility by assessing the application against publicly available criteria.

[26] From: https://www.dss.gov.au/disability-and-carers/disability-royal-commission-support-services

National Disability Representative Organisations

The Disability Representative Organisation (DRO) Program is a national program under the NDS that funds identified organisations to provide systemic advocacy and representation for specific populations of Australians with disability. The program provides the capacity for all people and their representative organisations to have their views communicated to the Commonwealth Government, regardless of type of disability, gender, cultural background, age or membership[27]. DROs provide advice to the Commonwealth Government on breaking down barriers and improving social and economic participation, and engage with a range of ministers and portfolios[28].

Eight organisations are currently funded under the DRO program to 30 June 2020[29], some as consortia. Three organisations currently receiving NSW Transitional Advocacy Funding Supplement (TAFS) funding also receive DRO funding or are part of a national organisation that does.

NSW Disability Inclusion Act 2014

The NSW Disability Inclusion Act 2014 highlights that people with a disability have the same human rights as other members of the community and that the state and the community have a responsibility to facilitate the exercise of those rights. NSW Government agencies continue to have a role to create a more inclusive community in which mainstream services and community facilities are accessible to people with disability to help them achieve their full potential. Each NSW Government department and local council is required to consult with people with disability when making policy that affects them and to develop Disability Inclusion Action Plans (DIAPs). The voices of people with disability need to be heard when the Government makes decisions about supports and services that affect them – either as people with disability specifically, or as part of the broader NSW community. Key documents are:

- NSW Disability Inclusion Plan 2014-2018, which currently has four focus areas:
    - developing positive community attitudes and behaviours
    - creating liveable communities,
    - supporting access to meaningful employment
    - improving access to mainstream services through better systems and processes.
- Individual DIAPs.

Although patterns of disability advocacy activity have changed, a constant body of work remains in relation to advocating directly with many NSW Government departments, such as Health, Housing, Education, Transport and Justice.

The NSW Government is currently reviewing the Disability Inclusion Act.

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[27] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/national-disability-peak-bodies
[28] Adapted from: https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/national-disability-peak-bodies
[29] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap

NSW Cross-government Outcomes Framework

The NSW Human Services Outcomes Framework provides a common set of wellbeing measures for human services programs in NSW[30]. The cross-government framework seeks to measure outcomes across seven domains:

- **Education and skills:** All people in NSW are able to learn, contribute and achieve.
- **Economic:** All people in NSW are able to contribute to, and benefit from, our community.
- **Health:** All people in NSW are able to live a healthy life.
- **Home:** All people in NSW are able to have a safe and affordable place to live.
- **Safety:** All people in NSW are able to be safe.
- **Empowerment:** All people and communities in NSW are able to contribute to decision-making that affects them and live fulfilling lives.
- **Social and community:** All people in NSW are able to participate and feel culturally and socially connected.

The Review is seeking to recommend clear links between the outcomes and performance measurement system for NSW disability advocacy and the NSW Human Services Outcomes Framework.

Local government

Local government has a role in facilitating the full inclusion of people with disability particularly in relation to planning and building regulations as well as community programs and local government services.

In NSW, local councils are required to develop DIAPs, in consultation with people with disability.

Advocacy sector initiatives

The disability advocacy sector has networked at state and national levels in many ways, including through some working groups. A NSW Disability Advocacy Alliance with 22 members mobilised activity around a campaign to increase dialogue for an effective advocacy sector, and responded with a written submission to this Review. However, there is no single peak body for disability advocacy services in NSW. The sector is highly diverse in the nature and types of organisations, some representing broad cohorts of people with disability, while others concentrate on specific conditions. Others focus on families as advocates, people with disability from CALD or indigenous communities, or regional communities.

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[30] (FACS, 2017 *Applying the NSW Human Services Outcomes Framework in FACS: An Overview*, May 30, 2017.

History of advocacy in NSW

The current disability advocacy sector in NSW comprises a large number of organisations; some receive direct funding from the Commonwealth including the NDIA[31], and some receive funding from the NSW Government. The sector is historical in nature and includes both statewide and regionalised bodies.

The current arrangements for disability advocacy in NSW reflect the state of change in broader disability service provision particularly over the last five years, the history of disability advocacy over many decades and the emergence of directions in NSW Government service provision.

DCJ prepared a report (in full at Appendix 6) which provides a very valuable history of the early years of advocacy in NSW, broader disability reforms (including advocacy) and the period of NDIS readiness. A summary of those matters is presented here.

Early years of disability advocacy in NSW

In 1986, disability rights advocacy was recognised as a program area to be funded under the Disability Services Act 1986[32]. The first Commonwealth-State Disability Agreement (1991) gave Commonwealth and the States joint responsibility for funding disability advocacy, information and print disability services[33].

Acknowledging that advocacy funding had developed in an ‘ad hoc’ way, the (then) NSW Ageing and Disability Department (ADD) sought to clarify what was being funded and the basis of its funding.

In March 2001, ADD developed and circulated a Discussion Paper on systemic advocacy titled *Improving and Expanding Disability Advocacy and Information Services in NSW*.

In July 2001, the Legislative Council Standing Committee No 2 held an inquiry into Disability Advocacy Funding. As a result of the Standing Committee’s findings, the newly created Department of Ageing, Disability and Home Care (DADHC), which superseded ADD, undertook to:

- Continue the Government’s commitment to provide $1 million growth funding in 2001-02 through a request for proposal (RFP) process.
- Provide all current providers with three-year funding agreements.
- Initiate a reform project to develop a State Plan for Disability Advocacy and Information services.

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[31] While the NDIA does fund information services, it is explicit that it does not fund individual advocacy – see National Disability Insurance Scheme. 2019: *A Framework for Information, Linkages and Capacity Building*. https://www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc/ilc-policy-framework.

[32] https://pwd.org.au/about-us/our-history/history-of-disability-rights-movement-in-australia/

[33] From Background Paper 2 1995-96 Commonwealth Disability Policy 1983-1995 https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/__Publications_Archive/Background_Papers/bp9596/96bp06

The $1 million growth funding was targeted to areas of high need: regional and remote areas, culturally and linguistically diverse (CALD) communities and Indigenous Australians. The RFP was finalised in 2002, and funding was allocated for new and expanded advocacy services in Newcastle and Albury, as well as a statewide advocacy service for CALD communities, leading to 40 organisations being funded to deliver advocacy services.

In 2003, DADHC initiated the Disability Advocacy and Information Reform Project. The Project aimed to develop new strategic directions and a policy framework for advocacy services. Discussion papers were developed to form the basis of consultation with the wider community.

In May 2008, the (then) Minister for Disability Services finalised the Disability Advocacy and Information Reform Project on the understanding that reforms to the advocacy sector would be implemented in a staged manner. Funding Agreements were rolled over for existing advocacy service providers for a three-year period until 30 June 2011.

Broader disability reform in NSW

NSW introduced *Stronger Together – a new direction for disability services in NSW* 2006-2016 in two phases (ST1: 2006-07 to 2010-11, and ST2: 2011-12 to 2015-16).

ST2 focussed on lifespan and person-centred approaches and included (among other things) expansion in decision support resources such as information, planning, advocacy, case management, service brokers and support coordination ($141.2 million over 5 years).

ST2 acknowledged significant changes at an international and national level since 2006 that affected disability administration, including Australia's ratification of the UNCRPD, the development of the National Disability Agreement (2009) and National Disability Strategy (2010), and the Productivity Commission report on Disability Care and Support (2011).

In October 2010, DADHC released the NSW Advocacy Program Guidelines (Disability) and the NSW Information Program (Disability)[34]. The guidelines outlined the objectives of these programs and provided a platform for improved quality, accountability and reporting on a Minimum Data Set. From 2011, advocacy and information service providers were required to develop and submit an annual work plan by 31 May each year that demonstrated how the service would use its funding to meet the purpose, objectives and outcomes for its service type.

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[34] https://web.archive.org/web/20101226040723/http:/www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Advocacy+and+Information+Services.htm

All funded organisations were also required to report against the Disability Services NSW National Minimum Data Set (NMDS) Collection Data Guide, issued by DADHC in conjunction with the Australian Institute of Health and Welfare (AIHW).

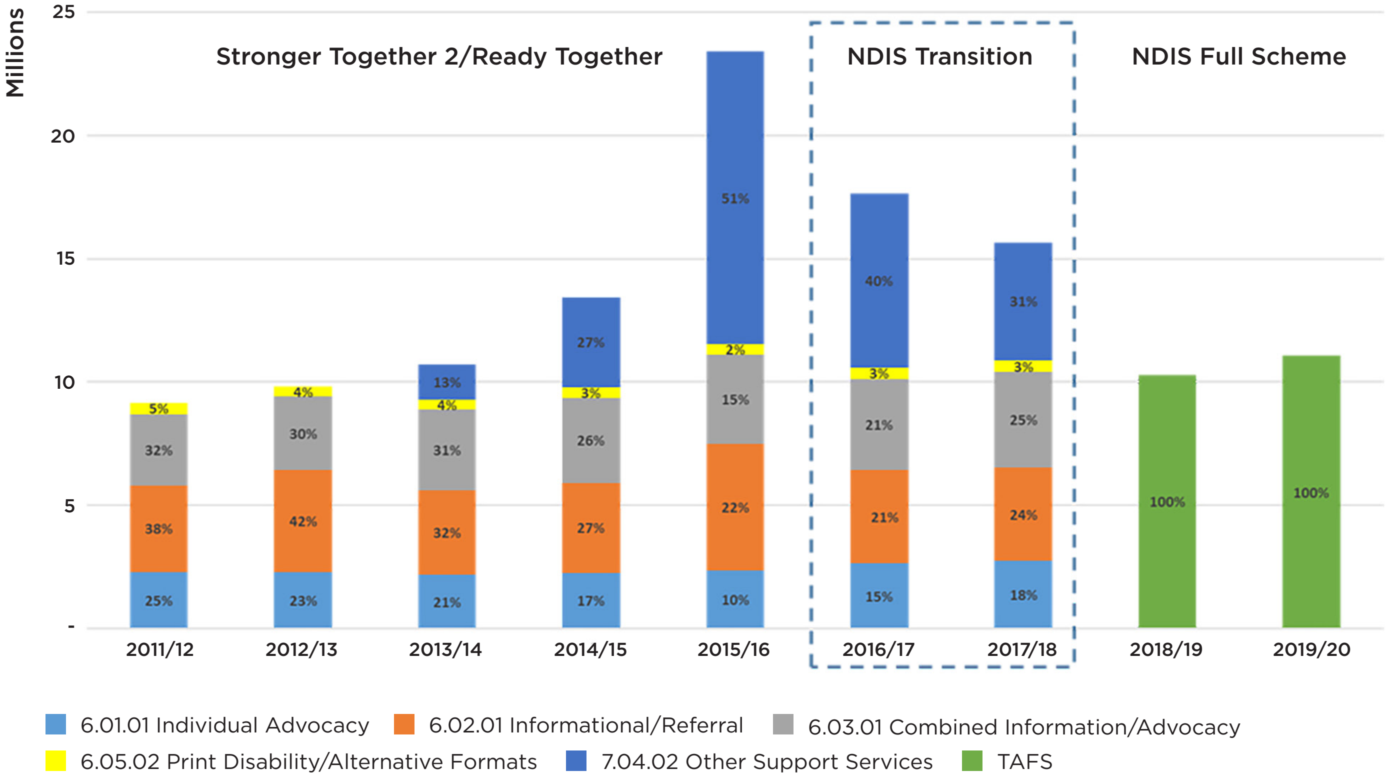
While the sector was preparing for the introduction of the NDIS and capacity-building funding was being rolled out to support this, three-year contracts were issued to advocacy and information services for the period July 2012 – June 2015.

Ready Together launched in December 2013 to continue ST2 reforms and prepare people with disability and the disability sector for the transition to the NDIS. Funding for all disability service providers, including disability advocacy, was renewed under a new three year Funding Agreement from 1 July 2015 to 30 June 2018[35].

> Advocacy hasn't invented itself. It has developed responsibly in response to people with a disability
>
> Submission to the Review

Figure 2 and Table 1 below shows the growth in advocacy funding by NSW across NMDS service types since disability reform significantly ramped up from ST2 in 2011/12 to full scheme NDIS.

Figure 2 – NSW Government funded disability advocacy 2011-12 to 2019-20



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[35] https://www.parliament.nsw.gov.au/la/papers/Pages/qaprofiles/non-government-disability-advocacy-fundi_188906.aspx

While most of the advocacy service types were consistently funded over time, the significant increase in 7.04.02 (Other Support Services) before and during transition to the NDIS reflected the NSW investment in building capacity for individuals and the system. The vast majority of this funding went to person-centred planning and NDIS transition support.

Table 1 - NSW Government funded disability advocacy 2011-12 to 2019-20

Service Model	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20
6.01.01 Individual Advocacy	2,301,922	2,278,312	2,195,473	2,272,001	2,367,620	2,656,208	2,749,707	-	-
6.02.01 Information/Referral	3,497,713	4,155,062	3,402,256	3,638,822	5,140,466	3,768,309	3,788,274	-	-
6.03.01 Combined Information/Advocacy	2,886,220	2,977,602	3,271,731	3,454,184	3,601,324	3,704,015	3,871,177	-	-
6.05.02 Print Disability/Alternative Formats	475,090	401,392	413,350	425,699	439,931	453,760	467,369	-	-
7.04.02 Other Support Services	-	-	1,417,123	3,632,428	11,847,464	7,048,047	4,778,228	-	-
TAFS	-	-	-	-	-	-	-	10,291,540	11,057,102
Sub-total	**9,160,946**	**9,812,368**	**10,699,932**	**13,423,134**	**23,396,805**	**17,630,340**	**15,654,754**	**10,291,540**	**11,057,102**
Other sevice models	58,329,010	48,739,214	52,209,957	53,318,366	56,401,900	39,048,681	8,502,574	-	-
Total	**67,489,955**	**58,551,582**	**62,909,888**	**66,741,500**	**79,798,706**	**56,679,021**	**24,157,327**	**10,291,540**	**11,057,102**

It should be noted that most of the disability advocacy organisations were also funded by the NSW Government for other disability related services. For example, in 2015/16, of the 44 organisations funded for advocacy services by the NSW Government, 18 organisations also received funding for other disability services to the value of $56.4 million.

As NSW direct service delivery funding stepped down during the transition to full scheme NDIS (2016-17 to 2017-18), the funding mix changed such that in first year of full scheme NDIS, 21 of the disability advocacy organisations received $77.1 million from NDIS IFPs and 24 organisations received $5.4 million in NDIS ILC funding. Figure 2 and Table 2 below show how the funding pool has continued to grow and the mix has changed from the ST2 reforms to full scheme NDIS. It should be noted that Figure 2 and Table 1 do not include other Commonwealth advocacy funding (for example NDAP), which would be additional revenue. It should also be noted that 17 NSW TAFS funded advocacy organisations do not access funds from NDIS IFPs.

Figure 3 – NSW Government and NDIS funding for disability advocacy organisations 2011-12 to 2019-20[36]

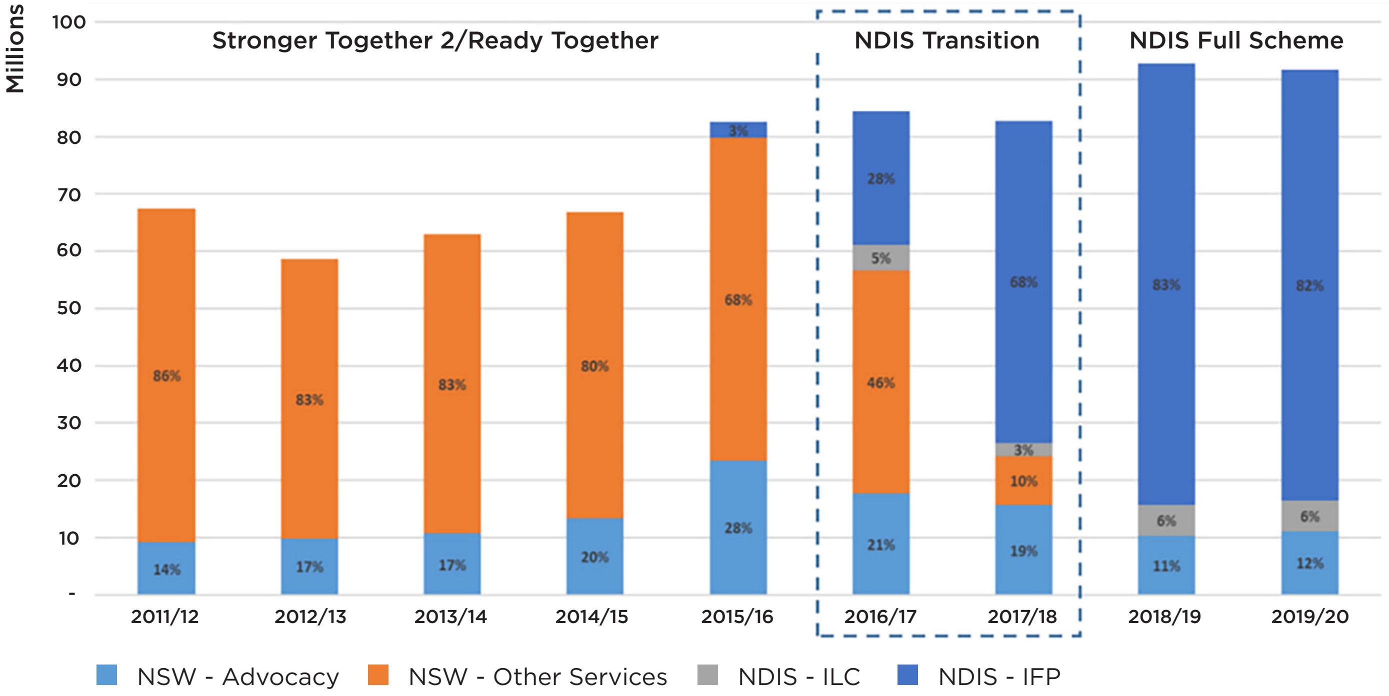

Table 2 - NSW Government and NDIS funding for disability advocacy organisations 2011-12 to 2019-20[37]

Program	**2011/12**	**2012/13**	**2013/14**	**2014/15**	**2015/16**	**2016/17**	**2017/18**	**2018/19**	**2019/20**
NSW - Advocacy	9,160,946	9812,368	10,699,932	13,423,134	23,396,805	17,630,340	15,654,754	10,291,540	11,057,102
NSW - Other services	58,329,010	48,739,214	52,209,957	53,318,366	56,401,900	39,048,681	8,502,574	-	-
NDIS - ILC	-	-	-	-	-	4,465,000	2,381,730	5,368,629	5,358,682
NDIS - IFP	-	-	-	-	2,695,409	23,299,237	56,228,604	77,112,401	75,261,693
Total	**67,489,955**	**58,551,582**	**62,909,888**	**66,741,500**	**82,494,114**	**84,443,258**	**82,767,662**	**92,772,570**	**91,677,478**

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[36] Note: FY 2019-20 NDIS – IFP values annualized based on YTD September (Q1).
[37] Note: FY 2019-20 NDIS – IFP values annualized based on YTD September (Q1).

NDIS readiness activity

In 2016-17, the initial NDIS ILC grants rounds were allocated. Grants totalling $6.8 million went to 13 organisations to support NDIS readiness activities in NSW, including:

- Continuing funding for the NSW Council for Intellectual Disability: *My Choice Matters* Information workshops, online learning and leadership courses, and peer networks. Expanding the My Choice Matters capacity building program, enabling people with disability, families, carers and supports to develop skills to identify and choose services and supports, preparing them for first contact with the NDIS.
- Grants to nine providers to support information and NDIS readiness activities for hard-to-reach cohorts and locations, such as people in remote locations, CALD communities and Indigenous Australians.

From 2016 to 2018, the *Skilled to Thrive* Project was a $1.5 million two-year FACS-funded project focused on building the capacity of the 40 eligible NSW advocacy and Information providers to be ready to make the most of the NDIS, and to continue to provide services under the NDIS to their clients.

The project delivered a number of resources and supports for service providers, including a Service Alignment Resource for Advocacy and Information Providers. This was a table that mapped correlations and interfaces between traditional advocacy and information activities and NDIS support categories – primarily Capacity Building in NDIS IFPs – to assist advocacy providers to consider how best to adjust their service offerings to reflect the NDIS landscape.

Transitional Advocacy Funding Supplement 2018-19 to 2019-20

During the period of transition to the NDIS and in the early stages of full scheme, the Transitional Advocacy Funding Supplement (TAFS) was introduced to ensure that people with disability had access to all necessary information and supports. TAFS addressed potential shortfalls for advocacy groups with funding set aside of up to $26 million for advocacy services over two years until 30 June 2020 – see details in next section of this chapter.

Current disability advocacy service provision and funding in NSW

In NSW, disability advocacy services may receive direct funding for advocacy services from:

- The NSW Government.
- The Commonwealth, via
    - the National Disability Advocacy Program (NDAP, under the Department of Social Services
    - the Disability Representative Organisation (DRO) Program, under the Department of Social Services

They may also attract funding for advocacy-like activity from:

- the Information Linkages and Capacity building (ILC program under the NDIA)
- items in IFPs.

NSW Government funding to disability advocacy

Prior to the introduction of the NDIS, the NSW Government directly funded various disability advocacy organisations plus information, referral and representative services for people with disability in need of specialist disability supports.

The Funding Agreement between Ageing, Disability and Home Care (ADHC) and disability service providers was updated in 2015 to support the transition to the NDIS and to comply with the Disability Inclusion Act. From the date of the full rollout of the NDIS in NSW on 1 July 2016, the vast majority of the funding for specialist disability supports for people with disability moved from ADHC to the NDIS. The NSW and Commonwealth bilateral agreement established that the rollout of the NDIS would be completed in NSW by 30 June 2018. The agreement committed NSW to transition responsibility for specialist disability support funding to the Commonwealth.

While this funding was transferred to the Commonwealth as part of the NDIS transition, some gaps in the provision of advocacy services remained[38]. In 2018, the NSW Government recognised the important role of advocacy and committed up to $13 million per annum over two years for TAFS, which ends on 30 June 2020.

TAFS was introduced to ensure that people with disability had access to all necessary information and supports. TAFS addressed potential shortfalls for advocacy groups with funding set aside of up to $26 million for advocacy services until 2020. Disability advocacy, information and representative organisations were only eligible for TAFS funding if they had applied for ILC grants. The outcomes of the NDIS ILC National Readiness and NSW jurisdictional grants rounds were taken into account to ensure that there was no duplication of funded services between the Commonwealth and NSW Government.

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[38] Productivity Commission. 2019 Review of the National Disability Agreement. Australian Government, 2019.

In 2018-19, the (then) Department of Family and Community Services (FACS) funding was used to ensure that disability advocacy providers received a total quantum of funding equal to what was previously funded per annum by the NSW Government. In 2019-20, FACS funding was rolled over from the previous year, as ILC grants rounds were not completed in time to be taken into account.

The NSW Government (through TAFS) currently funds 39 organisations to deliver disability advocacy. Excerpts from the fact sheet Advocacy for People with Disability in NSW[39] notes that:

> Many of the disability advocacy-related activities currently funded by NSW will be funded through individual National Disability Insurance Scheme (NDIS) plans; NDIS Information, Linkages and Capacity Building (ILC) grants program; and the Commonwealth funded National Disability Advocacy Program (NDAP) and Disability Representative Organisation (DRO) program.
>
> The purpose of the Transitional Advocacy Funding Supplement is to provide services to people with disability during the first two years following the transition to the NDIS, to ensure there are no short-term practical gaps around advocacy and inclusion activities in the early years of full scheme.
>
> It will also allow for the finalisation of the National Disability Advocacy Program (NDAP) review currently being undertaken by the Commonwealth, and to fill any service gaps pending the review outcomes.
>
> It means existing non-government organisations which receive disability advocacy, information and representative funding under a current Department of Family and Community Services (FACS) Funding Agreement can apply for the funding supplement.
>
> This will be a transitional safeguard for services that may not be funded by the Commonwealth including where providers may receive less funding or where there are gaps in funded services in the short term.
>
> Organisations will receive funding up to what has previously been funded per annum; ILC funding will be taken into account to ensure there is no duplication of funded services between the Commonwealth and NSW Government.

Figure 4 shows the NSW Government's reducing contribution to advocacy funding during the five-year period 2015-2020, designed to mirror the increase of advocacy funding by the Commonwealth during the same period. The NSW Government allocated a budget of $13 million per annum to implement TAFS, including direct funding of $11 million to 39 organisations to provide individual advocacy, information services and representative services.

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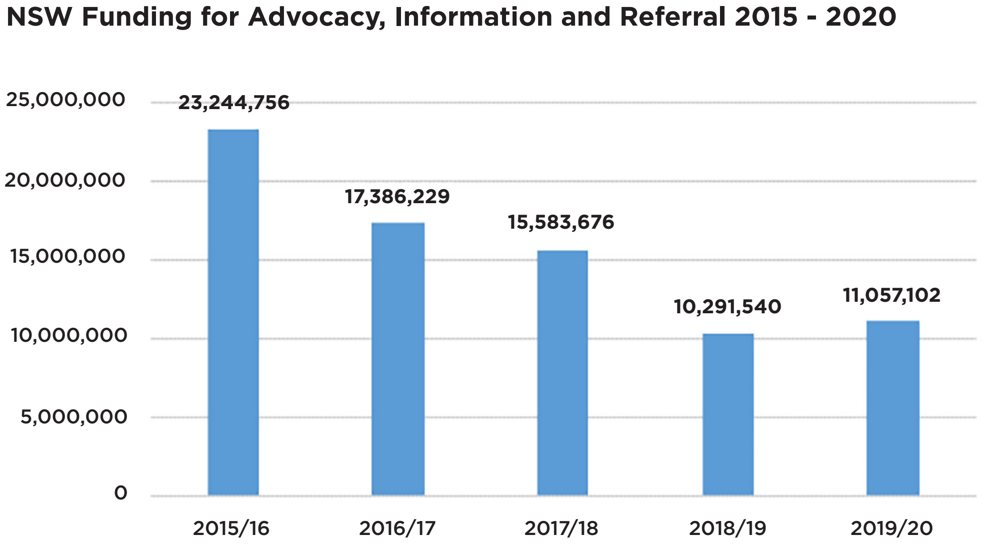
[39] NSW Undated, *Advocacy for People with Disability in NSW*

Figure 4 - NSW Funding for Advocacy, Information and Referral 2015 - 2020



The total NSW disability advocacy program spending in 2015/16 was in fact more than $79 million and in 2016/17 more than $57 million. The additional amounts are not included in Figure 2 because they were assorted one-off and project-based funding leading up to the implementation of the NDIS.

Figure 5 overleaf shows a breakdown of NSW advocacy funding during the financial year 2017/18 by different models of advocacy. Table 3 describes each of those models/funding categories as agreed in the National Disability Agreement and aligned with the NMDS[40]. Figure 4 is drawn from the period prior to the commencement of TAFS when advocacy, like all funded disability services, reported against the Disability Services NSW Minimum Data Set.

Table 3: Descriptor of service model categories as shown in Figure 5

Advocacy	Services designed to enable people with disability to increase the control they have over their lives through the representation of their interests and views in the community. Examples include: • self-advocacy/individual advocacy • citizen advocacy • group advocacy • system/systematic advocacy
Information/referral	Information services provide accessible information to people with disability, their carers, families and related professionals. This service type provides specific information about disability-specific and generic services, equipment, and promotes the development of community awareness. Information includes contact by phone, print or email that recommends a person to another service.

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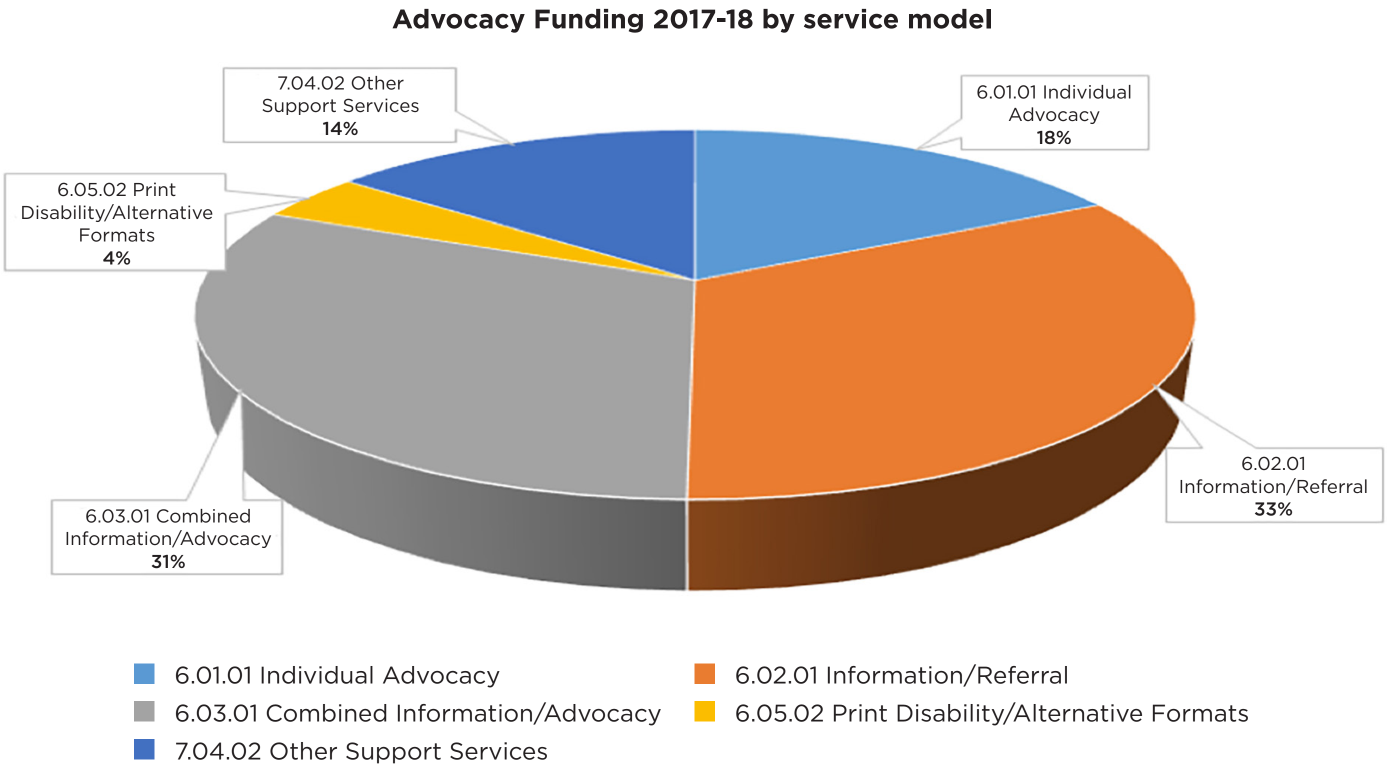
[40] https://meteor.aihw.gov.au/content/index.phtml/itemId/623523

Combined information/ advocacy	Services that offer both information and advocacy services to individuals where these two components cannot reasonably be separated.
Print disability/alternative formats of communication	Includes alternative formats of communication for people who, by reason of their disabilities, are unable to access information provided in the standard format. May include interpreter services, radio and alternative formats of print medium, for example, TTY and Braille.
Other support services	Services that are completely outside any of the defined service types. This service type also includes the provision of one-off funding for a defined event (for example, for promotional activities) or for the purchase of aids and equipment for a community facility (not for an individual). One-off and project-based funding.

Figure 5 - Advocacy funding 2017-2018 by service model



Commonwealth/NDIA contribution to disability advocacy in NSW

In addition to disability advocacy funding from the NSW Government, organisations in NSW may also receive funding for advocacy services from the Commonwealth through:

- The National Disability Advocacy Program (NDAP), under Department of Social Services.
- The Disability Representative Organisation (DRO) Program, under Department of Social Services.

They may also attract funding for advocacy like activity from:

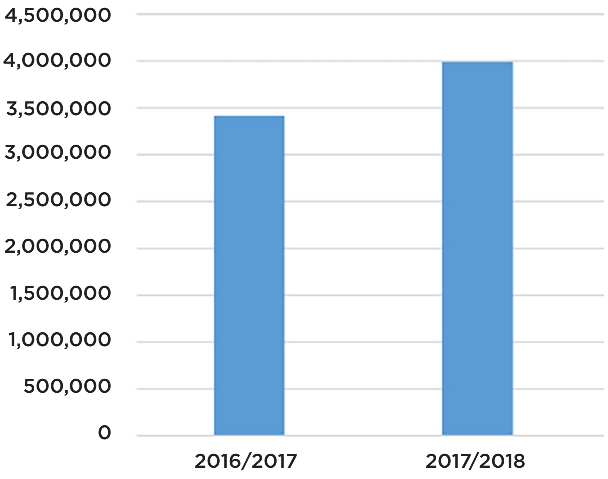
- The Information Linkages and Capacity building (ILC) program under NDIA.
- Items in IFPs.

Broad descriptions of these programs were provided earlier in this chapter. Key information is summarised here where it particularly relates to funding.

NDAP[41] agencies receive a grant of financial assistance under the Commonwealth Disability Services Act to provide advocacy support. They are also funded to provide support workers for the **NDIS Appeal Support Program**, and to provide individual advocacy for people who need extra support to engage with the **Disability Royal Commission**[42].

Fourteen organisations located in NSW currently receive NDAP funding[43]; 10 of these also currently receive TAFS. Figure 6 shows NDAP funding in NSW for the period 2016-2018.

Figure 6 - NDAP funding in NSW, 2016/17 – 2017/18



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[41] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap

[42] https://www.dss.gov.au/disability-and-carers/disability-royal-commission-support-services

[43] https://www.dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/national-disability-advocacy-program/models-of-disability-advocacy/national-disability-advocacy-agencies-funded-by-the-commonwealth-by-state-or-territory/disability-advocacy-agencies-new

The Disability Representative Organisation (DRO) program is a funded national program under the National Disability Strategy (NDS) to provide systemic advocacy and representation for specific populations of Australians with disability. The program provides the capacity for all people, and their representative organisations, to have their views communicated to the Government, regardless of type of disability, gender, cultural background, age or membership[44].

Eight organisations have been funded nationally to June 2020, some as consortia[45]. Three organisations currently receiving NSW TAFS funding currently receive DRO funding or are part of a national organisation that does.

The Council of Australian Governments (COAG) Disability Reform Council (DRC) endorsed the Policy Framework for the **ILC** component of the NDIS in August 2015. The policy was then provided to the NDIA to implement.

Figure 7 shows ILC grant funding to NSW-based organisations for the period 2016-2020. To date, all ILC funding has been project-based and for either one or two years, rather than ongoing.

People who are eligible to receive an IFP under the NDIS may have identified ‘support coordination’ as an NDIS support that is reasonable and necessary to achieve their goals. This coordination may include ancillary information, referral and decision-making support activities, but advocacy itself is explicitly excluded[46].

This Review found that ILC grants to organisations do not provide for direct advocacy services; although some activities arising during the period of some ILC grants may align with the supportive/ developmental role that is part of advocacy activities.

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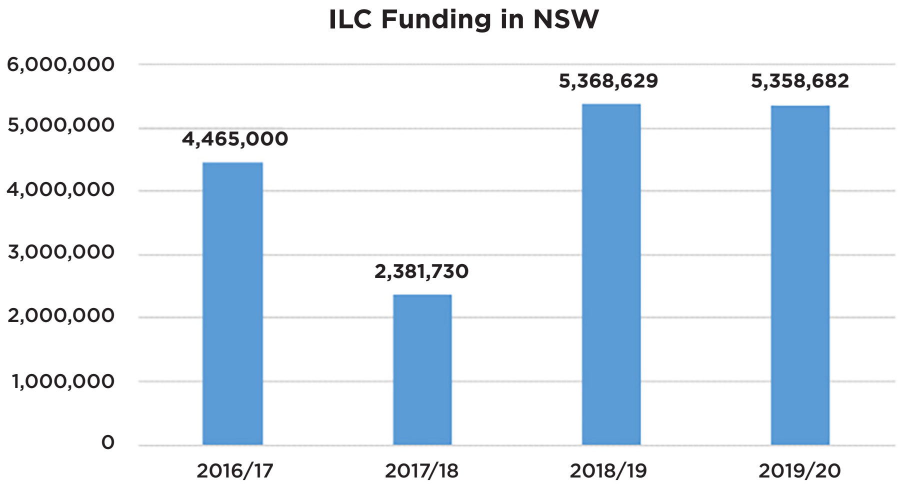
[44] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/national-disability-peak-bodies

[45] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap

[46] National Disability Insurance Scheme. 2019: A Framework for Information, Linkages and Capacity Building. https://www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc/ilc-policy-framework.

Figure 7 - ILC funding to NSW advocacy organisations, 2016/17 – 2019/20



> ILC grants to organisations do not provide for direct advocacy services; although some activities arising during the period of some ILC grants may align with the supportive/ developmental role that is part of advocacy activities.

A snapshot of legal advocacy in NSW

Legal advocacy for people with disability is a sub-set of individual advocacy and its funding in NSW is complex.

The main provider of legal advocacy services in NSW is the **Intellectual Disability Rights Service** (IDRS) which provides individual and systemic legal advocacy (including ancillary information and advice), which covers the full range of both civil and criminal legal matters across NSW for people with a ‘cognitive impairment. This is also in combination with a range of other services, most particularly, the Justice Advocacy Service (JAS), an expanded version of the Criminal Justice Support Network. JAS is a two year program of the former NSW Department of Justice – now merged with FACS as the Department of Justice and Families, which provides a 24hour/7-day custody legal service for people with cognitive impairment either under arrest or as a victim or witness of an alleged crime. It is viewed as a ‘justice service’ separate from what is normally considered legal advocacy.

Leaving aside the CJSN, core funding for IDRS in 2019/20 is $892,000 as shown in Table 4.

Table 4: Core funding for IDRS in 2019/20

FACS/DCJ (NSW)	$391,000 – individual legal advocacy (70%), rights training (25%), and systemic advocacy (5%)
Legal Aid (CLSP)	$251,000 for two separate fixed term contracts - one for parents with intellectual disability and the other to focus on rural, regional, remote communities and to CALD communities
DSS (C'th)	$250,000 – comprising individual legal advocacy (60%), rights training (25%) and systemic advocacy (15%)

IDRS also provides formal and informal advice and guidance to lawyers from Community Legal Centres, Legal Aid and private practice in their handling of cases involving clients with intellectual disability.

IDRS makes a strong case that the priority need for legal advocacy for people with disability is for people with intellectual disability/cognitive impairment (rather than other disabilities) because the most significant legal issues arise from an inability to comprehend legal documents, processes and systems.

However, there is a need for people with other disabilities to have assistance with legal issues that affect them.

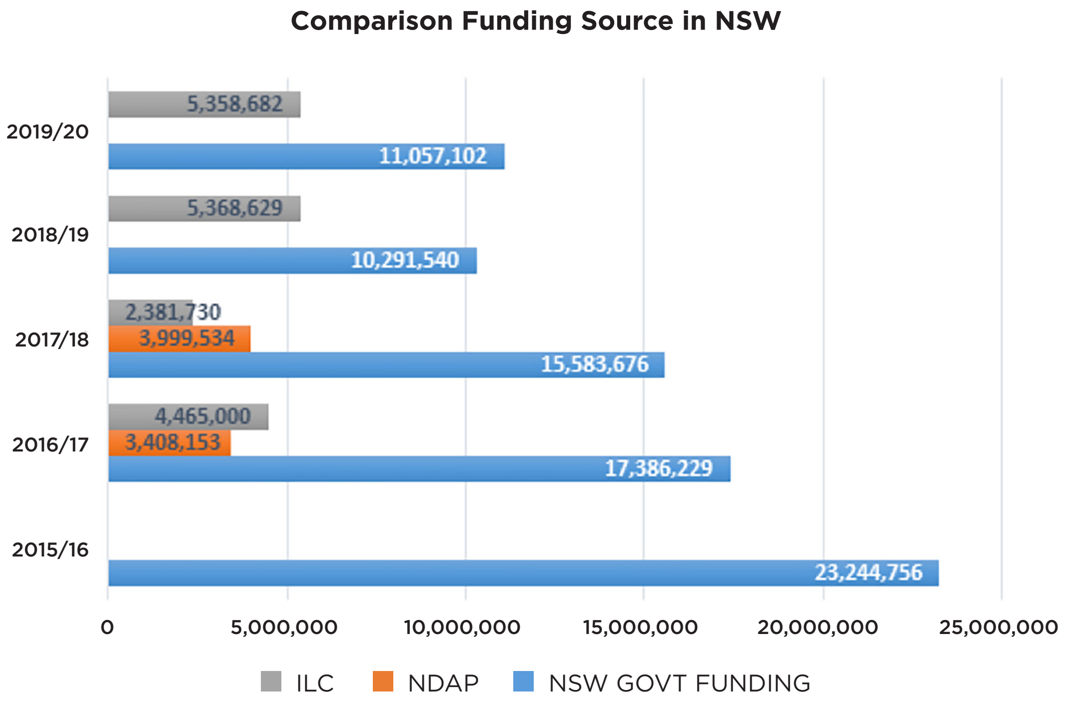
Other providers of legal advocacy for people with disability in NSW are:

- **The Advocacy Law Alliance**, which operates both legal advocacy (primarily NDIS appeals and supporting people giving evidence to the Disability Royal Commission) and non-legal individual advocacy (through NDAP – $1.4 million, and NSW TAFS – $761,000) in the name of Disability Advocacy NSW.
- **The Australian Centre for Disability Law (formerly the Disability Discrimination Law Centre)**, which offers some systemic advocacy, advice, referral and community education, funded through the Legal Aid (CLSP) program.
- **Community Legal Centres**, including IDRS and Mid-North Coast Community Legal Centre, which assist people with disability as part of their general work and, from time to time, turn to IDRS for specialist advice or support.
- **The NSW Mental Health Advocacy Service** (part of NSW Legal Aid) which provides services to people with psychosocial disability, primarily in hearings under the Mental Health Act 2007.
- **Legal Aid NSW**, like Community Legal Centres, assist people with disability as part of their general work and, similarly, turn to IDRS for specialist advice or support.
- **The Cooperative Legal Service Delivery (CLSD) Program** comprises regionally-based partnerships between legal and related non-legal services, coordinated by Legal Aid NSW, which aim to improve access to legal services for disadvantaged people in regional and remote NSW. CLSD Program partnerships aim to better target the needs of disadvantaged people, improve coordination of legal services and extend regional capacity through cooperation.

Summary of disability advocacy funding in NSW

This chapter has described the variations in disability advocacy funding streams that organisations in NSW may currently receive. Figure 8 provides a compilation of funding received from the NSW Government and from the Commonwealth (NDAP and ILC), noting that ILC grants do not provide advocacy services. Figure 8 does not included DRO funding as this could not be determined at the time of writing this report. In addition, there were only two years of NDAP funding clearly identified at the time of writing.

Figure 8 - Comparison of funding source in NSW over 5 years



Chapter 2: What we found

Introduction

This Review draws on a number of information sources and engagement mechanisms; the methodology is outlined in the Executive Summary. This chapter draws on the findings of the literature review (see Appendix 5), the submissions we received in response to the issues paper (see Appendix 2), the discussions that occurred at the community consultations (see Appendix 3) and through selected stakeholder engagement (see Appendix 4), which included people with lived experience of disability.

No major difference in views has arisen between the sources of input; rather each contributed to our understanding of disability advocacy in NSW. What we found was that the consultations provided more ‘real life examples’ and local experience of matters raised in the submissions; the literature review reinforced the importance of a number of matters that arose in both the consultations and submissions.

This chapter firstly provides findings through four lenses that describe the current disability advocacy sector in NSW largely through the eyes of Review participants. The latter part of the chapter notes impacts and challenges arising, and provides commentary about looking ahead.

Subsequent chapters in this Review describe the Commission’s views about the fundamentals of a good advocacy system (Chapter 3) and specifics about the way forward (Chapter 4).

The disability advocacy ‘system’ in NSW

We found that the disability advocacy sector in NSW does not currently operate as a ‘system’. Although it is not ‘broken’, it is currently fragmented, inequitable and confusing to people with a disability and the community.

The Review acknowledges that provision of disability advocacy is not confined to disability advocacy organisations; nor is it always funded. Citizens, family, carers, peers, peak bodies and representative organisations may all provide or assist with advocacy activities alongside the activities of organisations specifically funded to provide disability advocacy. Further advocacy takes many forms and evolves to meet different needs, disabilities, capacities and circumstances.

Despite this diversity, there are common elements and fundamentals that need to be put in place to create a more sustainable provision of disability advocacy in NSW.

> The disability advocacy sector in NSW does not currently operate as a 'system'. Although it is not 'broken', it is currently fragmented, inequitable and confusing to people with disability and the community.

Figure 9 below notes four lenses that provide a useful description of the current disability advocacy sector in NSW: value, operations, performance and access.

Figure 9 - Looking at disability advocacy in NSW

Lens 1: The importance and value of advocacy

There is no doubt that advocacy is a necessary part of an effective disability system; equally, disability advocacy plays a fundamental role in NSW meeting its national and international obligations[47].

The underlying principles of advocacy stem from the broader principles in the UNCRPD. It is through those principles that we understand the importance of advocacy in a well-functioning disability sector. A number of submissions emphasised advocacy as a right rather than a privilege. There were many examples of the role of disability advocacy in preventing and solving problems, and creating fair opportunities. Examples spanned disability specific services and mainstream services.

Rights

People with disability have the same right as other members of Australian society to realise their full potential. They should be supported to participate in and contribute to social and economic life

Value

For every dollar invested in independent advocacy for people with disability, the result was $3.50 worth of value.

Independent disability advocacy has been shown to provide a substantial net benefit to the Australian economy[48]. In 2017, the aggregate net present value of independent advocacy for people with disability in Australia was measured at almost $600 million. The benefit-cost ratio of 3.5:1 is high compared with other investments. The results validate the economic rationale for government funding for independent advocacy for people with disability and for its continuation.

This cost-benefit of investment in disability advocacy frees government resources for their next best use.

Investment in advocacy showed that people with disability were employed more productively and had better educational, health and child protection outcomes.

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[47] See Operating Context in Chapter 1

[48] Daley et Al, 2017

The Review heard that there were trends towards guardianship for some people with disability when the NDIS process and its appeals were too difficult to manage, informal supports were inadequate and disability advocacy was not available. We also found modelling that shows the cost-benefit of investment in advocacy as a means to prevent a more costly shift to guardianship arrangements[49]. Clearly, any drift from self-determination towards guardianship, other than as a last resort, is a drift away from the principles of the UNCRPD.

The literature review (see Appendix 5) identifies specific benefits of disability advocacy not only for government, but for people with disability, carers, the disability sector and the wider community. The **benefits for people with disability** from independent advocacy are substantial, notably gaining a voice; improved health and wellbeing; increased ability to access and use information and services; increased ability to gain and retain meaningful employment; increased ability to apply for housing and benefits; and networks and support to build relationships[50].

Benefits

There are benefits of advocacy for government, people with a disability, carers, the disability sector and the wider community.

Advocacy plays an important role in prevention and safeguarding and should not be just viewed as a mechanism to manage crises by responding to complaints.

Advocacy work needs to be flexible to effectively meet current, changing and future needs.

- The ageing of the Australian population influences the need for advocacy not only because of (1) the increased incidence of disability with increased age, but also because of (2) the growing longevity of people with disability and (3) the ageing of family carers of people with disability and associated reduction in their informal caring role.
- Advocacy is continuing to support groups of Australians with disability who have traditionally had low rates of participation in disability services – such as people with CALD backgrounds and Indigenous communities. These groups have a growing awareness of their rights but need advocacy support to turn that awareness into action and outcomes that provide equitable benefit for them.

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[49] A cost-benefit analysis of alternative funding scenarios for NDIS-related clients in Queensland (2018-23), Queensland Office of the Public Guardian, Dr Richard P. C. Brown

[50] Daily et al, 2017, pp16-17

- Demand for individual advocacy remains high as people seek help to navigate complex matters especially related to NDIS IFPs.
- Advocacy work supports people with disability to engage in the current Disability Royal Commission. In addition, recommendations arising from the Royal Commission are likely to involve system and service changes that will trigger the need for advocacy.
- Changes to Australia's Humanitarian Program since July 2012 has meant that there are more refugee applicants with disability arriving in Australia through the resettlement program[51].
- Advocacy plays an important protective role in the changing landscape of disability service provision, which can involve multiple government, not-for-profit and for-profit providers – involving separate agreements and different payment arrangements.

Advocacy work needs to be flexible to effectively meet current, changing and future needs.

An accurate picture of demand for advocacy is not available.

> "Advocacy leads to good outcomes for government, communities and individuals. Why the reluctance to invest?"
>
> Workshop participant

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[51] https://www.refugeecouncil.org.au/disability-report/4/

Lens 2: Operational matters in the advocacy sector

There are many variations in organisational and operational models between funded disability advocacy organisations in NSW. Regardless, they have a common focus on effective advocacy as person-centred and holistic, supporting empowerment and self-determination.

Key operational features in the sector relate to the actual roles and activities of advocacy, including its independence; the role of information and referral; variations in funding; the interface of advocacy with the NDIS; and use of technology. Each of these operational matters is expanded below.

> The principle of localism is very important – advocacy organisations need to be embedded in their local community, know the service 'map' of their local community.

Independence

There is a consistent view that advocacy is about 'being on the side of the person with disability'. As a consequence, there are strong views about the independence of advocacy to avoid any conflicts of interest. Many informants argued strongly for advocacy being totally independent of direct service provision. Other informants noted the 'common sense' from the client's perspective when direct service provision and advocacy are available from the one agency. These latter views tended to be held by organisations working in areas where the commonality of language was important (such as CALD communities, Deaf community) or where self-advocacy was strong (for example, Spinal Cord Injuries Australia, Deaf Society).

Regardless of diverse views, there was fundamental support for advocacy organisations to have clear and transparent processes for managing perceived or real conflicts of interest.

> Lots of worthy things are done by services and citizens but they are not necessarily advocacy.
>
> Submission to Review

Advocacy activities and roles

There are many variations in definitions of advocacy and types of advocacy (see Literature Review at Appendix 5). There is also debate about actual advocacy activities.

The Review found that disability advocacy exists across a spectrum of types and activities with overlap and flow-on effects; there is an interrelatedness of matters in the advocacy landscape. As an example, systemic advocacy is underpinned by information flowing from other types of advocacy.

Advocacy is complex and defies strict subdivision into discrete categories. Debate exists about advocacy distinctions across self-advocacy, peer advocacy, individual advocacy, systemic advocacy, legal advocacy, citizen advocacy, self-advocacy and representational advocacy activities (see Definitions before the Executive Summary and further discussion in the literature review at Appendix 5).

There is a defensible view that approaches to advocacy should be flexible and person-centred rather than activity-based – good advocates will identify, use and change their activities to meet needs. There is no real support for a 'list' of advocacy activities. People may need more than one approach, often at the same time. The Review found that the need for flexibility across broad cohorts of people with disability (physical, intellectual, psychosocial); across groups with specific characteristics (such as CALD and Indigenous communities, those who identify as LGBTIQ+, who live in regional areas, who are older people or children); and for groups with particular roles in advocacy (such as families and carers). However, flexibility in the way advocacy is delivered does not diminish the need for accountability to funding authorities and to the community. Indeed, outcomes-focused reporting facilitates a more robust approach, while allowing diversity of approaches in advocacy service provision.

The role of information, referral and advice

The Review found that information is fundamental to effective decision-making particularly in self-advocacy; as an ancillary input to all forms of advocacy; and as a component in 'soft referrals' to another agency. Information is a key ingredient to 'self-servicing', thus avoiding other forms of funded advocacy. Information and linkages are important.

There are different areas of information, forms of referral and types of advice that would assist the disability advocacy sector to work more systematically. Examples include:

- information about 'the disability system' (including NDIS) and about 'disability services'
- information about mainstream services, particularly health, education, housing, transport, justice and social security
- information about advocacy and about advocacy services
- information about local networks between disability advocacy, disability services and mainstream services.

While acknowledging the need for specialist information and referral services, the Review sees information, referral and advice as an ancillary component of both systemic and individual advocacy and of broader representative disability activity.

> The Review sees information, referral and advice as an ancillary component of both systemic and individual advocacy and of broader representative disability activity.

Funding

Chapter 1 has provided substantial information about current disability advocacy funding in NSW. We heard repeated and strong concerns about the level, certainty and longevity of advocacy funding. This is a major challenge to the sector and is discussed further in the Challenges section of this chapter. Irrespective of the total government committed funding, the sources of funding for advocacy are complicated, spread between different levels of government and agencies, and the funding instruments, terms and conditions lack coherency and common design features.

Interface with the NDIS

The NDIS is a key component in the operational landscape of disability advocacy services. Chapter 1 described its intent and the operation of the ILC component and the IFP component.

In practice, the Review heard about:

- The overall volume of work involved in advocating for people experiencing difficulties with the NDIS, representing a significant change from their previous 'core work' with mainstream services[52].
- Specifically, growth in advocacy work related to people seeking to access or manage an Individual Funded Package (IFP) under the NDIS. Key points in the process were identified as applying for eligibility/ access; the development of the NDIS plan and determination of the funding package; review of the NDIS plan; and appeal of reviewable decisions. Some attributed this workload to the relative immaturity of the NDIS and the associated inconsistent decision-making processes. However, the Review does not believe the need for advocacy in relation to NDIS matters will reduce in the foreseeable future – see assumption 1 about needs in Chapter 3.
- Lack of NDIS materials in accessible communication formats – including simple NDIS plans, easy language materials accessible by screen readers, materials in multiple languages, and Auslan videos. Advocacy is also complicated by uncertain availability of interpreters to assist in the 'complicated NDIS language'.

The role of technology

The Review found variable use of technology to support the internal effectiveness of disability advocacy organisations, with the variation loosely connected to organisation size and maturity. There was a wealth of examples of technology assisting in efficiency or effectiveness at the organisational level and at the individual worker level. There were also many examples of how technologies used between advocates and clients assist and improve advocacy outcomes; this was particularly noticeable in CALD communities (for example, using SMS rather than mail or phone so clients can use Google translate) and in advocacy services for people with sensory disabilities.

However, there was no identified major technology breakthrough that could be rolled out more broadly.

> There is no major technology breakthrough that could be rolled out more broadly; but there were many examples of technology usage to assist not only efficiencies for advocates and organisations but also to achieve client advocacy outcomes.

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[52] NCOSS report p 26

Lens 3: Performance of advocacy

The advocacy sector is keen to understand its own performance, be transparent about its performance, and learn from others.

Looking forward, a stable, proven, fit-for-purpose data system would assist service efficiency and effectiveness. Currently, TAFS-funded advocacy organisations report to DCJ by submitting a project plan for their annual work, which includes activities and objectives for each target group in their plan plus related quantity and quality measures. Analysis is not required; for example, on trends in advocacy issues. Most advocacy organisations have created their own databases and other mechanisms to evaluate their own performance.

The Review heard frustration about the lack of collated sector-wide data, lack of outcome data and little attention to measuring the professionalism of staff and quality of work. The ad-hoc historical development of the advocacy sector has allowed disparate measurement and reporting approaches to develop.

Where advocacy services receive funding from multiple sources, they have different reporting regimes and requirements that are reflected in their bespoke databases and other measurement tools.

There is a need for a robust performance management system that appropriately aligns with other advocacy programs and data collection mechanisms.

Common themes from the literature

- Disability advocacy is a necessary part of an effective disability sector
- Disability advocacy benefits everyone, and shows a significant return on investment
- Systemic advocacy is a necessary part of an effective disability sector, underpinned by information flow from other types of advocacy
- Individual advocacy should be independent
- Outcomes measurement is complex, but should be the basis for disability advocacy evaluation
- Approaches to advocacy should be flexible – people need more than one approach, often at the same time
- The availability of information about the system and about services, including mainstream, is necessary for an effective disability advocacy sector
- A common taxonomy is needed for the definitions of advocacy and the outcomes measurements
- State and Commonwealth disability advocacy systems must align and be clear, including clarity of requirements, reporting, funding and evaluation.

There is a need for a robust performance management system that appropriately aligns with other advocacy programs and data collection mechanisms.

Lens 4: Access to advocacy

Access to advocacy is a fundamental right. However, we have found an inequitable distribution of advocacy services across NSW. There is also confusion about how to access an advocate and where they might be, particularly in regional and remote NSW. Linked to this is the evident difficulty in understanding and measuring demand.

There is a need for a robust performance management system that appropriately aligns with other advocacy programs and data collection mechanisms.

> “We want to be open and accountable. We want someone to listen”
>
> Workshop participant

Understanding demand

An accurate picture of demand is lacking, largely because of minimal, inconsistent performance data (see Lens 3 above). It is also difficult to predict demand. The Review is aware of the work DCJ is doing to create a profile of people with disability in NSW – see Appendix 7. This work will be helpful to better plan service system responses. However, such data may not directly help with understanding the current or future need for advocacy.

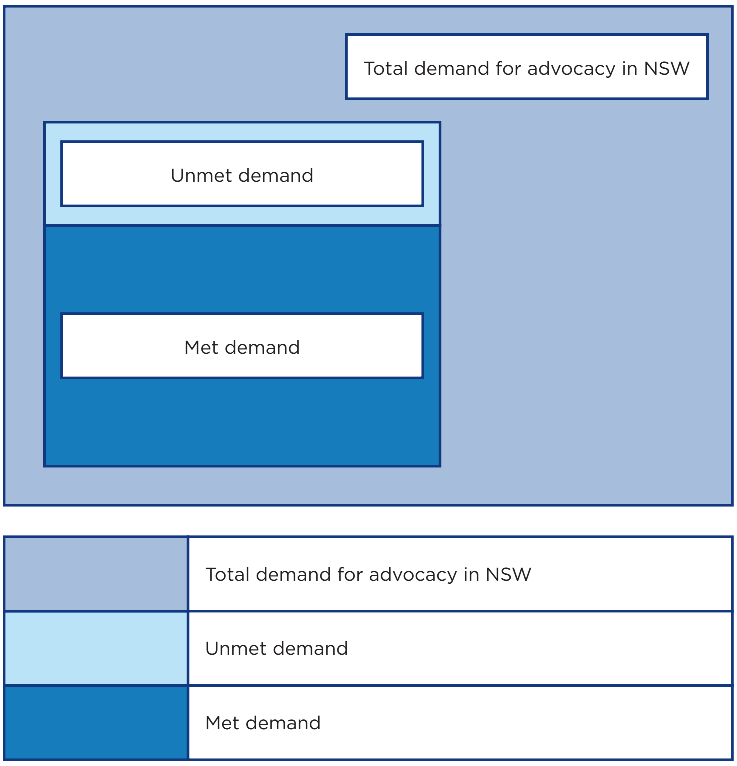
There is a sound argument to consider three elements

- **Met demand for advocacy** – that is, declared known demand that is met in a timely and effective way.
- **Unmet demand for advocacy** – that is, declared known demand for advocacy that cannot be met effectively (for example, no response, late response, or unskilled response).

- **Unknown demand for advocacy** – that is, undeclared need. This need for advocacy arises largely because people don't know about advocacy – they may simply be unaware that an advocate could help with their issue, or it may be a situation where information about advocacy is withheld from them. There are many examples from Official Community Visitors about finding urgent and critical needs for advocacy that would go unaddressed if they had not visited, identified the situation and linked the person to advocacy support.

Figure 10 shows total demand for advocacy in NSW, including known and unknown demand, and met and unmet demand.

Figure 10 - Understanding demand for advocacy in NSW



Measuring demand

Submissions from individuals noted personal wait times for individual advocacy – one person reported being told that it would be six months until an individual advocate could help him. Various disability advocacy organisations report holding waitlists, one up to 10 weeks. The Review also heard other matters contributing to the picture of demand for advocacy, including data showing increased demand for advocacy directly linked to promotional activities, and difficulty in finding self-advocacy training. There is no doubt that the roll out of the NDIS has affected the demand for advocacy across the sector, despite NDIS funding for support coordinators, ILC funding and the NDAP. Yet demand beyond NDIS participants remains high. There appears to be growth in advocacy work for the 90% of people with disability in NSW who do not receive an IFP under the NDIS.

Review participants described detailed and varied examples of the need for disability advocacy, including unmet need. Some noted the need for advocacy for particular groups, such as older people with disability who are ineligible for an NDIS package, people with degenerative conditions (noting they were not well accommodated within the NDIS), socially isolated people without the informal advocacy of family and friends, people from Aboriginal or particular cultural backgrounds, and people in regional and remote areas.

An accurate picture of demand for advocacy is not available.

Managing demand

The Review found that the sector uses various prioritising strategies to manage demand for advocacy, including:

- considering the impact (urgency/importance) of the presenting issue, the capacity of the individual to address the issue, and the other networks and supports the person has
- when a person is at risk, the matter is dealt with at the expense of other work
- problem-solving approaches at the point of first contact for **individual advocacy** to understand urgency, referral options, and/or provision of information as a holding option

Systemic Advocacy services needing to be disciplined and selective - prioritise areas of work and further prioritise matters within those areas.

> "The need for advocacy, rather than diminishing, is continuing to grow as people with disability rightly seek to exercise their rights to participate equally within the community"
>
> Workshop participant

Impacts and challenges

Summary

There is a range of impacts and challenges arising from the current status of disability advocacy in NSW. Figure 11 notes key areas of challenge, which are expanded in subsequent pages. Helpfully, Review participants had many suggestions for addressing the current challenges; these, and those of the Commission, are included as a means to look forward.

In summary, we found that the advocacy sector wants a clear funding and operational framework – a framework that delivers equity in access and quality across cohorts and geography. They want reduced complexity for their organisations and for their clients. Importantly, they are keen to be more accountable and transparent with government as well as between themselves. They want to build the capacity and capability of the disability advocacy sector. However, they report a range of impacts arising from the current arrangements; and they are fully aware of challenges that changes could cause to them and the sector . Not surprisingly, government seeks a better way to assess the value and outcomes of its funding for disability advocacy and to identify how it fits within its broader strategic objective of creating a more inclusive society for NSW citizens with disability.

Figure 11 - Key challenges in the NSW advocacy sector

> The advocacy sector is seeking a clear framework of funding and operations delivering equity of access and quality across cohorts and geography. They want reduced complexity, increased accountability, and to build the capacity and capability of the disability advocacy sector.

Challenge 1: The level, certainty and longevity of advocacy funding

There is a strong view from Review participants that:

- disability advocacy funding in NSW is insufficient to meet the demand for individual advocacy
- disability advocacy funding in NSW is insufficient to meet the engagement expectations of NSW departments and agencies
- the distribution of funding across organisations lacks a transparent logic
- the current short-term funding (TAFS to 30 June 2020) adversely affects advocacy provision and outcomes.

The impact of short-term advocacy funding with no transparent sector-wide framework is evidenced in many ways, including minimal capacity to retain or upskill staff, evaluate programs and develop inter-organisational relationships. A short funding horizon severely limits innovation.

This reduced capacity of advocacy services also affects the direct providers of disability services who say they *continue to invest substantial time and resources to support individuals to navigate the NDIS. Only 15 per cent agree that there is sufficient advocacy available for their clients. 75 per cent of providers agree that helping people understand and navigate the Scheme has been taking them away from service provision*[53].

Looking forward: addressing funding

The Review findings note the value arising from agreed, transparent funding principles and from a funding horizon that supports organisations to invest in both themselves and the sector. A series of funding principles are proposed in Chapter 3. In the absence of robust client or outcomes data from either the disability advocacy sector or the NSW Government, the level of funding to meet current or future demands, especially in respect of individual advocacy, remains highly contested. Nevertheless, in Chapter 4 we seek to establish a baseline for future funding levels, based on a proposed reformed advocacy system and funding program.

> Short term funding erodes trust.
>
> Submission to Review

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[53] State of Disability Services Report 2019

Challenge 2: Measuring performance

The current situation leads organisations to hold multiple datasets and to have an out-of-proportion reporting load to different funders with associated costs. We found the sector uses multiple platforms, and organisations lack staff skills, with no real funding for hosting and developing measurement systems.

In addition, advocacy services report that they don't know what happens to the data they provide to DCJ. They advised that the funding body and Government do not appear to fully understand their sector and their needs, despite the ongoing funding support provided post NDIS roll out. Equally, the Government struggles to identify with sufficient clarity and rigour the outcomes of disability advocacy provision in this State. These dual concerns call for a more robust reporting mechanism within a reformed funding program for disability advocacy in NSW. The current reporting regimes are not effective.

> Advocacy needs to be threaded through the whole of service provision
>
> Submission to Review

To this end, it is encouraging that the sector, throughout this Review, has expressed a keenness to agree to an **effective, transparent reporting process** that acknowledges difficulties in measuring advocacy outcomes but also understands the importance of input and throughput data.

> "National alignment should not be achieved at the expense of NSW, which has unique historical, geographic, economic and social factors"
>
> Workshop participant

> Outcomes should be 'that' issue for the client – not 'whole of life' or 'whole of plan' issues

Looking forward: building a meaningful and effective performance measurement system

The Review notes how important valid and reliable data is to assist with accountability to government and the NSW community, and to build capability across the sector and to build capability within organisations. Information gathered should be shared with the sector to inform sector development and practice improvement. Performance and reporting measurement should ultimately be co-designed with the sector to maximise their utility to the sector, government and people with disability.

Challenge 3: The interface between advocacy and the NDIS

A major issue is the lack of clarity noted by the Productivity Commission about the role and funding of advocacy within the NDA arrangements: '…the exact supports to be provided through the National Disability Advocacy Program, ILC grants and NDIS plans at full scheme are yet to be fully clarified or established'[54]

Advocacy organisations provided multiple examples of the shift in their advocacy work towards advocating for people experiencing difficulties with the NDIS. Many of these difficulties arise from NDIS processes, including delays and inconsistencies in decision-making.

Although the ILC policy and commissioning frameworks are clear in what the ILC intends to achieve, in practice there is confusion over its purpose and funding decisions.

Looking forward: A workable interface between advocacy and NDIS

The Review heard of the recent clarification of aspects of the interface between health and the NDIS; we are also encouraged by the recent announcement about six key areas of reform to the NDIS[55]:

- Quicker access and quality decision making
- Increased engagement and collaboration
- Market innovation and improved technology
- A financially sustainable Scheme
- Equitable and consistent decisions, and
- Improved long term outcomes for people with disability, their families and carers.

Nevertheless, these reforms are unlikely to have any real impact on the demand for advocacy in the foreseeable future and we have thus articulated some assumptions about the interface with NDIS in Chapter 3. Clarifying the future funding responsibilities between the Commonwealth, NDIS and States in a formalised agreement would be of great benefit.

> "Self-advocacy doesnt happen in a vacuum"
>
> Workshop participant

> "Other mainstream agencies should bear some responsibility and costs for the provision of disability advocacy in relation to their specific services, beyond that provided for through the disability advocacy program, without creating conflicts of interest for advocacy services"
>
> Workshop participant

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[54] Productivity Commission Report into the National Disability Agreement, Commonwealth of Australia, 2018a, p11

[55] https://www.ndis.gov.au/news/4016-minister-reveals-plan-improve-ndis

Challenge 4: The interface between disability advocacy and NSW departments and agencies

There is increasing demand on both advocacy organisations and other disability-focused representational organisations to engage with NSW departments and agencies, particularly Health, Housing, Education and Transport. On one hand, these requests are welcomed as a sign of good intent in relation to obligations under the NSW Disability Inclusion Act to consult with people with disability when making policy that affects them. On the other hand, expectations can be onerous, unrealistic and costly – for example, to attend multiple meetings, respond to major documents within 24 hours, and consult widely with the disability community.

Looking forward: a rational interface between advocacy and NSW departments and agencies

Our framework in Chapter 3 proposes some supplementary approaches to address this. However, this review has been unable to examine the broader funding for advocacy by other mainstream agencies.
Much appears to be project based or as part of funding broadly based consumer initiatives. What is clear is that other mainstream agencies should bear some responsibility and costs for the provision of disability advocacy in relation to their specific services, beyond that provided for through the disability advocacy program, without creating conflicts of interest for advocacy services.

> “Other mainstream agencies should bear some responsibility and costs for the provision of disability advocacy in relation to their specific services, beyond that provided for through the disability advocacy program, without creating conflicts of interest for advocacy services”
>
> Workshop participant

There is a need for a robust performance management system that appropriately aligns with other advocacy programs and data collection mechanisms.

Challenge 5: Awareness and understanding of advocacy

The Review heard about the absence of a common understanding about disability advocacy and its vital role across so many matters. We heard views that:

- **Government** doesn't fully understand the vital role of advocacy in assisting NSW to meet its international, national and State legislative obligations. In addition, advocacy can help NSW progress the NSW Human Services Outcomes Framework – it has a good fit with the Framework's domains,[56] but advocacy seems to get little government attention.
- The **general community** doesn't understand the transformative role that advocacy can play in the lives of people with disability.
- **Specialist disability service providers** don't understand their obligations to inform their clients about advocacy.
- **People with disability** and their families and carers are often unaware that advocacy is available.

Looking forward: Creating awareness

The role of information and awareness has a clear place in the framework proposed in Chapter 3. The substantive issue is not its value, rather who should bear the responsibility for funding specialist information and referral services, and how should it be provided.

> Disability advocacy organisations are subject to greater demand from government to support people with disability affected by government policies; to contribute views in regard to inclusion strategies; to sit on advisory councils; to advise on new legislation; and to facilitate access to people with disability in order to seek their views.

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[56] FACS, 2017 *Applying the NSW Human Services Outcomes Framework in FACS: An Overview*, May 30, 2017

Challenge 6: Advocacy sector support and capacity-building

Review participants report that the current status of disability advocacy in NSW restricts innovation, cooperation and capacity building of individual organisations and the disability advocacy sector. There is an identifiable need to develop the competency, capacity and capability of the disability advocacy sector and its workforce.

Looking forward: strengthening the sector

Review participants are seeking a means to unite the sector more closely in building a more coherent, better connected service sector and to build its capacity through key areas such as the following

- building the skills and capabilities of advocacy staff (paid and voluntary) – for example, to support a workforce with skills in the right mix, and cultural competencies
- sharing learnings across the sector – for example, sharing how and why a systemic campaign was successful; sharing documents and resources
- growing advocacy leadership and practice – such as a code of conduct

The Review recommendations will assist to collectively build the capacity of the sector. We have also made specific recommendations in relation to building capability through resources and development.

In summary: An advocacy framework

The Review has identified that there is a need for a new transparent framework for disability advocacy provision in NSW that underpins a reformed funding program. At a minimum, the framework should cover the purpose and role of advocacy, principles of funding, services to be delivered and performance measurement. This should be underpinned by a new base line for funding future advocacy in NSW.

It is encouraging that the sector wants to grow the **capability and reputation of disability advocacy** by building awareness and sharing outcomes. It also accords with the NSW Government's desire for robust, outcomes-focused advocacy provision. The Review supports the need for a well-designed framework that can equitably deliver access and quality across disability advocacy services.

> "Advocacy is not only linked to services and the service system. Much advocacy work is done to change the hearts and minds of typical citizens as to who people with a disability are and what they can achieve"
>
> Workshop participant

Chapter 3 outlines a rationale and principles for an effective disability advocacy framework while Chapter 4 describes the specific components in the framework, program funding design and links these with other key operational matters.

Chapter 3: What should be: a framework

The Review has identified a clear need for reform to achieve an effective disability advocacy system in NSW. We found some clear drivers to achieve the proposed reforms and thus propose a framework that facilitates advocacy organisations and government to work together to define, demonstrate and share the outcomes and impacts of disability advocacy. This framework will underpin a new disability advocacy funding program for this State.

Importantly, the Review also saw many examples of good advocacy practice and organisations delivering effective advocacy within an uncertain funding environment. Many have creatively obtained funding from different sources and created effective integrated service responses for clients and the groups they represent.

This Review has found:

- The current advocacy sector in NSW is not broken, but it is not working as an effective 'system'. The **future is less about 'new thinking' and more about 'clear and strategic thinking'.**
- There is a **clear and ongoing role for State and Territory Governments in disability advocacy**[57].
- It is vital to identify and distinguish between the **specific roles of the Commonwealth, the NDIS and the State in relation to disability advocacy.**
- The responsibility of the NSW Government in disability advocacy provision needs a new **Framework** that covers purpose, roles, principles, eligibility and assumptions with the aim of creating an equitable, responsive, accountable, quality disability advocacy system.
- There is a need for **development and coordination within the disability advocacy sector** in a way that builds capability and encourages innovation and provides value for the community as well as people with disability.
- Advocacy needs to be provided for **specific cohorts** of people with disability as well as **broader based advocacy for all NSW citizens with disability. It must be responsive to the needs, will and preferences of people with disability.**
- Information and referral is an important ancillary component of all advocacy work, but funding for **specific stand-alone information and referral services is primarily the responsibility of the Commonwealth/NDIS.**
- Advocacy in NSW must work in a way that is **broadly consistent** with and complements other advocacy programs and initiatives, and allows **comparability** across Australia.
- Funding of disability advocacy in NSW needs to be sufficient, secure and meet a set of **funding principles.**

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[57] The National Disability and Carers Advisory Council Communique 30 October 2018

Key elements of the proposed framework are briefly described below. While the Review considered numerous options and heard many alternative views, we have concluded that these elements provide a necessary and sufficient basis for much-needed reform.

Framework

Purpose

The benefits for the NSW Government of funding disability advocacy are significant, including assistance in meeting its legislative and regulatory obligations under the UNCRPD, the National Disability Strategy, the Disability Inclusion Act, and oversight obligations. Importantly, it enables the voice of people with disability to inform systemic issues and service delivery design, critical to their lives, through an organised and well-informed network of dedicated advocacy and representative bodies.

The benefits for **people with disability** are in three particular areas:

> *Disability advocacy enables people with disability to participate in the decision-making processes that safeguard and advance their human rights.*
>
> *Individual advocacy supports people with disability to exercise their rights, through either one-to-one support, or by supporting people to advocate for themselves individually, through a third party or on a group basis.*
>
> *Systemic advocacy seeks to introduce and influence longer term changes to ensure the rights of people with disability are attained and upheld to positively affect the quality of their lives*[58]*.*

Defining advocacy

Despite multiple possibilities, for the purposes of this Review, and to promote a nationally consistent approach, we consider the definition of advocacy in the National Disability Advocacy Program to be helpful because it is descriptive about the **scope of advocacy.**

> *Advocacy for people with disability can be defined as speaking, acting or writing with minimal conflict of interest on behalf of the interests of a disadvantaged person or group, in order to promote, protect and defend the welfare of and justice for either the person or group by:*
>
> - *Acting in a partisan manner (i.e. being on their side and no one else's);*
> - *Being primarily concerned with their fundamental needs;*
> - *Remaining loyal and accountable to them in a way which is empathic and vigorous (whilst respecting the rights of others); and*
> - *Ensuring duty of care at all times.*

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[58] National Disability Advocacy Framework 2008

[59] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap

Role of advocacy

The Review recognises that advocates play an **interventionist and protective role** as well as a **supportive and developmental role.** It also recognises that advocacy must have a **proactive role** in prevention and safeguarding, not just a **reactive role** in managing crises and complaints.

This means that advocacy is an important element in:

- safeguarding people from abuse and neglect
- protecting and promoting the human, legal and civil rights and safety of people with disability
- supporting people with disability to determine their own will and preferences
- enabling people with disability to access appropriate supports and services that maximise independence, autonomy, productivity and inclusion
- informing and achieving systemic responses to the needs and aspirations of people with disability
- supporting people with disability to take an active part in public debate and government decision-making that affects them.

Eligibility for advocacy

The Review has identified that here should be no eligibility criteria for people with disability to access funded disability advocacy services. Nevertheless, the funding principles (see below) will allocate resourcing and then organisations will use a transparent and fair process to prioritise their advocacy activities. The system itself may need to establish some general priorities, subject to any resource constraints, which is discussed in Chapter 4.

Defining the role of the NSW Government in disability advocacy

There is an ongoing role for the Commonwealth and the NDIS in delivering funding for some advocacy, information and referral services, capacity building and related activities. These should generally not be the focus of the NSW funding program.

The NSW Government's focus should be linked to:

- Assisting NSW residents with disability to:
  - navigate and access NSW Government services, departments and agencies
  - navigate and access commercial services like utilities, retail, and entertainment
  - navigate and access local councils and community services and facilities
  - ensure lifestyle choices do not result in discrimination
  - enhance their opportunities for genuine inclusion in the community.

- Particular, but not exclusive, consideration of:
    - the needs of people with disability who require supports and services outside of that provided through an NDIS IFP
    - older people with disability who are captured by 'continuity of support' arrangements[60]
    - people with disability in regional and remote areas.

While the Review identified many issues relating to access to government and other services as a strong reason for government involvement, the NSW Government's role in disability advocacy is also underpinned by the following profile data[61]:

- Each year, the Australian Human Rights Commission (AHRC) receives more complaints about disability discrimination than about other forms of discrimination – 42% AHRC complaints are about disability discrimination.
- In 2018, of people aged 15 years or over and living with disability in households, 1 in 4 have experienced some form of discrimination, with:
    - 1 in 11 experiencing disability discrimination
    - 1 in 6 saying the discrimination related to health care staff
    - 1 in 6 having difficultly using public transport
    - 1 in 3 have had difficulty accessing buildings or facilities
    - of adults who have experienced violence at some point over age 15, 47% have a disability.

The NSW Government has a real and ongoing responsibility in safeguarding people with disability, and its support of a robust system of disability advocacy is a critical part of this. It is vital to promoting, protecting and securing the rights of residents of NSW who have a disability.

Funding principles

The current funding principles in NSW for TAFS disability advocacy are short term and not appropriate for a robust system. As noted earlier, they are a response to the complex and evolving funding landscape following the introduction of the NDIS.

Future long term funding of disability advocacy in NSW should be based on the following principles. Resourcing will:

- Demonstrate value for money to the Government, people with disability and the community of NSW[62].
- Be managed in a way that is transparent and provides a secure foundation for service operations including through longer term funding commitments.

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[60] The Commonwealth Continuity of Support (CoS) Programme makes sure that older people with disability currently receiving State and Territory-managed specialist disability services, who are not eligible for the National Disability Insurance Scheme (NDIS), receive ongoing support https://agedcare.health.gov.au/programs-services/commonwealth-continuity-of-support-programme

[61] AIHW, People with disability in Australia 2019

[62] https://www.procurepoint.nsw.gov.au/policy-and-reform/nsw-government-procurement-information/statement-value-money

- Achieve equity of access to disability advocacy across NSW, regardless of location.
- Be cognisant that there are no eligibility criteria for accessing funded disability advocacy in NSW.
- Support the delivery of timely, competent advocacy activities regardless of culture, gender and nature of disability.
- Recognise the interdependent nature of different forms of advocacy in supporting an effective advocacy system.
- Support the capacity of funded organisations and the sector as a whole to adapt to meet the demands of a dynamic service and system environment.

Funded organisations

The Review recognises there are many high quality advocates, who are both skilled and have a detailed understanding of the needs and preferences of their clients. Equally, there are highly effective organisations delivering advocacy and related services despite significant constraints. Yet, the providers of disability advocacy through this Review acknowledge the need for greater transparency and accountability, and embrace the need for both professional and sector development. Funded disability advocacy organisations in NSW and their staff should:

- Operate in a way that is free from conflicts of interest.
- Operate in a way that recognises the importance of local advocates with local knowledge.
- Support choice of advocate where practical.
- Have regard for the will and preferences of each person with disability.
- Demonstrate skills and competencies to build the capacity of the people they support.
- Use a transparent and fair process to prioritise their advocacy activities.
- Demonstrate, and be accountable for, the outcomes, impacts and quality of their service delivery practice and approach.
- Be prepared to work in collaboration to further develop the sector’s capacities, promote innovation and to optimise outcomes for people with disability.

Assumptions

The proposed NSW Disability Advocacy Framework is based on a set of assumptions about the current and future operating and policy environments. We recognise the paucity of the availability of hard data; however, we believe that, based on the multiple sources of information examined in this Review, the following assumptions are robust. These assumptions critically underpin our recommendations to create a sustainable disability advocacy system with some certainty, and for the NSW Government to establish a stable, independent funding program, not responding to the individual and often short term funding decisions of either the Commonwealth or the NDIS.

Assumption 1: The need for disability advocacy in NSW will increase

The need for advocacy will grow.

- While it is impossible to know the extent, there is some evidence of **current known unmet demand** as well as a broad consensus about a level of undeclared demand which is both unacknowledged and unmet.
- **The Australian population is ageing.** The implication for advocacy arises because of: (1) the increased incidence of disability with increased age, (2) the increased longevity of people with disability, and (3) the ageing of family carers of people with disability and associated reduction in their informal caring role.
- **The take up of NDIS IFPs will rise** towards predicted levels over the next few years (see assumption 3). The implication for advocacy arises because the NDIS is linked with increased advocacy work at multiple points. Many people require advocacy as they learn about the NDIS, seek to access it, and when they create and implement their NDIS plans. They also tend to require advocacy when their NDIS plans are reviewed and if there is a need to appeal the reviewable decisions.
- **People with disability have broader awareness about services and rights.** This includes many people who have either lived on the fringe (for example, in homelessness) and/or are not engaging effectively with the NDIS (such as people who have had a stroke, people with mild intellectual disability or acquired brain injury). Need for advocacy arises not only from heightened awareness about the NDIS and specialist disability services, but also from awareness of rights to access mainstream services, including education, transport, housing, health, and justice services.
- **NSW agencies have heightened awareness of their obligations** to involve people with disability in planning to respond to the Disability Inclusion Act. They are seeking more access to representational bodies and systemic advocacy organisations.
- **Progress arising from NSW Disability Inclusion Action Plans is slow** so the equitable access of people with disability to NSW Government programs and services – and those of departments and local councils – is likely to require a need for advocacy for the foreseeable future.
- **The Disability Royal Commission** creates a need for advocacy during the hearings (this is supported by the NDAP). It is also highly likely that system and service changes arising from the findings of the Royal Commission will create a need for advocacy, much of which will need to be picked up by NSW.
- **Government and commercial activities move online.** Much information remains inaccessible to people with disability for reasons related to both the format and channels of the information itself, as well as structural barriers faced by people with disability to digital inclusion[63]. Research shows that people with disability have a much lower level of digital inclusion than other Australians. This reduces their ability to self-serve their information needs – they cannot simply ‘get online to find what they want’ – and they turn to advocacy.

[63] A Thomas, J, Barrakat, J, Wilson, CK, Rennie, E, Ewing, S, MacDonald, T 2019, Measuring Australia’s Digital Divide: The Australian Digital Inclusion Index 2019

Assumption 2: The NDAP will continue

This Review assumes that, regardless of the review of the NDAP[64], that:

- The NDAP will continue to fund advocacy organisations (currently called NDAP agencies).
- Funded NDAP agencies will be a blend of generalist and specialist advocacy organisations and be funded to provide disability advocacy support in specific geographic areas.
- NDAP agencies based in NDIS sites will continue to assist people through the planning and internal review processes with the NDIA.
- The NDAP will continue to fund the NDIS Appeals program to support people with disability who seek an external review of NDIA decisions through the AAT.
- The NDAP will continue to fund advocacy assistance to the Disability Royal Commission for the life of that Royal Commission.

Assumption 3: The DRO will continue

This Review assumes that the Commonwealth DRO funding program will continue in its current form.

Assumption 4: The National Disability Agreement

This Review assumes that Recommendation 3.4 of the Productivity Commission's Review of the NDA[65] will have been actioned in 2020. The recommendation states that:

The new National Disability Agreement should set out the responsibilities of the Australian, State and Territory Governments to provide disability services outside the National Disability Insurance Scheme … where there is lack of clarity … including for … advocacy services, including systemic, individual, legal and self-advocacy.

Any ongoing confusion as to the roles and responsibilities of the various government parties can only be damaging to the provision of disability advocacy services and ultimately harmful to the wellbeing of people with disability, their families and carers.

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[64] Commonwealth Government. 2017. Review of the National Disability Advocacy Program Consultation Report Jul 2017

[65] Productivity Commission. 2019 Review of the National Disability Agreement. Australian Government, 2019.

Assumption 5: NDIS arrangements

This Review assumes that the NDIS (or the Commonwealth)

- takes responsibility for long term funding of Information and Referral services through the ILC
- continues grants rounds or other funding mechanisms through ILC which focus on organisational initiatives that support capacity-building for individuals
- continues to fund items in IFPs that support capacity-building for individuals to speak up (where reasonable and necessary to meet goals in their NDIS plan)

Assumption 6: NSW state agency arrangements regarding advocacy

The Review assumes that, while the main program for funding disability advocacy in NSW will be the proposed Disability Advocacy Futures Program through DCJ, other mainstream government agencies will additionally continue to support advocacy for people with disability in relation to their specific services and needs, including those responsible for Health, Education, Housing, Justice and Transport. The Review was not able to establish the extent nor effectiveness of existing supports, but has made some observations in Chapter 4 with regard to the contributions that could be made by these agencies.

Chapter 4: Way ahead: specific elements

The way forward for the funding of disability advocacy in NSW by the State Government is based on the Framework, Principles and Assumptions in Chapter 3. These inform the development of a proposed new long term disability advocacy funding program to be known as the **NSW Disability Advocacy Futures Program (DAFP)**. Yet this program will sit within a much broader context.

We acknowledge that advocacy for people with disability will be provided in diverse ways, by multiple groups and organisations. The nature of advocacy will also take many forms, as determined largely by people with disability, their families and carers. Funding to support these activities will also come from various sources – Commonwealth, State and local governments, the NDIS, community and philanthropic contributions – and will be applied to support a broad range of supports, services and activities.

Nevertheless, it is important that the limited NSW Government funding available to support disability advocacy is strategically targeted to maximise the value of such funding for people with disability, the community and funded organisations. It is not the role of government to dictate how the sector should organise itself generally, nor how any particular organisation operates.

While many funded services will provide multiple activities beyond those directly funded by the DAFP, it is important that the NSW Government creates a clear, logical, accountable and sustainable model for the services and activities it does fund.

The Disability Advocacy Futures Program

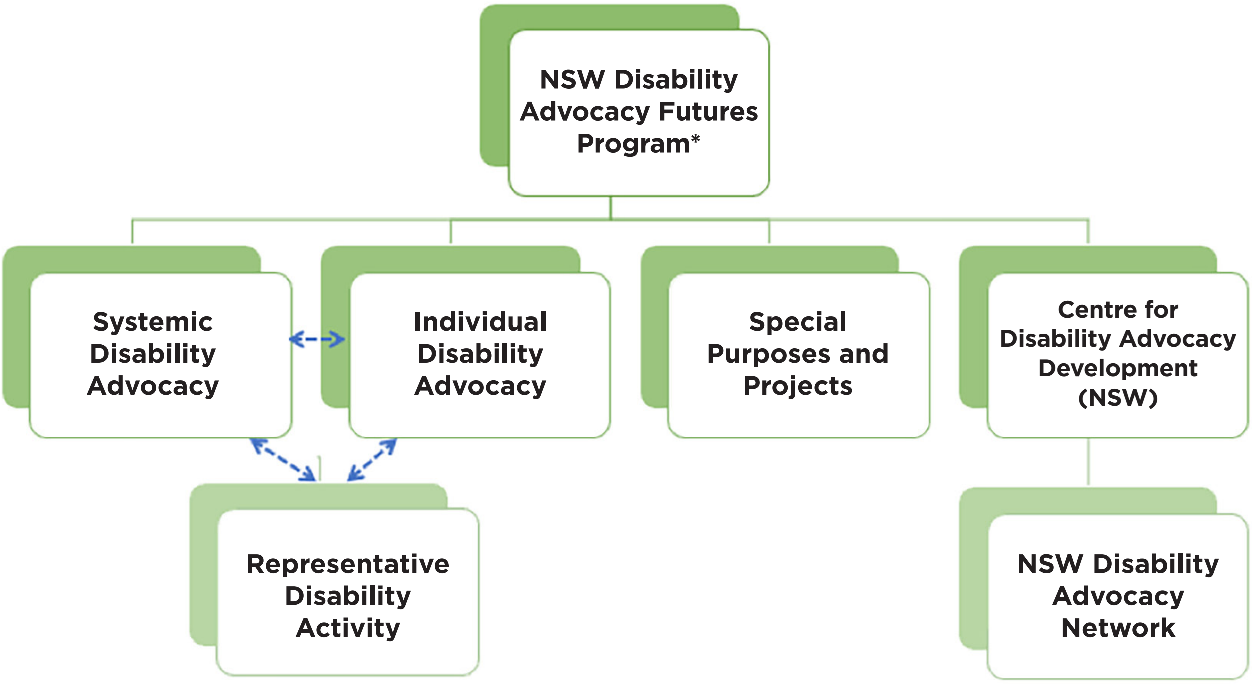
This chapter describes key elements and their interrelationship with DAFP components – it does not seek to set out a plan for all advocacy for people with disability in NSW. The following diagram sets out the basic structure of the DAFP.

Importantly, the DAFP will be the principal means by which the NSW Government will fund the provision of advocacy for people with disability in NSW.

- It is based on the funding principles previously set forth and, importantly, the key assumptions concerning the continuation of Commonwealth and NDIS funding regimes.
- It is designed to have a much clearer, more targeted focus on systemic and individual advocacy, while recognising support for representative activity.
- It recognises the particular or distinctive needs of certain cohorts of people with disability including people with disability from CALD communities and Indigenous communities.

- It recognises the need for flexibility in the provision of advocacy services and supports, while requiring proportionate, comparable and meaningful accountability.
- It recognises the need for the will and preferences of people with disability to be respected within a better designed and more focused funded disability advocacy system.

Figure 12 - NSW Disability Advocacy Futures Program



*oversight of the establishment and performance of this Program by the NSW Ageing and Disability Commission

In designing the DAFP, the Review considered numerous options and alternative approaches. In assessing these, we had regard to the costs and benefits to people with disability, the sector and government. We assessed the likely disruptive effects, especially having regard to the uncertain funding environment over recent years. In particular, we note the following issues:

- The Review examined whether the number of funding contracts for **systemic advocacy** could be reduced with greater reliance on one or two state-wide contracts, with the ability of such providers to sub-contract elements of their work. While there would be some efficiencies, we concluded that it is imperative to recognise that some cohorts require their own specific funding, including people with physical, intellectual and psychosocial disabilities. Equally we recognised the need to separately acknowledge the particular systemic issues relating to CALD and Indigenous communities and families/carers.

- In relation to **individual disability advocacy**, the Review considered the best way to achieve equity for people, no matter the nature of their disability or where they live. Again, we considered the use of one or two statewide cross-disability contracts. This is the approach we have adopted for legal advocacy, and for people from CALD and Indigenous backgrounds. Nevertheless, to minimise unnecessary disruption, to acknowledge the importance of local knowledge and connectedness, and to achieve coverage quickly (especially in regional NSW), we determined that a decentralised regional model was most appropriate. Even so, some existing organisations will no longer receive direct funding for individual advocacy, as the number of regional contracts will be limited. Efficiencies will be generated and the attendant scope and scale of these regional providers will allow practice improvement. Innovative collaborations, subcontracting or partnering arrangements may emerge.
- The Review considered the **right mix of advocacy models and approaches.** In particular, we weighed up the appropriate focus that should be given to supported individual advocacy compared to individual self-advocacy, citizen advocacy, and other forms. While we acknowledge the need to promote and encourage self-advocacy for individuals, which is explicitly recognised in all proposed funding streams, we determined that NSW funding needs to be focused predominantly on supported individual advocacy, at least at this stage. Nevertheless, there are explicit provisions in the program to provide support for self-advocacy initiatives and to encourage self-advocacy within the individual advocacy funding arrangements.
- The Review gave consideration to the important and contentious issue of how a reformed program should deal with **the advocacy needs of older people with disability**. We recognise that there is a significantly growing population of people who have acquired their disability in older age. The DAFP should not restrict eligibility for funded disability advocacy service provision; however, given the inevitable resource constraints, the overall Program may need to initially prioritise people with disability who have acquired their disability before the age of 65, irrespective of their current age. This should be subject to review as governments at the Commonwealth and State levels, together with the disability and aged care sectors, work to resolve current system interface and service access issues for older people who have acquired a disability later in life. If the DAFP is to increase its scope and coverage, and subsequently change its prioritisation approach, it will need additional funding, which could include contributions from other mainstream agencies. The Review acknowledges that often representative organisations will and should represent people with specific disabilities irrespective of the age at which such disability was acquired.

Consequently, the proposed DAFP will result in a shift away from NSW funding specialist information and referral activities generally (now the funding responsibility of Commonwealth /NDIS), to a greater focus on systemic and individual advocacy. It will streamline the number of directly funded organisations, who will in turn be able to enter into effective arrangements with other disability advocacy organisations. It will encourage sector-wide practice improvement and innovation. It will simplify funding arrangements while requiring more meaningful outcomes and performance reporting. It will establish a new baseline for funding by the NSW Government, and a guide to the distribution of such funding.

Key components of the Disability Advocacy Futures Program

1. Centre for Disability Advocacy Development (NSW

Purpose

The Centre for Disability Advocacy Development (the Centre) is designed to:

- enhance and improve the development of high quality, sustainable disability advocacy services
- provide community information about access to disability advocacy
- foster collaboration and innovation among disability advocacy providers
- support self-advocacy initiatives.

Activities

The Centre (see schematic at Figure 13) will:

- develop and provide information about disability advocacy services to the community
- aggregate and disseminate data from disability advocacy services
- develop internal and customer-facing resources for disability advocacy services
- provide information and advice for people wishing to form self-advocacy/ peer support initiatives
- provide a Secretariat function for the Disability Advocacy Network (see below)
- work with the Disability Advocacy Network to:
    - identify and disseminate best practice
    - develop a code of practice for disability advocacy providers
    - review sector-wide performance and outcomes as reported as part of the outcomes framework for organisations receiving funding under the Disability Advocacy Futures Program.

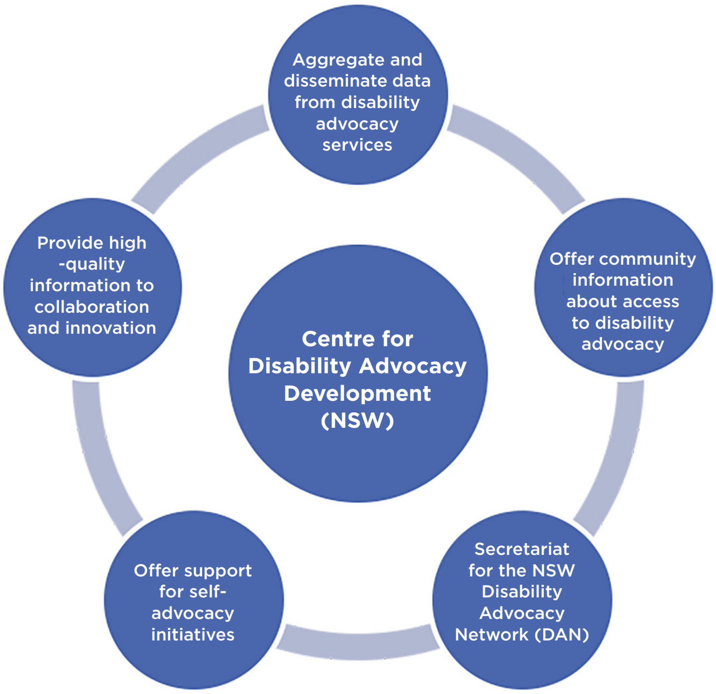
Key features

Funding will initially be provided to a single non-profit, non-government organisation through a limited tender to establish the Centre. Within two years, the Centre should be separately incorporated with membership comprising NSW disability advocacy providers.

The Centre will not be a peak body; neither will it deliver disability advocacy services nor provide disability services.

Funding will cover both core funding and some discretionary funding for specific initiatives to meet its purpose, strengthen the Disability Advocacy Network and/or seed self-advocacy initiatives.

Figure 13 - The Centre for Disability Advocacy Development (NSW)



2. NSW Disability Advocacy Network

Purpose

The Disability Advocacy Network (the Network) will be a membership-based network of disability advocacy providers, with the purpose of:

- enhancing quality improvement, collaboration and innovation among Network members specifically
- enhancing networking and learning between disability advocacy providers and advocates more broadly
- creating a community of practice.

Activities

The Disability Advocacy Network will operate as a collaborative forum that will:

- facilitate the exchange of information between Network members
- provide input to the materials, resources and code of practice developed by the Centre for Disability Advocacy Development
- work with the Centre to identify best practice and means to support both skill and practice improvements.

Key features

All organisations directly receiving funding for individual or systemic advocacy under the Disability Advocacy Futures Program will be required to be members of the Network and abide by the code of practice established by the Centre.

Other organisations providing disability advocacy services, whether or not funded under a NSW program, can voluntarily become members of the Network.

The Centre will provide the secretariat for the Network, which will not be separately funded.

3. Systemic disability advocacy

Purpose

Systemic disability advocacy is designed to provide high quality evidence-based advice to inform the resolution of systemic issues. Systemic advocacy aims to inform government and service systems owners of ways to uphold the rights of people with disability and improve the quality of life of people with disability through their access to services.

Activities

Systemic advocacy will:

- build evidence in respect of systemic issues from a wide range of sources including information, research, and individual advocacy services
- be particularly informed by the views and direct experience of people with disability
- identify and promote means to improve service systems and the interaction of those systems with people with disability
- contribute to government consultations, inquiries and reviews as reasonable
- disseminate systemic information to particular cohorts of people with disability affected by the systemic issue and its reform as well as the broader community
- undertake planned work focused on particular systemic matters, and may also provide input into systemic issues and activity on an ongoing basis.

> Disability advocacy organisations are subject to greater demand from government to support people with disability affected by government policies; to contribute views in regard to inclusion strategies; to sit on advisory councils; to advise on new legislation; and to facilitate access to people with disability in order to seek their views.

Table 5 - Systemic advocacy in NSW

	Scope	Focus: **Systematic Advocacy**	Notes
Category 1 (1 contract)	Statewide	Cross disability	Category 1 advocacy activity to particularly include cohorts that do not have specific coverage through Category 2 systemic advocacy All Categories anticipated to undertake ancillary information and referral activities and occasional individual advocacy but consume no more than 15% of the funding allocation.
Category 2 (3 contract)	Statewide	For people with intellectual disabilities	
	Statewide	For people with physical disabilities	
	Statewide	For people with psychosocial disabilities	
Category 3 (3 contracts)	Statewide	For people with disability from CALD communities	
	Statewide	For people with disability from Indigenous communities	
	Statewide	For families and carers of people with disability	

Key features

Funding contracts will be entered into with non-profit, non-government organisations through a limited tender basis. Such organisations (disability advocacy providers) must have a membership predominantly of people with disability, their families or carers. They should not be disability service providers.

Funded disability advocacy providers will be expected to collaborate with and draw from the experiences of the broader range of disability advocacy and representative bodies operating in NSW.

While specific funding has been identified for people with disability from CALD and Indigenous communities, all contracted systemic advocacy disability advocacy providers are to have regard to the interests and needs of people with disability generally (including in relation to issues in respect of gender, sexual orientation, culture, location and age).

> “The need for advocacy, rather than diminishing, is continuing to grow as people with disability rightly seek to exercise their rights to participate equally within the community”
>
> Workshop participant

In respect of the Category 1 funding contract for cross-disability, the disability advocacy provider will provide systemic advocacy for people with disabilities of all kinds, but with a particular emphasis on those that do not have specific systemic advocacy coverage, including people with sensory disabilities, brain injury, higher functioning autism and cerebral palsy. Some of these conditions may already, to some limited degree, be covered within other cohorts but over time, they may become more fully integrated into the scope of other systemic advocacy providers.

The focus for Category 3 systemic advocacy for families and carers of people with disability will differ from the activities of other funded systemic advocacy organisations. The role will be representation of the interests of families and carers, and capacity building for families to advocate on behalf of their family member with disability, especially by providing training and support.

It is recognised that, while the predominant funded activity is systemic advocacy, funded disability advocacy providers will undertake limited incidental or ancillary information and referral activities and occasional individual advocacy.

4. Individual disability advocacy

Purpose

Individual disability advocacy is designed to provide supported advocacy activities to address specific issues for individual people with disability. A priority will be on issues related to upholding rights, accessing services, and resolving disputes and complaints.

Activities

Individual advocacy will:

- primarily be focused on supported individual advocacy for specific issues
- assist in the development of individual self-advocacy skills where desired
- identify and highlight systemic issues.

Table 6 -Individual Advocacy in NSW

	Scope	Focus: **Individual advocacy**	Notes
Category 1 (1 contract)	Statewide	Legal Advocacy for people with disabilities of all kinds	Legal advocacy (Category 1) expected to focus on people with intellectual, psychosocial or cognitive disability. All Categories expected to contribute input into systemic issues but to consume no more than 10% of the funding allocation. All Categories anticipated to undertake ancillary information and referral activities but to consume no more than 10% of the funding allocation.
Category 2 (6/7 contracts)	Regional	Cross-disability	
Category 3 (2 contracts)	Statewide	For people with disability from CALD communities	
	Statewide	For people with disability from Indigenous communities	

Key features

Funding contracts will be entered into with non-government, non-profit organisations through a limited tender basis. Such organisations (disability advocacy providers) should not be disability service providers. No individual disability advocacy provider may hold more than two regional contracts.

Statewide individual disability advocacy providers may choose flexible arrangements to achieve the statewide coverage, including through the co-location of personnel within regional disability advocacy providers, subcontracting, consortia or partnerships.

Individual disability advocacy providers are to have regard to the interests and needs of people with disability generally (including regards to issues in respect of gender, sexual orientation, culture, location and age).

In relation to Category 1 legal advocacy, the individual disability advocacy provider will be required to provide legal advocacy to all people with disability, but with particular regard to those with psychosocial, intellectual and cognitive disability. A transparent prioritisation and referral process to other legal services or supports will be needed, and the funding contract will need to appropriately account for such activity.

A person with disability may choose and be free to access services from a regional individual disability advocacy provider outside their region, where it is practical to do so.

While specific funding has been identified for people with disability from CALD and Indigenous communities, all contracted regional individual disability advocacy providers are to have regard to the interests and needs of people with disability generally, and to provide advocacy services to all people with disability.

All individual disability advocacy providers will develop transparent guidelines for prioritising intake and caseloads.

It is acknowledged that, while the predominant funded activity is individual advocacy, disability advocacy providers will undertake limited incidental or ancillary information and referral activities and activities associated with identifying and highlighting systemic issues.

5. Representative disability activity

Purpose

Representative disability activity is primarily conducted by an organisation focused on a defined cohort of people with specific disabilities, their families or carers. It seeks to promote and represent its members' views and interests and other people with similar disabilities.

Activities

Representative disability activity will include:

- engagement with members to ascertain views and priority issues
- liaison with, and contribution to the work of, systemic disability advocacy providers
- encourage peer and collaborative initiatives as appropriate
- provide information and referral activities for members, particularly in relation to accessing individual disability advocacy providers
- encourage self-advocacy of people with disability, families and carers as needed.

Key features

Funding will be provided by way of contract to a limited number of non-government, non-profit organisations whose majority membership is people with disability, their families or carers, where the disability is predominantly long-term and, if the disability arises from a disease, then there is a need to access disability services (disability representative organisations).

Such funding is in respect of the above representative disability activities and only forms a contribution to the overall income of such organisations. Disability representative organisations may provide additional funded or unfunded supports or services to their members and others.

Organisations who are contracted to provide systemic advocacy or individual advocacy under the DAFP will not be eligible for representative disability activity funding.

The DAFP should identify three funding levels available for disability representative organisations, having regard to such factors as the NSW population of people with specific disability represented by the representative organisation, the complexity of issues associated with such disability, and incapacity, size of the organisation and organisational need.

6. NSW disability advocacy – special purposes and projects

Purpose

Funding for special purposes and projects is designed to support community-operated initiatives to assist people with disability to actively engage in their communities in a more informed and empowered way, for which alternative funding sources are not available.

Key features

Funding will be provided to non-government, non-profit organisations through commissioning processes best suited to the particular special purpose or project.

Such funded projects may be specifically targeted to meet government priorities, identified special needs, or address issues not covered in alternative funding streams under the DAFP.

Funding may be short or medium term, with clearly identified objectives and outcomes.

7. The role of the Ageing and Disability Commissioner

There has been strong feedback from sector participants about the need to introduce greater oversight of any program for disability advocacy funding. While various options were canvassed, we are of the view that funding allocations and contract management should reside with the NSW Government, currently through DCJ.

However, there may be a role for an independent body, such as the Ageing and Disability Commissioner, to oversight the implementation of the recommendations of this Review and have an ongoing oversight role in relation to the establishment and performance of the DAFP and the performance the disability advocacy sector.

Such a function would be consistent with the Commissioner’s statutory obligation to monitor, assess and report on NSW’s implementation of the National Disability Strategy.

Operationalising the way forward

Funding

The Review has examined the current and historic funding arrangements, which are more fully detailed in Chapter 1. The current year budget allocation stands at $13 million for the NSW disability advocacy information and referral program, with just over $11 million in direct payments to advocacy/representative organisations.

This Review has considered the past financial arrangements as set out in Chapter 1 and the appendix. While there has been an increasing in funding into the sector in recent years much has come from NDIS IFP, which is not regarded as advocacy. by the NDIS nor sector. The Review concurs with this view. Nevertheless, there has been important funding from the NDIS ILC program and NDAP, which can be regarded as being related to advocacy ,including self advocacy, information and referral type activities. Acknowledging the on-going support by the NSW Government, the approach of this Review has been to look forward to what will be required to provide a robust advocacy system given reasonable assumptions about the NDIS ILC program and NDAP contributions. It has not looked at the viability of individual organisations as all organisation can and do access funding from multiple sources. The DAFP is not a vehicle to address viability rather it is a program to deliver advocacy and related services.

In assessing future funding requirements, the Review has identified current funding constraints and the likelihood for increasing demand for advocacy. Even without the proposed reforms, a continuation of current levels of funding would be required at a minimum.

However, to fully implement the reforms proposed by this Review, additional resources will be necessary, especially to fund the new Centre for Disability Advocacy Development and increase individual disability advocacy funding to provide better coverage and equity across disabilities and regions.

Given the fluidity in the NDAP and NDIS annual funding allocations, as noted above, it would be unsound to try to assess their likely impact on the financial viability of NSW disability advocacy providers. Nor is it sound to have a NSW scheme that is constantly shifting and responding to such annualised decisions.

The Review estimates that in the first full year of implementation of the new framework, the DAFP will need an annual budget of $15 million for direct allocation to disability advocacy organisations, including the new Centre for Disability Advocacy Development. A lesser allocation will jeopardise the success of the reform agenda.

This level, based on the Review's assumptions, should be the **new minimum baseline funding contribution** by the NSW Government to organisations under the DAFP, adjusted over time to reflect increasing real costs of service provision and identifiable demand. It does not include the additional direct costs of administering the scheme by the Government.

Assuming that implementation will occur over two years, we have formed the view that the NSW Government should provide a budget allocation of $13 million for 2020/21 and $14 million for 2021/22, with a full allocation of $15 million for 2022/23. This would be adjusted depending on the timetable for full implementation.

Subject to the implementation timetable, the current TAFS program should be extended to at least 30 June 2021.

Importantly, the Review has found that whatever the size of the funding pie, total DAFP funding should be based on the clearly identified allocations as set out below. It enables the Government to be clear about its funding priorities. It is vital to the transparency of the scheme that such allocations are clearly foreshadowed to the sector. It will also greatly enhance the ability of the Government to manage expectations, create a funding logic and allow for a strong foundation for the development of a commissioning process that engages with the sector.

We are strongly of the view that the individual advocacy funding stream should account for no less than 50% of the total allocation. The Review has not put forward proposed funding allocations within each funding stream. The Government will need to establish funding criteria for such allocations, preferably in consultation with the sector. And consequently not all contracts within a stream or category will necessarily be for equal amounts – having regard to the likely demand, coverage or complexity of delivering the proposed service.

There is one further issue for consideration – **that is the role of other mainstream government agencies in the funding of disability advocacy in NSW.** Much of the activities of disability advocacy providers relate to agencies responsible for Health, Education, Transport, and now within DCJ – Justice and Housing. This Review has not been able to fully assess their current funding contributions. However, there is a strong case for these agencies to contribute to an expanded disability advocacy funding pool, especially if there is a desire to extend the scope or coverage of the DAFP.

In particular, we have recommended that the type of representative organisations eligible to apply for representative disability activity funding should be restricted to a limited number of non-profit, non-government organisations, whose majority membership is largely people with disability or their families or carers, where the disability is predominantly long-term and, if the disability arises from a disease, then there is a need to access disability services.

If the Government wishes to expand the type of representational organisations eligible, say for more general disease based disabilities/illness, then the appropriate agencies, such as Health, should be required to make an additional contribution to the funds available for that disability advocacy funding stream.

There is a strong case for additional contributions by Health, Transport and Education to expand the funding pool beyond the proposed minimum baseline, given the very high level of engagement with these services by people with disability and their advocates. This can be done without creating conflicts of interest for disability advocacy/representative organisations.

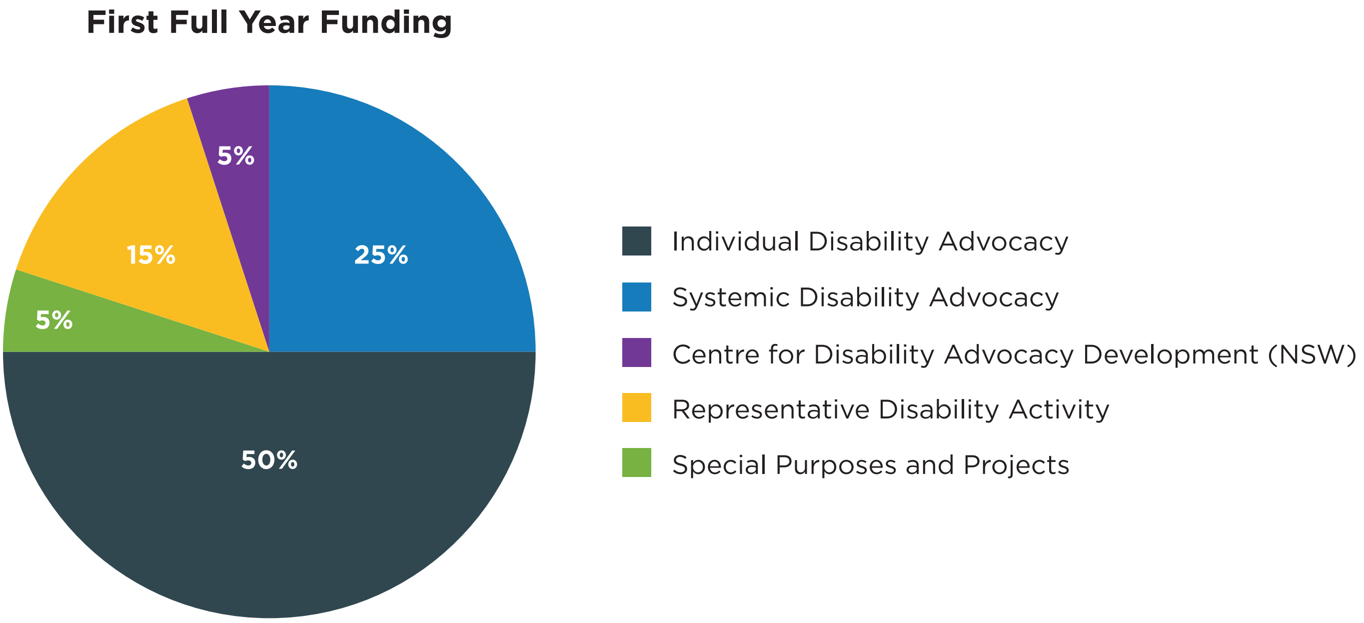
Irrespective, NSW mainstream agencies do have an obligation to ensure the voice, needs and interests of people with disability are formally recognised and funded.

Figure 14 shows proportional allocation of the NSW Disability Advocacy Futures Program by funding stream for the first full year of the Program's implementation.

Table 7 - Disability Advocacy Futures Program funding

Funding Stream	Allocation
Centre for Disability Advocacy Development	5%
Systemic Disability Advocacy	25%
Individual Disability Advocacy	50%
Representative Disability Activity	15%
Special Purposes and Projects	5%

Figure 14 - First full year of funding for Disability Advocacy Futures Program



Performance and outcomes

A Performance and Outcomes Reporting Framework should be developed and administered by DCJ. The framework should initially be aligned with the NDAP Outcomes Framework and DCJ Commissioning Framework, and modified during the commissioning processes as needed and preferably in consultation with the sector. Further future developments of this framework should be co-designed with the Disability Advocacy Network. DCJ should provide de-identified data and information collected under this framework to inform the ongoing work of the Centre for Disability Advocacy Development.

Performance and outcomes reporting should operate at several levels and for several purposes:

- At a **macro level** (for the DAFP as a whole and not for individual services or components/elements), to ensure outcomes identified in the NSW Outcomes Framework are advanced
- At a **program and sub-program level** (that is, elements as described in this chapter) to ensure outcomes as identified in the NDAP Framework (as adapted) are met
- At a **contracted service level**
    - to ensure service level outcomes are met, including, where relevant, NDAP outcomes (as adapted), but also client satisfaction and other agreed ‘quality’ outcomes
    - to enable services to monitor and compare their own performance for the purpose of service improvement
    - to allow for the gathering of (mostly) quantitative data for the purposes of building and tracking over time an accurate picture of what is being provided, where and for whom.

Performance measurement principles

The Performance and Outcomes Reporting Framework should be based on the following principles:

- While accountability is important, outcomes and other reporting as described above should serve the interests of clients, services and the community, and hence, as far as possible, should be conducted collaboratively and constructively.
- Data collection and reporting should be kept to an absolute minimum, consistent with meeting the needs and purposes described above, particularly where smaller services are involved.
- The resources required to collect and report data for these purposes should be factored into relevant budgets and funding, and the Centre’s role should be maximised as a way of reducing the time and effort of individual services.

Examples of indicators

Apart from **quantitative data** on numbers, issues (including source, such as school, department, employer, and landlord), location, characteristics of clients, and advocacy inputs, **outcome indicators** will include:

For **individual advocacy:**

- Changed impact of immediate crisis for individuals – outcome goals met (partly/fully)
- Changed skills or capacity to deal with problems in future
- Satisfaction with the (advocacy) service received – timeliness, courtesy, dignity, culturally appropriateness.

For **systemic advocacy**:

- Changed impact of systemic issue on represented cohort – outcomes goals met (partly/fully)
- Relevant ‘system’ better informed about and responsive to the needs of people with disability
- Issue informed by the views and lived experience of people with disability.

For **representative advocacy** – similar to systemic advocacy, but will include:

- Improved information and support for people with disability and their families/carers to enhance community inclusion
- Improved engagement of people with disability and their families/carers in informing and responding to issues
- Improved community awareness of issues affecting the lives of people with disability
- Engagement with systemic advocacy organisations, reflecting the views of members.

Commissioning

There are many matters that arise in relation to the change process that is required to shift to new contracting and organisational arrangements.

This Review is confident that the DCJ Commissioning Framework is the most suitable framework for implementing the NSW Disability Advocacy Futures Program, as it is client-centric and aims to achieve the best possible long term outcomes for clients in the most efficient, effective and sustainable way.

The DCJ Commissioning Principles have five basic elements – client centric, outcomes-based, value for money, integrated and evidence-informed – all relevant for the effective implementation of the proposed disability advocacy reforms.

The Commissioning process should:

- Have regard to the interests and needs of people with disability generally, including from diverse communities – including all ages, genders, sexual orientation, Indigenous people, culturally and linguistically diverse groups and those who live in regional and remote communities
- Engage with the disability advocacy providers and local communities, including Indigenous and CALD communities, to improve the local supply and quality of advocacy services delivered by funded providers
- Be committed to building capacity, sustainability and viability of the NSW Disability Advocacy Futures Program (DAFP) and disability advocacy services.
- Commission organisations that can demonstrate their commitment to upholding and promoting the rights of people with disability.

In respect of the proposed funding streams under the DAFP, the contractual funding arrangements should permit the funded organisation to manage the contract in a flexible manner, including the development of consortia, sub-contracts, partnerships or other appropriate mechanisms. Without limiting these approaches, any approach must maintain the integrity of the contract, with the primary contracted organisation being responsible for the delivery of the contract obligations, including meeting the performance and outcomes measures.

One critical factor in the effectiveness of the proposed funding reforms will be **greater certainty through extended contract terms**. The Review identified this issue as one of the most important, in order to address high levels of uncertainty both for organisations and their personnel. Greater certainty also supports longer term innovation, practice improvement and investment.

Consequently, the Review proposes under the DAFP that:

- The Centre for Disability Advocacy Development, systemic disability advocacy and individual disability advocacy have an **initial contract term for three years**. Subsequent contracts should be for five years' duration.
- Representative disability activities have a **contract term of three years.**
- Special purposes and projects initiatives have **contracts determined individually** with regard to the specific proposal.

A second critical factor will be the specific matters in the contract with each funded service. The new service delivery requirements may require major changes from past practice for successful organisations.

Transitioning and timing

The implementation of the reforms and the establishment of the DAFP should be completed by the start of the 2022/23 financial year at the latest. The NSW Government should establish an implementation taskforce or working group of government and sector experts to guide the establishment and implementation of the proposed reforms.

Subject to Government acceptance of the Review’s findings and recommendations prior to 30 June 2020, the establishment arrangements for the Centre and for the systemic disability advocacy and representative disability activities funding streams, should be achieved within 2020/21 so new funding arrangements will be in place for the following year.

Arrangements for the provision of individual disability advocacy, especially the appointment of regional disability advocacy providers, might need additional time during 2021/22 to be fully operational in the next financial year 2022/23. Should this be the case, some transitional funding may be required for organisations predominantly engaged in individual advocacy and who may be existing recipients of TAFS funding.

The Review is also mindful that some ILC funding currently received by TAFS-funded organisations will cease in June 2020; some in June 2021.

Appendix 1: Issues Paper

Ageing and Disability Commission

NSW Disability Advocacy Review[1]
Issues Paper

9 September 2019

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[1] The full title and scope of this Review is of "funding arrangements for independent specialist advocacy, information and representative organisations for people with disability in NSW" (see Commissioner's foreword)

Contents

NSW Ageing and Disability Commissioner's Foreword

Thank you for taking the time to read this important issues paper.

I was appointed as NSW's first Ageing and Disability Commissioner on 1 July 2019 under the (NSW) Ageing and Disability Commissioner Act 2019 (the Act).

The NSW Disability Advocacy Review (the Review) provides an opportunity to look at how advocacy funding and services are delivered and to make recommendations for any future NSW advocacy funding arrangements.

This issues paper is the beginning of a dialogue with people with disability and the organisations that support them to help us achieve these tasks. Everyone is invited to respond.

My scope

Under Section 26 of the Act, by 31 December 2019, I am required to:

- Prepare a report in relation to the funding arrangements for independent specialist advocacy, information and representative organisations for people with disability in NSW. In preparing this report I must take in to account any funding provided by the Commonwealth, under the *National Disability Insurance Scheme Act 2013* to independent specialist advocacy, information and representative organisations for people with disability in NSW,
- Consult with independent specialist advocacy, information and representative organisations for people with a disability NSW in relation to the report,
- Provide the report to Parliament.

In addition, the Act ensures that I am independent and not subject to Ministerial direction and control in exercising my functions.

For people with disability, advocacy is an important element in protecting and promoting their rights and enables people with disability to access appropriate supports and services, as well as to determine what is in their own best interest. In addition, advocacy can inform systemic responses to the needs and aspirations of people with a disability.

Advocacy services should be appropriately resourced to deliver responsive, timely, competent supports and services. In NSW, advocacy services are delivered by non-government agencies funded by a mix of Commonwealth and State funding arrangements, including some performance indicators to support ongoing funding of any non-government agency.

Key areas we need to explore include:

- What are the advocacy needs of people with disability and what are the types of advocacy services needed (a taxonomy or classification)?
- What are different approaches to developing a service system to deliver advocacy services?
- What resources (training, information, workforce, financial) are needed and what is the best way to deliver such resources?
- How do we measure the outcomes and impacts of advocacy services?

This Review covers advocacy, information, referral and representational services for all people with disability including - people with physical disability, intellectual disability, and psychosocial disability (other than in relation to clinical services), adults and children. It acknowledges that advocacy delivered by funded services is only part of the advocacy activity needed and currently received by people in NSW.

On 30 August 2019, I announced that I had appointed WestWood Spice to assist me in the conduct of the NSW Disability Advocacy Review and to facilitate the consultations as part of the Review process, including this issues paper and analysis of submissions.

This issues paper is available for comment on our website for a six week period. You can provide comment via email (commissioner@adc.nsw.gov.au) or by mail to PO BOX, 40, Parramatta NSW 2124. Brief comments can also be made by calling (02) 4904 7500 (Monday to Friday, 9-5PM). Submissions will close Friday 18th October at 5PM.

For more information on how to submit comments on this consultation, and my role, please visit: www.ageingandisabilitycommission.nsw.gov.au

Robert Fitzgerald AM
NSW Ageing and Disability Commissioner

The changing landscape of disability services in NSW

NSW's transition to the National Disability Insurance Scheme (NDIS) started with the Hunter trial in 2013/14 and continued with the early roll-out to children and young people in the Nepean Blue Mountains region in 2015/16. The remainder of the NSW transition took place during 2016/17 and 2017/18; and full scheme roll-out was achieved in 2018/19.

By the end of June 2019 there were almost 110,000 people with access to the NDIS in NSW, with $12.7 billion committed in participant plans and $8.9 billion actually paid to date.

The NDIS is projected to support up to 140,000 people with disability in NSW with individual support plans. However, the Information, Linkages and Capacity Building (ILC) component of the NDIS is intended to support a broader disability population. To support this latter commitment, NSW Government funding for specialist disability services was transferred to the NDIS, and in 2019/20 this amounted to $3.3 billion.

Under the NSW Disability Inclusion Act 2014, NSW Government agencies continue to have a role to create a more inclusive community in which mainstream services and community facilities are accessible to people with disability to help them achieve their full potential. This includes ensuring that the voices of people with disability are heard when the Government makes decisions about supports and services that affect them – either as people with disability specifically, or as part of the broader NSW community.

The NSW Government recognised the important role of advocacy, and committed additional funding of up to $26M for advocacy services until June 2020 to support access to these services during the early stages of the full NDIS scheme.

Concurrent with NSW advocacy funding and in view of the maturing NDIS ILC landscape, the Commonwealth is reviewing the National Disability Advocacy Program and related programs. All of this is against the backdrop of:

- The Commonwealth's current review of the National Disability Strategy,
- The Productivity Commission's recommendations for the future of the National Disability Agreement published in February 2019, and
- The NSW government's current review of the Disability Inclusion Act 2014.

Decisions regarding future funding for advocacy organisations in NSW will need to be made in the context of the broader policy process and the changed and maturing service system landscape. NSW decision making will necessarily include consideration of the funding provided by the Commonwealth for information and advocacy services, including ILC funding under the NDIS Act.

Some principles that could be applied when considering review of disability advocacy in NSW

In conducting this Review, key principles should be developed that could underpin the Review recommendations, and the future shape of any disability advocacy services program. Some suggested principles that could be applicable are as follows:

Advocacy is an important element in:

- Protecting and promoting the rights of people with disability.
- Enabling people with disability to determine what is in their own best interest.
- Enabling people with disability to access appropriate supports and services.
- Informing systemic responses to the needs and aspirations of people with disability.
- Enabling people with disability take part in public debate and government decision-making that affects them.

Advocacy service providers:

- Should be resourced to deliver responsive, timely, competent supports and services.
- Should be resourced to support their capacity to adapt to changing service system demands.
- Should be able to demonstrate the outcomes and impacts of their services.

Questions

Are these the right principles to apply?

Are there any others?

Patterns of need for people with disability in NSW

The 2015 Survey of Disability, Ageing and Carers (SDAC) estimates that there are 1.4 million people in NSW with disability. Of these, approximately 140,000 are expected to be covered by the NDIS individual funding packages.

The Department of Communities and Justice (DCJ) has engaged consultancy firm PwC to analyse publicly available information contained within the 2015 SDAC and other sources to stratify the NSW population with disability. This may include age, gender, Indigenous or CALD status, functional impairment, reported long term health condition, geographical location or living conditions.

This information will be used to help define a number of homogenous ‘need groups’.

Where possible, PwC will carry out comparisons with broader national results, prior SDAC or publicly available NDIS information to assess the reasonableness of the results and refine splitting criteria.

The results of this work will have broader use than this Review and hence it is a discrete DCJ administered project. It is the expectation that the preliminary results of this work will be available to inform the consultation sessions in October 2019.

Questions

Are there changing patterns of need that should inform the future provision of advocacy services; for example, emerging disability related conditions, changing circumstances giving rise to new or different needs?

What areas of focus, mechanisms and kinds of activities come under the broad heading of ‘advocacy’?

The term ‘advocacy’ is very broad. It can be used in different ways and can mean different things to different people. To ensure there is a shared understanding of the focus areas, mechanisms and activities we are talking about, it is helpful to develop a taxonomy (or classification) of these focus areas, mechanisms and activities of ‘advocacy’, as well as the different kinds of services that provide them.

The National Disability Advocacy Program defines some of the disability advocacy elements like this[2]:

- **Self-advocacy:** supports people with disability to advocate for themselves, or as a group.
- **Individual advocacy:** upholds the rights of individual people with disability by working on discrimination, abuse and neglect.
- **Legal advocacy:** upholds the rights and interests of individual people with disability by addressing the legal aspects of discrimination, abuse and neglect.
- **Systemic advocacy:** seeks to remove barriers and address discrimination to ensure the rights of people with disability.

We have attempted a ‘first cut’ taxonomy of the generally accepted areas, mechanisms and activities of advocacy, each usually relating to particular cohorts of people with disability.

Advocacy categories could include the following:

- **Information and referral** – the provision of information, sometimes accompanied by advice, and referral for people with disability to help them understand their rights and find and understand the services and supports they need to participate in community life.
- **Individual advocacy** - acting, speaking or writing to promote, protect and defend the rights of a particular person with disability. Mechanisms may include:
    - **Self-advocacy** - where an individual speaks/acts for themselves, sometimes with assistance;
    - **Supported advocacy** (commonly called *‘individual advocacy’*) - where an individual speaks/acts for themselves, sometimes with assistance;
    - **Legal advocacy** - a form of supported advocacy, but specifically in relation to legal matters and rights.

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[2] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap

- **Systemic/Group/Representative advocacy** – acting, speaking or writing (including campaigning and submission-writing) on behalf of a group of individual people with disability, a category of people with disability with a common cause, grievance or purpose, or on behalf of all people with disability. Mechanisms may include:
    - Systemic/common purpose advocacy, where a “system” is believed to require changing or improving in the way it impacts some or all people with disability. The “system” may be the way services are delivered to people with disability, the way people or organisations behave (e.g. Police, or Centrelink) or the way a particular law affects such people;
    - Policy influence, where a government policy is believed require changing or improving in the way it impacts some or all people with disability;
    - Sector development, where the “sector” that organises, serves and supports people with disability is believed to warrant improvement.

The above types of advocacy can be applied across different cohorts of people with disability (physical, intellectual, psychosocial), families and carers, adults and children, and people with specific characteristics including CALD, LGBTI, Indigenous and those who live in regional areas.

Provision of disability advocacy is not confined to disability advocacy organisations; nor is it always funded. Citizens, family, carers, peers, peak bodies and representative organisations for all or a defined group of people with disability may all provide or assist with advocacy activities alongside the activities of organisations specifically funded to provide disability advocacy.

In each of these advocacy focus areas, there are particular activities that can be identified and employed. The figure below shows three main focus area and the mechanisms that apply to each. The mechanisms may apply to different cohorts, perhaps in different ways, and each will involve a range of activities. “Activities” are discussed further in the next section.

Advocacy

Information and Referral			**Individual Advocacy**			**Systemic / Group / Representative Advocacy**		
INFORMATION	ADVICE	REFERRAL	SELF	SUPPORTED	LEGAL	SYSTEMIC	POLICY	SECTOR DEV
Cohorts Activities	Cohorts Activities	Cohorts Activities	Cohorts Activities	Cohorts Activities	Cohorts Activities	Cohorts Activities	Cohorts Activities	Cohorts Activities

Questions

Is it important to distinguish between different advocacy focus areas (e.g. information and referral, individual advocacy, group/systemic/representative advocacy) and different advocacy mechanisms (e.g. self-advocacy, campaigns, skills training, resource development).

Should any of the above focus area categories or definitions be added to or changed?

How important do you think it is that a NSW disability advocacy framework aligns with disability advocacy frameworks in other States/ Territories and nationally?

What activities are involved in carrying out different categories of advocacy?

We are also interested in identifying the activities that sit under each of these focus areas and mechanisms. For example:

- **Self-advocacy** may include supported decision-making, undertaking research, making phone calls, attending meetings, writing emails, and training.
- **Supported (individual) advocacy** activities may include undertaking research, making phone calls, attending meetings, writing emails.
- **Legal advocacy** activities may include research, writing briefs of evidence, considering legal precedent, making a legal claim.
- **Systemic advocacy** activities may include research, sitting on advisory groups, responding to inquiries and issues papers, conducting campaigns.
- **Policy influence** activities may include conducting research, writing submissions, attending meetings, sitting on advisory groups, responding to inquiries and issues papers, conducting campaigns.
- **Sector development** activities may include conducting research, writing submissions, attending meetings, sitting on advisory groups, responding to inquiries and issues papers, conducting campaigns.

Clearly these mechanisms and the activities involved can over-lap.

A matrix of those activities might look like this:

	Self	Supported/ Individual	Legal	Systemic	Policy Influence	Sector Development
Writing emails	X	X	X	X	X	X
Conducting research	X	X	X	X	X	X
Collecting data	X	X	X	X	X	X
Sitting on advisory boards				X	X	X
Supported decision-making	X	X				
Attending meetings (external)	X	X	X	X	X	X
Responding to Government inquiries			X	X	X	X
Writing briefs of evidence			X			
Participating in training	X	X	X	X	X	
Training other people	X	X	X	X	X	X
Developing education/ awareness resources		X	X	X	X	X
Speaking to the media	X	X	X	X	X	X
Designing campaigns				X	X	
(Other?)						

Questions

What other activities occur as part of effective advocacy within each advocacy mechanism?

Is this a useful approach to analyzing advocacy?

What outcomes do we hope to achieve with these services?

We also want to identify a good way to measure the outcomes of the various types of advocacy. Outcomes reporting assists governments to make better and more evidence-based decisions about where to expend money to do the most good. For example:

- **NSW Government** budgets and reports its data for all government programs and services according to outcomes, including social welfare. It measures how success is tracked and how citizens will be kept informed throughout delivery. It ensures that all government funded supports and services provide demonstrable value for money. "Value for money" includes activities that deliver clear community benefit that aligns with government policies or programs[4].
- **Productivity Commission Report into NDIS** costs (2017) recommended that "data collection and evaluation of disability advocacy be increased".[5]
- **National Disability Advocacy Program (NDAP)** also requires regular reporting. NDAP agencies must provide information annually to the Disability Services Data Collection conducted by the Commonwealth Department of Social Security (DSS)[6].
- **Victorian Government** identified that it is important to be able to measure disability advocacy outcomes in order to build capacity in the sector[7]. In Victoria, funded advocacy services report quarterly to the Disability Advocacy Resource Unit (DARU)[8].

Victoria's experience: Improving measurement of performance and outcomes.

In 2015, the Victorian Government conducted a program review of disability advocacy services. The review identified opportunities to build the program's capacity by:

- Developing clearer performance measures and targets and better ways to identify demand and measure outcomes.
- Simplifying reporting, monitoring and quality assurance processes. This includes aligning these to the National Disability Advocacy Program where possible.
- Reviewing the way targets are measured.
- Standardising the way outcomes are measured.
- Improving information sharing between advocacy services and using individual advocacy reporting to inform the work of the sector and government.

[4] https://www.budget.nsw.gov.au/outcome-budgeting

[5] https://www.procurepoint.nsw.gov.au/policy-and-reform/nsw-government-procurement-information/statement-value-money pp39-40

[6] NDAP Operational Guidelines https://www.dss.gov.au/sites/default/files/documents/03_2018/ndap_operational_guidelines_february_2018.docx Information about the Disability Services Census and a Data Guide for disability advocacy agencies is available here: https://www.dss.gov.au/disability-and-carers/programs-services/for-service-providers/disability-services-data-collection-2016-17. Disability services Data Guide: https://www.dss.gov.au/sites/default/files/documents/07_2019/dsdc-2018-19-data-guide-disability-service-providerstext-changes.pdf

[7] https://providers.dhhs.vic.gov.au/sites/default/files/2017-07/Victorian-Disability-Advocacy-Program-summary-review_0.docx

[8] https://www.daru.org.au/

Questions

How could NSW best measure the outcomes of advocacy organisations?

How frequently should outcomes be reported?

How should outcomes reporting use the same indicators as the NDAP? (See: https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/national-disability-advocacy-program/national-standards-for-disability-services-indicators-of-practice-and-examples-of-evidence-for-ndap-agencies)

Should advocacy reporting only cover outcomes of funded advocacy? Or should it include broader non-funded disability advocacy?

What assists or prevents advocacy organisations from measuring their outcomes?

Does the Victorian report provide some helpful ideas for NSW too? If so, what should NSW concentrate on in measuring outcomes of disability advocacy?

How could NSW best measure the outcomes of advocacy organisations?

Should the findings of the Victorian review of disability advocacy services (see table above) also form part of a NSW Disability Advocacy Framework?

What factors should inform the development of a new system for the provision of funded advocacy services in NSW?

The current advocacy service system comprises a large number of different kinds of organisations directly funded by NDIA[9], Commonwealth and/or State Governments. The system is historical in nature and includes both statewide to regionalised bodies.

It is important in designing a NSW advocacy service system for the next decade that the most effective system is developed to maximise benefits for people with disability and represent good value to the broader NSW community. Government funded service delivery models have evolved over time from direct grant-based funding, competitively tendered fee for service agreements and outcomes-based funding and, from time-to-time, project funding.

The models of delivering services have also evolved. There are some lead agency models with a main funded provider with multiple subcontracted delivery agencies. There are also models that promote service integration covering a broad range of services to a wide cohort of clients. Funding continues for highly specialised services with a limited range of services meeting the needs of identified cohorts of clients.

There is a debate and question about whether advocacy services should be independent from the disability support system, and even the ILC funded services, in order for them to freely perform their work effectively.

A further consideration is the extent to which new technologies can be used to provide advocacy supports and what is an appropriate approach/mix to providing face to face supports, compared to telephone and internet methods.

Questions

What factors should help guide the design of an advocacy service system to meet the future needs of people with disability?

What are the advantages or disadvantages of integrating funded advocacy with service support provision?

Should funded advocacy should be directed towards broader or more specific cohorts?

What level of independence from the disability support system should advocacy organisations have in order to be eligible to be funded?

What are the advantages and disadvantages of alternative funding arrangements?

What are factors to be considered in seeking to provide services to meet the needs of special communities like regional and remote communities, CALD, LGBTI and indigenous people with disability?

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[9] While the NDIA does fund information, it is explicit that it does not fund advocacy.

Are there technological advances that can be leveraged to help provide advocacy services to people with disability?

What resources are required for effective and efficient system provision of funded advocacy services in NSW?

The nature and extent of future resourcing for a disability advocacy service system to meet the needs of people with disability in NSW over the next decade is an important aspect of this Review. Much will depend on the responses to previous questions set out in this issues paper and the demographic study being conducted to inform this Review. Resources are not only financial. Resources include a competent and sufficient workforce, training and skills development, organisational and sector capacity.
How such resources are utilized as well as their quantum are important issues to be considered.

Questions

What types of advocacy resources will be required to meet future demand?

What are the most significant resource deficiencies in the current disability advocacy service system?

Which level of government, Commonwealth or State, should be responsible for the funding or provision of the different types of resources identified?

What is the role of peak bodies in delivering any of the needed resources to the rest of the sector?

Are there specific resource requirements to enable self-advocacy supports or services to be more widely available?

Are there capacity-building resources that advocacy services require to support their sustainability?

What are the sources of funding?

One of the outcomes of the Ageing and Disability Commissioner's report to NSW Parliament will be that we will have a better idea of what types of advocacy are needed and where funding needs to be directed to ensure that advocacy is available for the people who need it. This includes the different advocacy mechanisms and activities required to meet identified or identifiable needs.

Both the NSW and Commonwealth governments fund disability advocacy. We need to work out the responsibilities of each so we can identify any gaps in the service system and ensure that funding is going to where it is needed.

NSW Government funding for disability advocacy

Prior to the introduction of the NDIS, the NSW Government funded various organisations to provide information, advocacy, and referral services and as peak bodies.

This funding was transferred to the Commonwealth as part of the NDIS transition. However, because there were still some gaps in the provision of advocacy services, the NSW Government committed to funding the Transitional Advocacy Funding Supplement (TAFS) for an additional two years.

Under TAFS, the NSW Government funds 39 organisations to deliver specialist disability advocacy, information and referral services. Some are also funded as disability representative organisations in their own right.

The NDIS and other Commonwealth-funded disability advocacy in NSW

People funded under the NDIS can receive support co-ordination and decision-support services as part of their NDIS plan, but advocacy itself is explicitly excluded.

The Information, Linkages and Capacity Building (ILC) program of the NDIS also supports information and referral services for all people with disability, regardless of whether they are NDIS participants. To date, all ILC funding has been project funding rather than ongoing.

The National Disability Advocacy Program (NDAP) provides some people with disability with access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation.

A number of reviews of the NDIS and other Commonwealth disability policies have also made recommendations about the value of independent advocacy services and how we can better understand and administer funding for disability advocacy.

National Disability Agreement Review 2019

The Productivity Commission review of the National Disability Agreement found that the Commonwealth and States and Territories have not made an agreement about who funds which types of advocacy funding. This means that advocacy funding is not coordinated, and some people may miss out on what they need.

The report recommended that:

> *A gap analysis — which involves identifying community needs and government objectives and assessing them against the services that are available or planned — would help governments identify where service gaps exist. It would also provide guidance as to where roles and responsibilities need to be further clarified in the new National Disability Agreement.*[10]

Productivity Commission 2017 Report into NDIS costs

The Productivity Commission also made recommendations about measuring the outcomes of advocacy services in its Report into NDIS costs:

> *The Australian, State and Territory Governments should also collect data from funded disability advocacy organisations about people with disability who use their services, and their outcomes. (p60).*[11]

Collecting reliable data that shows how people use the advocacy services will show us how advocacy outcomes are changing, allowing us to predict what services people need and calculate what funding is needed to support that.

A Cost Benefit Analysis of Australian independent disability advocacy agencies

In 2017, Professor Anne Daly and her team performed a cost-benefit analysis on independent disability advocacy agencies funded under the National Disability Advocacy Program.

They found each dollar spent on independent disability advocacy saves government $3.50, making disability advocacy “a highly effective use of resources”. [12]
We know there is value in disability advocacy. This consultation will provide information to allow us to make recommendations that will ensure that independent disability advocacy in NSW is targeted to where it can do the most good.

Questions

In what ways can the roles and responsibilities of the Australian, State and Territory Governments be better apportioned or clarified?

Are there innovative, ‘new thinking’ approaches that the ADC should be considering in his report to government?

Thank you for sharing your thoughts.

Please note that all submissions will be treated as public, unless otherwise advised. If you wish for your submission to be treated as confidential, please clearly identify this when you send through your submission.

To send your comments, please:

- **Email** your comments in this document (or if preferred in a separate document) to commissioner@adc.nsw.gov.au, or
- **Post** your comments to PO BOX, 40, Parramatta NSW 2124.

Brief comments only can be made by **calling the Commission** (02) 4904 7500.

For any questions relating to this paper, please contact the Commission
(02) 4904 7500.

Submissions can be made until **Friday 18th October, 5PM**.

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[10] https://www.pc.gov.au/inquiries/completed/disability-agreement/report/disability-agreement.pdf p.33
[11] https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf
[12] https://www.dana.org.au/wp-content/uploads/documents/Disability-advocacy-CBA-2.pdf p.144

Appendix 2: Submissions

The Issues Paper encouraged multiple forms of engagement in the Review process. This Appendix notes input through three different channels:

- Submissions received to the Issues Paper
- Emails received by the Commission
- Phone messages received by the Commission

Some of the individual submissions were from people with lived experience of disability as were many of the emails and the majority of the phone messages. See also Appendix 4 for further details about input to the Review provided specifically from people with lived experience of disability.

Written submissions

In response to the issue paper, 44 submissions were received from both individuals (11) and from a range of organisations (33, noted at Table 7). Table 7 also shows some of the profile characteristics of the organisations from whom submissions were received.

Many of the organisational submissions noted their effective advocacy work over many years as a preface to their specific comments about the Issues Paper. The submissions from individuals provided very valuable detail from a range of personal and policy perspectives.

Table 7: Submissions received from Organisations

	Receive TAFS	Receive NDAP funding	Receive DRO funding	Currently receiving ILC grant
ACTION for People with Disability	✓			
Albury City Council Access Advisory Committee				
Blind Citizens Australia	✓		✓	✓
Carers Advisory Council NSW				
Carers NSW				
CID Advocacy Group				
Council for Intellectual Disability (NSW)hy	✓			✓
Community Access Western Sydney	✓			
DeafBlind Association				
Department of Social Services				
Disability Advocacy Alliance				
Disability Advocacy NSW	✓	✓		✓

	Receive TAFS	Receive NDAP funding	Receive DRO funding	Currently receiving ILC grant
Down Syndrome NSW				
Ethnic Community Services Co-operative	✓			✓
Family Advocacy		✓		✓
IDEAS	✓			
Legal Aid				
Mental Health Coordinating Council				
Mental Health Commission of NSW				
Multicultural Disability Advocacy Association	✓	✓		✓
NCOSS				
National Disability Services				
Northern Sydney Regional Families and Friends of People With Disability				
NSW Trustee and Guardian				
PATH Inc.	✓			
Penrith Disabilities Resource Centre Inc	✓			
People With Disability Australia	✓	✓	✓	✓
Physical Disability Council of NSW	✓			✓
Radio for the Print Handicapped	✓			
Regional Disability Advocacy Service	✓	✓		✓
Spinal Cord Injuries Australia	✓	✓		✓
Vision Australia	✓			✓
Western Sydney Community Forum				

Emails

75 emails were received by the Commission by 13 November. Respondents included many people with lived experience of disability or their families, as well as direct service providers, health professionals and interested community members. Respondents' comments broadly covered the following matters:

- A single but strong message to retain funding for effective advocacy in NSW. These emails came from people with a disability, families and various health professionals in contact with people with disabilities and their families.
- A single but strong message to retain funding for one or other particular advocacy group in NSW. Conversely, one email urged the government not to fund a particular advocacy service.
- Descriptive information about the value of advocacy, often including lengthy examples. Some noted the interventional/ protective role of advocates; some noted the supportive/ developmental role of advocates.

- Extensive examples of the risk of abuse/ failure/ neglect in the current disability service system – with increased risks noted during periods of change as NDIS matures. This was linked to the need for increased advocacy
- Extensive examples of perceived problems with NDIS and LAC. This was linked to the need for increased advocacy.
- Response to a selection of key areas from the Issues Paper noting that advocacy provision cannot be homogenous; there is a need for a 'system' of advocacy – multi-faceted with a clear range of categories; need to raise awareness of advocacy; the importance of extensive and ongoing training; the importance of consistent data collection

Major Themes

A summary of comments arising from the Submissions is noted in the following pages across five themes. Many respondents noted how complex it is to achieve an effective advocacy system; they often provided suggestions accompanied by cautions.

Theme 1: The importance and the place of disability advocacy in NSW
Theme 2: Current and changing need for advocacy
Theme 3: Delivering disability advocacy in NSW
Theme 4: Performance measurement of disability advocacy in NSW
Theme 5: Features of a fit-for-purpose advocacy system in NSW

At the end of this Appendix we have provided additional commentary about advocacy in CALD communities and in Indigenous communities.

Theme 1: The importance and the place of disability advocacy in NSW

There was universal support for disability advocacy to continue to have a place in the disability landscape in NSW. Many submissions also emphasised the importance of disability advocacy for NSW to meet its national obligations and those of UN CRPD. There was also universal support for equitable access to advocacy.

A number of submissions referred to advocacy's role in safeguarding and prevention not just advocacy's role as a mechanism to manage crises and complaints. Some emphasised advocacy as a right rather than a privilege; some sought recognition of the importance of the carer or family voice – not replacing, but complementing, the voice of the person with disability.

There was general support for **principles to underpin an effective advocacy system** with some respondents suggesting amendments, new principles and/or separate principles for funding.

There were many, many examples of the role of disability advocacy in preventing problems, solving problems and creating fair opportunities. Examples spanned disability specific services and mainstream services.

Submissions from individuals tended to reinforce the importance of equitable access to mainstream services and also the importance of systemic advocacy … *it improves things for many people including those who will acquire disability in the future.*

Theme 2: Current and changing need for advocacy

Respondents described detailed and varied examples of need for disability advocacy including unmet need (particularly submissions from individuals). Some noted the need for advocacy for particular groups - older people with a disability not eligible for NDIS packages; people with degenerative conditions (noting they were not well-accommodated within the NDIS model); socially isolated people without the informal advocacy of family and friends; people from Aboriginal or particular cultural backgrounds; people in regional and remote areas.

Many respondents noted the immaturity of NDIS as an organisation and associated inconsistent decision-making processes, highlighting a **particular need for advocacy arising from the NDIS:**

- Growth in advocacy work related to NDIS processes – key points being eligibility/ getting access, development of NDIS plans/ reasonable funding package, review process for plans, assistance with appealable decisions.
- Growth in advocacy work for the 90% of people with disability in NSW who do not receive an IFP under NDIS[66], who still rely on mainstream government and other services to meet their everyday needs.
- Added load for carers arising from NDIS – spending increased time organising support[67] and often needing advocacy support.
- Underdevelopment of the disability service delivery sector resulting in long waitlists for therapy, allied health, interpreters – requiring advocacy and engagement with service providers including support coordinators.
- Lack of NDIS materials in appropriate communication formats e.g. simple plans, materials accessible by screen readers, easy language, alternative formats.

Other aspects of **current, changing and future need for advocacy** were noted:

- Views about the protective role of advocacy given the emergence of for-profit providers in disability, ageing and many mainstream services.
- Advocacy work supporting people with a disability engaging in the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability*. And commentary that recommendations arising from the Commission are likely to involve changes that will trigger need for advocacy.

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[66] See further commentary on data about people with disability in NSW in Appendix 7, NDIS provides support for around 10% of people with disability in NSW up to the age of 65. The other 90% or people with disability (which includes children, young people and older people) continue to rely on mainstream and specialist services most often delivered by NSW Government and its agencies Carers NSW (2018) Carers NSW 2018 Carer Survey: unpublished data

[67] Carers NSW (2018) Carers NSW 2018 Carer Survey: unpublished data

- The ageing of the Australian population – relevant matters being the increased incidence of disability with increased age; the increased longevity of people with disability themselves; the ageing of family carers of people with disability and reduction in their informal caring role.
- Changes to Australia's Humanitarian Program since July 2012, have meant that there are more refugee and humanitarian applicants with a disability arriving in Australia through the resettlement program.

Theme 3: Delivering disability advocacy in NSW

Submissions contained substantial comment about the nature of advocacy that NSW ***should*** provide and ***how to*** provide it. There were many **big-picture comments about disability advocacy** including:

- Disability advocacy exists along a spectrum of types and activities with overlap and flow-on effects; there is an interrelatedness of matters in the advocacy landscape. Advocacy is complex and often messy; it defies subdivision into discrete categories or focus areas.
- Broad support for the major groups of advocacy – individual and systemic, plus legal - but there was ***Caution*** to avoid over-complicating by too many sub-categories.
- Broad support for specialised services that provide support to specific groups (people with particular disabilities or people in particular cultural groups or geographic areas) but ***Caution*** to ensure equitable access for all before considering specialisation.
- The important role of 'unfunded advocacy' in a civil society and some reservation about the 'professionalisation' of advocacy, with others pointing out the need for a more professional approach for more specialised or complex issues.

Submissions contained many comments about **specific types of advocacy**

- In relation to **systemic advocacy**, respondents mentioned the need to differentiate where systemic issues affect many groups from systemic issues that are specific to particularly disability groups. There was also comment about the ongoing misapprehension that 'accessibility' often means only physical access. An emerging systemic issue is advocacy to ensure disaster preparedness.
- In relation to **individual advocacy** some respondents commented that ''supported advocacy'' is not well understood and best avoided as a term.
- There was strong support for specialised **disability legal advocacy**, as well as support for the role of disability advocacy in supporting legal advocacy – i.e. disability advocates attending court when the legal advocate is there, or helping to gather evidence.

- In relation to **information and referral** there were many references to information, often accompanied by advice and/or referral, as an **ancillary** input to all forms of advocacy; either as fundamental to effective decision-making; as 'soft' advocacy; as 'self-servicing' - and thus avoiding other forms of funded advocacy. Another set of comments noted the need for an ongoing, trusted, reliable information source which had clear policies and procedures around verification, storage, access, currency, updating. There was a general view that standalone provision of information and referral is the responsibility of the NDIS; but that the availability of information in NSW needs to be maintained by NSW until the NDIS establishes universal availability of information and referral.
- **Representative organisations** are seen as a 'voice' for members of their community; it takes time and resources to faithfully canvas views of all members; is ongoing, unlikely to come to an end. Additional comment included the role of DPOs in representational advocacy and the mutually supportive and beneficial roles played out between DPOs and independent advocacy organisations.
- Respondents commented that **peak organisations** often represent 'a sector' with members including service consumers, service providers and other stakeholders related to the 'sector'. ***Caution …*** the focus on the rights of the individual person with a disability may be difficult.
- In relation to **family advocacy**, there were many comments about the importance of the carer/ family voice – not replacing but complementing the voice of the person with disability. How can carer/ family role be included/ respected?
- There was minimal mention or support for **citizen advocacy**.
- The importance of **peer advocacy** was emphasised by specific organisations including Spinal Cord Injury Association, Mental Health Coordinating Council.
- A number of submissions noted the fundamental goal of building **self-advocacy** specifically. *Self-advocacy doesn't happen in a vacuum*.

Submissions included comment about **the role of technology in delivering disability advocacy** in NSW. In summary, there were multiple examples of helpful technologies which could assist organisational effectiveness if they were funded; and examples of technologies that could help particular groups. Most of these related to technological supports that assisted staff to be more efficient. Less were about easing the client/ advocate interface, where face-to-face contact was seen as important and most effective.

Theme 4: Performance measurement of disability advocacy in NSW

Compared with other matters in the Issues Paper, respondents had a great deal to say about performance measurement of disability advocacy in NSW. There were many **big-picture comments about performance measurement** including:

- Recognition that if you receive public funding, you expect to measure, evaluate and report; but there is a need for improvement in how disability advocacy is currently reported.
- Noting need for input, throughput **(quality, timeliness and satisfaction)** and output, but particularly **outcome** measurements.
- Measuring advocacy success through a 'next generational approach' – *Does the next generation have access to improved service and are all participants finding valued improvement reflecting change? Are there people falling through the cracks? If so, why? How do we respond?*
- Acknowledging the **complexity of measuring outcomes:**
  - long timeframes
  - need for consumer voice
  - subtlety of changes
  - limited control of people with a disability to influence outcomes – how reliant they are on the ability and willingness of other people to change
- Variable support for **measuring advocacy outcomes from both funded and non-funded** advocacy; where people supported it, there was a view that this would allow a better measurement of advocacy need currently not met by funded advocacy services.
- **Reporting frequency** varying from quarterly to every 2 years with recognition that reporting frequency may be different for different forms of performance measures.
- Support for **national alignment of performance measurement** with a number of respondents noting they deliver advocacy services cross-border.
- Strong support for the NDAP being used as a starting point but strong urging to link back to UN CRPD, plus adaptation for NSW, and improvement where purpose. ***Caution:*** *this Review provides for NSW to lead the other states rather than accept a framework agreed by the majority. Caution: national alignment should not be achieved at the expense of NSW which has unique historical, geographic, economic and social factors.*
- There was a strong view of the need to invest in a common **measurement and reporting system** rather than everyone building their own databases.

There were many ideas re **specific measures and indicators** noting importance of outcomes as well as inputs and throughputs. There were many views about the need for different measures for different advocacy types and need for clarity of indicator definitions. ***Caution:*** *avoid tickbox;* ***Caution:*** *don't compromise long term effort by only measuring short or medium term.* ***Caution:*** *Policy adherence might assist with understanding quality of service but this is not necessary the same as outcomes of advocacy; don't confuse quality assurance of the organisation with outcome measures of the work.* ***Caution:*** *Difference between accountability, evaluation, service improvement and straight forward identification of what's happening (or not happening) and for whom.*

Barriers to effective reporting include the load of reporting to different funders, multiple or poor technology platforms, lack of staff skills, cost of developing and hosting measurement systems.
There was **no real support for a list of advocacy activities**, noting that good advocates would identify, use and change their activities to meet needs, that flexibility is important; and that advocacy is a person-centred function rather than an activity-based function. There was ***Caution*** against conceiving effective advocacy as quantities of particular activities or reporting at a micro level.

Theme 5: Features of a fit-for-purpose advocacy system in NSW

There was a wealth of commentary about a 'better' system for disability advocacy in NSW, a 'fit for purpose' system. This commentary is summarised below under four headings:

- Advocacy design and delivery
- Funding
- Independence
- Coordination/ capacity-building of the sector

Advocacy Design and Delivery

There was general agreement about:

- Need for a **system** which has an overarching purpose of supporting people with disability to exercise their rights and voice, choice and control over their own lives.
- Need for **different forms of advocacy** as there is a complementarity between them.
- Need for some specialised advocacy for different types of disability and different cultural expectations as well as advocacy services that address issues across disability. ***Caution:*** Not all people in a 'specialist group' are homogenous.
- The importance of advocacy being person-centred, responsive.
- The importance of advocacy being locally delivered, having the ''feeling'' of a local service which is familiar with local conditions (regardless of whether it is managed from elsewhere).

- Need transitional period while recommendations from the Review are put in place.
- Need for **explicit** recognition of the role of advocacy in addressing issues within mainstream services.
- Need for consistent access points - *No wrong door* - with understanding of different types of advocacy at point of enquiry.
- Need for transparent expectations – including performance framework, associated measures and definitions; need a communication portal with state government.
- Need a communication, engagement and 'positioning' strategy for disability advocacy - awareness raising, breaking down stigma, developing positive community attitudes

Funding

There was overwhelming agreement that funding of NSW advocacy through NDIS IFPs is unworkable. In addition,

- Need for **reliable, long term, secure funding** – *there will always be people with a disability*. Short term-funding limits capacity to do things like retain or upskill staff, evaluate programs, develop inter-organisational relationships
- Need for **adequate funding at state level**, be based on need across NSW not a rationed supply
- Funding should be **equitable** with a priority on statewide access, fair and reasonable geographic coverage. If this is met, then consideration should be given to specialist advocacy streams (for different disability cohorts, different cultural backgrounds)
- Need for **adequate funding at the organisational level**, sufficient to support matters like staff training, administration including reporting, real cost of delivering in regional and rural areas, marketing, management committee support, collaboration, sharing, capacity building

There were some views that **management of disability advocacy funding in NSW** should be managed outside of the government area that manages disability programs e.g. should be managed by PMC or ADC.

There were differing views about **sources of advocacy funding** with recognition of Commonwealth role as well as state government (because latter are closer to local needs). A number of respondents suggested that mainstream NSW government services should fund the input of people with a disability to meet NSW mainstream legislative obligations, not expect advocacy to fund that. There was a view that State government needs to step in at least until Commonwealth advocacy is clear and universal.

Other matters related to the **broader funding environment** included need for sufficient translators and interpreters to work with advocates especially when working on complex matters involving technical language.

Independence

There was strong, but not unanimous, support for advocacy being independent of service provision. Some particularly mentioned the importance of separating provision of advocacy from provision of ‘core supports’ under the NDIS and/or from ‘support co-ordination’ under the NDIS.

Other submissions noted the ‘sense’ that was made (from client perspective) by having direct service provision and advocacy from the one agency; these views tended to be held by organisations working in areas where the commonality of language was important (e.g. CALD communities, Deaf community) or where self-advocacy was strong e.g. Spinal Cord Injuries, Deaf Society.

Regardless of diverse views, there was strong support for organisations to have clear and transparent processes for managing perceived or real conflicts of interest.

> We can’t refer their clients on because they won’t go – they want to stay within their own community with organisations they know.
>
> Submission to the Review

Coordination/ capacity building of the sector

Respondents are seeking a means to unite the sector more closely and build its capacity to better deliver. In particular, mention was made of:

- **Building skills and capabilities of advocacy staff** - qualifications, skills in the right mix, cultural competencies.
- **Sharing learning across the sector** –e.g. sharing how/why a systemic campaign was successful; sharing documents and resources.
- **Growing advocacy leadership**
- **A means to engage with** State government.

Specific commentary about Culturally and Linguistically Diverse Communities

First, it is salutary to recognise that one in four Australians were born overseas, and there is no reason to believe this is different in the disability community. In fact, with refugees, it may be significantly higher, and under current arrangements, many refugees are required to move to regional areas.

Much of the commentary by CALD advocacy organisations was consistent with the general commentary noted above.

Exclusion is seen as the biggest issue for CALD people with disabilities: *"social exclusion is a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities available to the majority of the people in society, whether in economic, social, cultural, or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole[68]"*.

Many people with disability from CALD backgrounds are subject to a "triple whammy" of social exclusion where their disability, culture and language may all limit their capacity to engage; and this may be exacerbated where there is ignorance or active discrimination at play.

"The factors that would help to guide the design of an advocacy service system to meet the future needs of people with disability from CALD backgrounds include:

- *Bilingual workforce*
- *Free access to interpreting services*
- *Information translated or written in easy English*
- *Community outreach to identify hidden people with disability from CALD backgrounds*
- *'Cultural Competency' and 'Working Effectively with Interpreters' training for disability service providers*
- *Monitoring mechanism to see that service providers are meeting needs of CALD clients as per the demographic data in their working regions."*[69]

Hence, and not surprisingly, there is strong support for specialist services for these communities, to provide both individual and systemic advocacy. Also, it was pointed out that CALD advocacy services may be more likely to provide other support services, leading to potential conflicts of interest. Appropriate measures/policies are required to avoid such conflicts where advocacy was required directly in relation to a service provided by the same organisation.

Specific commentary about Indigenous communities

The First Nations Disability Network Australia (FNDN) is the primary body representing and advocating for the interests of Aboriginal and Torres Strait Islander people with disability, their families and communities in Australia and internationally. It is owned and governed by First Peoples with lived experience of disability. The Aboriginal Disability Network NSW has merged with FNDP.

FNDN receives its funding from a range of sources; private and government. It receives no NDAP funding for individual advocacy from either the Commonwealth or the NSW government. It receives TAFS funding from the NSW government for sector development and (recently) from NDAP for the Disability Royal Commission.

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[68] Levitas, R., Pantazis, C., Fahmy, E., Gordon, D., Lloyd, E & Patsios, D. (2007). The multi-dimensional analysis of social exclusion. Bristol Institute for Public Affairs, University of Bristol. Pg. 6, quoted at P3 of the submission of Multicultural Disability Advocacy Association of NSW In

[69] P9, submission of Ethnic Community Services Cooperative

Materials provided by FNDP made the following points:

- Census data show that at least 50% of all Aboriginal and Torres Strait Islander people have some form of disability or long-term health condition. This equates to approximately 130,000 people in NSW today, of whom around a quarter live in the Sydney region (2016 Census).
- The high prevalence of disability, approximately twice that of the non-indigenous population, occurs in Aboriginal and Torres Strait Islander communities for a range of social reasons, including poor health care, poor nutrition, exposure to violence and psychological trauma (e.g. arising from removal from family and community) and substance abuse, as well as the breakdown of traditional community structures in some areas.
- The number of Aboriginal and Torres Strait Islander people with disabilities accessing individual advocacy services is very small, primarily because many Aboriginal and Torres Strait Islander people with disabilities simply do not identify as people with disabilities. This occurs for a range of social and cultural reasons including:
    - (in FPDN's words) *"Why take on another perceived negative label"*
    - in traditional language there is no comparable word to disability.
    - in some communities, particularly those practicing a more traditional lifestyle, there is a stigma or 'bad karma' attached to disability.
    - diseases resulting in hearing or vision loss that are common in some Indigenous communities have a secondary and often ignored consequence of learning disabilities.
- For similar reasons, the advocacy needs are often complex. A case that presents as a need for a Disability Support Pension, *"invariably turns into a matter related to housing, education, employment, access to health services or any number of other more substantive issues."*
- This is all compounded by the complexity of the disability system itself, the multiplicity of government and other agencies involved (see previous point) and the information needed to navigate it.

These issues not only present a compelling case for the advocacy needs of First Nations people, but for these to be addressed with the help of Indigenous owned and operated specialist services, AND for these services to provide both individual and systemic advocacy, and strong links to specialist legal advocacy services. Such services also need to adopt models of operation that are adapted to the communities and cultural environments in which they operate.

Appendix 3: Consultations

Overview

WestWood Spice facilitated seven consultations across NSW between 2nd and 25th October 2019 attended by over 70 participants. Each meeting was for 4 hours with the purpose being to explore the matters raised in the Issues Paper (see Appendix 1). Face-to-face discussion with a diverse group of participants allowed expanded discussion and testing of ideas. There were five core discussion areas as follows, which were adapted to each group:

- Advocacy needs of people living with disability (in NSW/regional NSW);
  - What does this mean for future advocacy services?
- Role/s advocates play (different kinds of advocacy)
  - Will these roles serve NSW best in the future?
- How well does the current system of advocacy work?
  - How could it work better for people with disability in NSW?
- How do people find out/connect with advocates?
  - How could this be improved?
- How do we know if advocacy is working well?
  - What do we see in a ‘good’ advocate or a ‘good’ advocacy service including outcomes that should be reported?

Participants

There were over 70 participants from a variety of organisational backgrounds as the table below shows; at least 18 were advocates who had lived experience of disability. (See also Appendix 4 for meetings held specifically for people who had lived experience of disability).

Table 8 also shows some of the profile characteristics of the organisations who sent representatives to the consultations. It was extremely valuable to know hear from participants whose organisations were variously involved with TAFS funding, NDAP funding and ILC grants. A number of their organisations were also state branches of organisations that received DRO funding or were part of consortia who received DRO funding.

Table 8: Participants at Consultations

	2 Oct Newcastle	4 Oct Lismore	8 October Sydney	11 October Parramatta	17 October Wollongong	21 October Wagga Wagga	25 October Sydney	Receive TAFS	Receive NDAP funding	Receive DRO funding	Currently receiving ILC grant
ACTION for People with Disability			✓					✓			
ARUMA		✓		✓							
Aussie Deaf Kids		✓									
BEING							✓				
Blind Citizens Australia	✓							✓		✓	✓
Carers NSW			✓								
Community Access Western Sydney				✓							
Community Disability Advocacy Alliance	✓										
Council for Intellectual Disability NSW				✓			✓	✓			✓
DAISI Services LTD		✓									
Deaf Blind Association of NSW				✓✓							
Deaf Society NSW							✓				✓
Disability Advocacy NSW	✓✓ ✓✓			✓✓	✓	✓	✓	✓	✓		✓
Disability South West				✓							
Ethnic Communities Council of NSW Inc							✓				
Ethnic Community Services Co-operative							✓	✓			✓
Family Advocacy				✓					✓		✓
Fighting Chance Australia							✓✓				
Finding Your Own Way				✓							
Forsight							✓				
GWC Community Services					✓						
IDEAS						✓		✓			
Illawarra Advocacy Inc					✓				✓		
Intellectual Disability Rights Service		✓						✓	✓		✓
Mercy Connect											
Multicultural Communities Council of Illawarra					✓						

	2 Oct Newcastle	4 Oct Lismore	8 October Sydney	11 October Parramatta	17 October Wollongong	21 October Wagga Wagga	25 October Sydney	Receive TAFS	Receive NDAP funding	Receive DRO funding	Currently receiving ILC grant
Multicultural Disability Advocacy Association of NSW	✓			✓✓	✓		✓✓	✓	✓		✓
Muscular Dystrophy NSW							✓✓				
National Disability Coordination Officer Program					✓						
North West Disability Services				✓							
NSW Agency for Clinical Innovation							✓				
NSW Council of Social Services			✓								
Official Community Visitor	✓				✓	✓	✓				
PATH inc				✓✓				✓			
Physical Disability Council of NSW							✓	✓			✓
RED Inc		✓									
Regional Disability Advocacy Service						✓✓		✓	✓		✓
Settlement Services International							✓				
Spinal Cords Injury Australia		✓✓					✓✓	✓	✓		✓
Stroke Recovery Association				✓				✓			✓
Synapse Australia LTD							✓	✓	✓		✓
The Deaf Society							✓	✓			
Western Sydney Community Forum				✓✓							

Findings

The **findings from the seven consultations had many similar themes to those of the Submissions** (see Appendix 2). The consultations were particularly valuable in extending the discussion and providing varied real life examples and day-to-day detail of the issues raised in the Submissions.

Discussion was robust with many differing views. Key points and quotes are noted under the five major themes that also arose in the Submissions.

The importance and place of disability advocacy NSW

- Important, important, important
- Advocacy leads to good outcomes for government, communities and individuals. Why the reluctance to invest?

> "Advocacy leads to good outcomes for government, communities and individuals. Why the reluctance to invest?"
>
> Participant in consultations

Current and changing need for advocacy

- Work related to NDIS matters is certainly increasing but this has not reduced other work with mainstream, government, private and commercial services.
- Advocacy services are prioritising on a daily basis, based on crucial needs and urgent matters.

Delivering disability advocacy in NSW

- The importance of having a local presence.
- The range of skills needed is huge. Advocates need a strong organisation behind them to support this skill development.
- The importance of peer work.
- Individual advocacy feeds into systemic advocacy; and the other way.
- Managing conflicts of interest.
- We want to share ideas and share resources.

> "For everyone who reaches out to an advocacy agency People don't have a concept of the shape of the advocacy activities"
>
> Many participant in consultations

- There's a lack of community awareness about advocacy – it's like a lottery if people know about us and can find us. There is also a lack of awareness of advocacy by staff of disability providers.
- NDAP won't work on state issues like justice and health. It's a confusing landscape.

“We want to share ideas and share resources”

Many participant in consultations

Performance measurement of disability advocacy in NSW

- There is a wealth of data items that are currently collected by some organisations but could be included by all.
- Data doesn't show the pain – we have to find a way to join the dots – to tell the stories.
- Avoid a rigid framework.
- Outcomes from systemic advocacy take time to arise
- ‘We want to be open and accountable. We want someone in government to listen”
- We work across state borders – there needs to be a common sense approach to accountability.

“We want to be open and accountable; we want someone in government to listen”

Many participant in consultations

A fit for purpose advocacy system in NSW

- Long term funding so organisations can invest in development – stop the patchwork of funding
- Good technology is expensive and needs to be funded
- Detail about the cultural and contextual needs of different groups – people with Indigenous or CALD backgrounds, women, LGBTIQ+
- We need to network to learn, be a solid presence in our local communities
- There may be room for advocates with different skill levels; and perhaps specialising in different areas like health
- We need a resource base – support around training and professional development to build capacity

Appendix 4: Selected Sector Engagement

The Review undertook a number of engagement activities to supplement the major Review streams arising from the issues paper (see Appendix 2) and from the statewide consultations (see Appendix 3).

In summary, these activities comprised:

- A roundtable on 17 September 2019 with key stakeholders prior to the consultations. This comprised 13 participants plus Commissioner Fitzgerald and other representatives from the ADC and WestWood Spice (see Table 1). The purpose of the roundtable was to seek guidance from the group about particular matters to explore through the consultations.
- A tailored discussion on 14 November 2019 with a small group after the consultations. This comprised eight participants plus Commissioner Fitzgerald and other representatives from the ADC and WestWood Spice (see Table 9). This allowed discussion of the major findings from both the submissions and consultations, and enabled exploration of possible directions.
- Interviews and other meetings with selected stakeholders (see Table 10).
- The ADC arranged **four specific meetings for people with lived experience of disability**, as shown in Table 11. The seven consultations across NSW (see Appendix 3) were attended by a number of advocates who noted that they live with disability.

Table 9: Participants in roundtable and tailored discussion

	Round table participants on 17 September	Participants in Tailored Discussion on 14 November
Council for Intellectual Disability	1	1
Disability Advocacy NSW	1	
Family Advocacy:	1	1
Intellectual Disability Rights Service	1	1
Mental Health Coordinating Council	1	1
Multicultural Disability Advocacy Service:	1	1
National Disability Services	1	
NDIS Quality & Safeguards Commission:	1	
NSW Carers Council	1	
NSW Council of Social Service:	1	1
Physical Disability Council of NSW	1	1
People With Disability Australia	1	1
NSW Ageing & Disability Commission:	Robert Fitzgerald, Maria Petrou, Renee Kastanias and Kathryn McKenzie	
Department of Communities & Justice	Brian Woods	
WestWood Spice	Roger West, Julie Hamblin, Jenny Owen	

Table 10: Selected Stakeholder Engagement

16th August	Disability Advocacy Alliance	Meeting with the disability alliance group and Commissioner Fitzgerald.
16th August	Council for Intellectual Disability + Down Syndrome	Meeting with Executive team and Commissioner Fitzgerald
4th September	ACTION	Meeting with Executive team and Commissioner Fitzgerald
19th September	First Nations Disability Network	Phone discussion with Damian Griffis (Roger West)
19th September	Multicultural Disability Advocacy Association	Meeting with association members and Commissioner Fitzgerald
26th September	Family Advocacy	Meeting with Executive team and Commissioner Fitzgerald
26th September	DARE Disability	Meeting with Executive team and Commissioner Fitzgerald
3rd October	People with Disability Australia	Meeting with Executive team and Commissioner Fitzgerald
14th October	Self-Advocacy Resource Unit	Meeting with Executive team and Commissioner Fitzgerald
17th October	NSW Council of Social Services	Meeting with Joanna Quilty and Anna Bacik (Robert Fitzgerald & Roger West)
21st October	WestHaven	Meeting in Dubbo (Robert Fitzgerald)
21st October	Disability Advocacy NSW	Meeting in Dubbo (Robert Fitzgerald)
21st November	Office of Public Guardian, Qld	Phone discussion with Natalie Siegel-Brown (Phone discussion with Deborah Fullwood)
25th November	Office for Disability, Victoria	Phone discussion with Heidi Peart and Belinda Johnson (Phone discussion with Deborah Fullwood)
27th November	IDRS	Phone discussion with Janene Cootes (Roger West)
27th November	Disability Advocacy Alliance	Phone discussion with Serena Ovens (Roger West)
9th December	Disability Advocacy Network Australia	Phone discussion with Mary Mallet (Phone discussion with Roger West)

Table 11: Meetings with people with lived experience of disability

	Focus: People living with ..	Facilitated by ..
17th October	Psychosocial disability	Being
22nd October	Physical disability	Physical Disability Council, NSW
29th October	Intellectual disability	Council for Intellectual Disability
10th December	Indigenous	First Nations Disability Network

Intellectual disability

The Council for Intellectual Disability (CID) facilitated an advocacy focus group attended by five people with intellectual disability who have had experience of systemic and individual advocacy services in the Sydney and Illawarra areas.

Key points included that:

- advocacy organisations need funding not only to function day-to-day but also to plan for the longer-term
- government needs to put more trust in advocacy organisations – it's not just about the money
- more disability advocacy services are needed in regional areas
- very often, people find out about advocacy services through service providers and friends - but what about those who don't have those networks?
- disability advocacy organisations like CID support self-advocacy and help people with disability have their say about the big picture issues
- disability advocacy organisations can help people sort out problems before they get to crisis point. Sometimes people are 'triaged' away from advocacy services when a situation could have been resolved earlier.

Physical disability

Key points included that:

- Historically, effective advocacy is why people with physical disability have kerb ramps, accessible toilets and accessible public transport. However, accessibility and inclusion are not promoted in all government plans and strategies – that are still many accessibility gaps.
- Both individual and systemic advocacy need to be funded. Individual advocacy is often onerous, stressful and time-consuming. Self-advocacy can also be very emotional.
- What types of disability advocacy are needed?

  - Diagnostic-specific with expertise and knowledge about specific disabilities and the intricacies of 'minor' disabilities.
  - General disability (such as physical or intellectual) with a broader brief to look at the bigger picture systemic/inclusion issues. They can act as a voice between people with disability and policy makers.
  - Representational – people with disability who can speak for others with disability.
- Advocacy organisations need to cover individual, legal, self and systemic advocacy.
- There are very few advocacy services in rural areas – they are hard to find and you don't get face-to-face contact.
- Information and referral are part of the 'advocacy circle'.
- People with physical disability on My Aged Care packages also need access to better advocacy services.

Psychosocial disability

The Mental Health and Wellbeing Consumers Advisory Group facilitated a consultation with eight people who are regular attendees at Buckingham House, a drop-in centre for people living with psychosocial disability.

Key points included that:

- People with psychosocial disability face challenges in dealing with government agencies such as NSW Trustee and Guardian. For many, Legal Aid NSW has acted as their advocate through the Mental Health Advocacy Service (MHAS) – the MHAS may be a model that could be drawn on for this project.
- Self-advocacy is only possible if a person with disability has access to information and resources, and support to develop their technology skills.
- Work was recently carried out by Being and the NSW Department of Fair Trading to develop NDIS consumer resources specifically for people living with psychosocial disability. It was a co-design process.
- Continuity of advocates over time is important so that a meaningful relationship and good communication can be developed between the person with disability and the advocate.
- Drop-in centres provide access to informal advocacy support.
- Peer advocates have fewer barriers when it comes to understanding the lived experience of others with similar stories. Given the variety of services that people with psychosocial disability engage with, having peer advocates with a range of different service knowledge (such as housing services, Centrelink) would be helpful.

Indigenous communities

First Nations Disability Network's CEO, Damian Griffis, arranged a face-to-face consultation with several people with lived experience of disability. One person participated by phone.

Key points included that:

- FNDN has been making submissions and recommendations to governments (State and Commonwealth) for more than 20 years, and the same points have been made – mostly without any or adequate response.
- FNDN receives no government funding for individual advocacy, notwithstanding a huge and demonstrated need.
- Aboriginal people have a far higher incidence of disability, including psychosocial disability than non-Indigenous people (approx. 2x) for many reasons, including poor health and health care, poor diet, violence and trauma, alcohol and drugs. They frequently have multiple forms of disability which compound each other.
- Examples were given of misdiagnoses by medical professionals due to inexperienced practitioners, poor communication and sometimes (too often) poor attitudes.
- They are less likely to 'label' disability and to seek assistance for their disability for cultural reasons, or because of fear and distrust of the medical and bureaucratic systems; for example, loved ones being taken away from their community to hospital and then getting sicker or dying.
- Often the justice system and the health system coincide. For example, a person with brain damage or psychosocial disability may find that police are called to a health service or hospital and the person is arrested or mistreated or injured. (An example was given from one region where parents are putting coloured wrist bands on their adult or teenage offspring with brain damage or psychosocial disability so that police will recognise them and not arrest or injure them.
- Disability advocates can have a huge impact to improve the lives of Aboriginal people with disability because they are trusted by their communities and know the systems, so can intervene to address the kinds of issues mentioned above.
- Well-resourced advocates based, for example, in Coffs Harbour, Dubbo and Nowra and/or Wagga would be a very good beginning. They could be based either in Aboriginal Legal Services or co-located with generalist advocacy services (both should be tried) in shopfront locations.
- Individual advocacy needs to be combined with legal advocacy and systemic advocacy, plus opportunities for community awareness, capacity building and education.

Appendix 5: Literature and Document Review

Introduction

This disability advocacy literature review is a reading and reporting back on some of the papers and documents that set the context or may inform the development of a disability advocacy system in NSW.

Methodology

The focus of this review is disability advocacy frameworks already in place, as well as any reviews of those frameworks.

It includes many documents that will be well-known in the disability sector. Some of those documents suggested further reading; documents suggested by stakeholders as a part of this review were also included where relevant.

We have also included some other advocacy frameworks from Australia outside of the disability sector, and some international examples of disability frameworks.

Some common themes arise across the literature and documentation; these are useful for the current review and are summarised in the box at right.

Common Themes from the literature

- Disability advocacy is a necessary part of an effective disability sector.
- Disability advocacy benefits everyone, and shows a significant return on investment.
- Systemic advocacy is a necessary part of an effective disability sector, underpinned by information flow from other types of advocacy.
- Individual advocacy should be independent.
- Outcome measurement is complex, but should be the basis for disability advocacy evaluation.
- Approaches to advocacy should be flexible – people need more than one approach, often at the same time.
- The availability of information about the system and about services, including mainstream, is necessary for an effective disability advocacy sector.
- A common taxonomy is needed for the definitions of advocacy and the outcome measurements.
- State and Federal disability and disability advocacy systems must align and be clear, including clarity of requirements, reporting, funding and evaluation.

The Appendix covers the topics of:

- Definitions
- Underlying principles
- Critique of models
- Funding
- Performance and reporting
- Governance and oversight

This literature review has referenced the sources that we have relied on for information, but information on the models isn't always readily available, or transparent. This is particularly true of the funding models. On that basis while we have endeavoured to ensure the accuracy of all statements, we cannot guarantee that they are accurate and up to date. Nothing in this literature review should be relied on as being correct or used as information to inform advocacy decisions.

As a literature review to set the context for the review of the NSW framework this is not an exhaustive review of the literature that pertains to disability advocacy.

Definitions

The definitions of disability advocacy are many and varied. Some definitions focus on process, some on actions and some on outcomes. Some are statutory.

Many of the definitions refer to individual advocacy, while others have a wider focus.

A logical starting point for this paper given the Australian context of the NDIS is the *National Disability Insurance Scheme Act* (Cth, 2019). This is a statutory definition focusing on individual advocacy and with a focus on independence. The definition consists of attributes and actions of the advocate.

The National Disability Insurance Scheme Act (Cth, 2013) defines an independent advocate, in relation to a person with disability, to mean a person who:

- is independent of the Agency, the Commission and any NDIS providers providing supports or services to the person with disability
- provides independent advocacy for the person with disability, to assist the person with disability to exercise choice and control and to have their voice heard in matters that affect them
- acts at the direction of the person with disability, reflecting the person with disability's expressed wishes, will, preferences and rights
- is free of relevant conflicts of interest.

The Department of Social Services (Department of Social Services, 2018) describes disability advocacy as a process and a set of actions:

> *acting, speaking or writing to promote, protect and defend the human rights of people with disability.*

DSS adopts the statutory definition cited from the Act above with the exception that the first dot point is in wider more generic terms.

> *An independent advocate, in relation to a person with disability, means a person who:*
>
> - *is independent of the organisations providing supports or services to the person with disability; and…*

In moving beyond individual advocacy Ryan and Jackson (2015, p.2) state in Disability Advocacy in Victoria - the Ombudsman's Report and the Parliamentary Inquiry, that:

> *It is absolutely essential that in any discussion regarding advocacy, the discussion recognises that the generally accepted view of advocacy goes beyond what is commonly called individual advocacy. Indeed, there is a range of activities – including information provision, capacity building, awareness raising – which, although not necessarily specifically tagged as 'advocacy', nonetheless do constitute representation and support for people with disabilities.*

In keeping with this wider understanding of disability advocacy, The National Disability Advocacy Program (Department of Social Services, 2018) says:

- *Advocacy for people with disability can be defined as speaking, acting or writing with minimal conflict of interest on behalf of the interests of a disadvantaged person or group, in order to promote, protect and defend the welfare of and justice for either the person or group by:*
- *Acting in a partisan manner (i.e. being on their side and no one else's);*
- *Being primarily concerned with their fundamental needs;*
- *Remaining loyal and accountable to them in a way which is empathic and vigorous (whilst respecting the rights of others); and*
- *Ensuring duty of care at all times.*

The program goes on to set out the different approaches:

- **Citizen advocacy:** matches people with disability with volunteers.
- **Family advocacy:** helps parents and family members advocate on behalf of the person with disability for a particular issue.
- **Individual advocacy:** upholds the rights of individual people with disability by working on discrimination, abuse and neglect.
- **Legal advocacy:** upholds the rights and interests of individual people with disability by addressing the legal aspects of discrimination, abuse and neglect.

- **Self-advocacy:** supports people with disability to advocate for themselves, or as a group.
- **Systemic advocacy:** seeks to remove barriers and address discrimination to ensure the rights of people with disability.

Daly, Barrett & Williams (2017, p.5) in their cost/benefit analysis of disability advocacy define “independent advocacy” as a process:

> *the process of ensuring that the voice of people with disability is heard in matters that affect their lives. One purpose of independent disability advocacy is to provide supported decision-making, allowing people to engage in decision-making to the full extent of their capacity. It stands in contrast to substitute decision-making, depriving people of control.*

The above definition includes individual advocacy but also systemic advocacy as the authors make clear in going on to state that:

> *The purpose of systemic advocacy is to change society so that people with disability have fuller access to social capital.*

As well as these definitions of disability advocacy the authors include a useful view on the actions that disability advocacy includes (p. 15):

> *Disability advocacy includes:*
>
> - *Providing information to people with disability about their human rights and identifying instances of discrimination;*
> - *Assisting people with disability to uphold their rights by speaking with and writing to people and organisations to raise awareness of problems and seek solutions;*
> - *Helping people with disability negotiate complaints processes or legal action to enforce their human rights;*
> - *Writing submissions and lobbying government to make changes that promote and protect the rights of people with disability; and*
> - *Campaigning for social change by speaking to the media to raise awareness and highlight situations where people with disability are treated unfairly.*

In the UK the Advocacy Outcomes Framework (Mercer and Petty, 2016, p.4) there is a common definition, which includes an ultimate outcome:

> *Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy providers work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice.*

There is also a definition of "independent advocacy", described as "a powerful tool" with several outcomes (p. 1):

> *Independent advocacy is a powerful tool in enabling people to:*
>
> - *have a strong voice that is heard and responded to*
> - *achieve equality and social inclusion*
> - *have their rights upheld*
> - *increase their resilience and independence*
> - *live the life that they want in the way that they want.*

Underlying Principles

As described above there are numerous definitions of disability advocacy and individual advocacy.

What the definitions have in common is that they're all based on some consistent underlying principles.

The underlying principles of advocacy stem from the Convention on the Rights of Persons with Disabilities (UN General Assembly, 2007) which sets out well known principles within the disability sector which aren't repeated here. However, it is through those principles that we understand the importance of advocacy in a well-functioning disability sector.

The Victorian Disability Advocacy Program Review Summary (State of Victoria, 2016, p.1) states that advocacy is a critical safeguard to uphold and promote the rights of people with a disability. The underlying strength of the [Victorian] system is in its commitment to human rights and empowerment of people with a disability.

Rights

People with disability have the same right as other members of Australian society to realise their full potential. They should be supported to participate in and contribute to social and economic life.

One of the underlying assumptions of disability advocacy is that it results in social benefit.

Professor Anne Daly and others measured the social benefit in economic terms, undertaking a cost benefit analysis of independent disability advocacy (Daly Et al, 2017, p.5). Their central finding is that:

> *Independent disability advocacy provides a substantial net benefit to the Australian economy. In 2017, the aggregate NPV of independent advocacy for people with disability in Australia is measured at almost $600 million in 2017 dollars. The benefit cost ratio of 3.5:1 is high compared with other investments. The results validate the economic rationale for government funding for independent advocacy for people with disability in Australia and its continuation.*

In other words, for every dollar invested in independent advocacy for people with disability, the result was $3.50 worth of value.

The authors also argue in support of individual advocacy on other grounds. They note the important role that advocacy plays in helping to stem abuse, in acting on behalf of those that couldn't otherwise act, in providing information for those that need it across numerous areas, and in providing information necessary for assisting with systemic advocacy.

It is worth quoting the extensive benefit side of the equation put forward by the authors (p16 -17):

> *The benefits of independent advocacy included in this CBA are:*
>
> - *Reduced costs for governments (resources freed for their next best use); and*
> - *More productive employment for people with disability; and*
> - *Better educational outcomes for people with disability; and*
> - *Better health outcomes for people with disability; and*
> - *Better child protection outcomes for people with disability.*
>
> *The benefits for* ***people with disability*** *from independent advocacy are substantial. People with disability gain:*
>
> - *A voice;*
> - *Increased confidence, self-esteem, dignity, respect, independence, choice and control;*
> - *Empowerment and personal development;*
> - *Raised expectations about what is possible;*
> - *Improved health and wellbeing;*
> - *Reduced mental distress;*
> - *Increased feeling of being safe and secure;*
> - *A more positive self-identity;*

- *Increased ability to access and use information and services;*
- *Increased ability to gain and retain meaningful employment;*
- *Increased ability to apply for housing and benefits; and*
- *Networks and support to build relationships.*

*The benefits for **carers** from independent advocacy are substantial. The carers gain:*

- *A voice;*
- *Boosted morale;*
- *Increased confidence, self-esteem, dignity, respect, independence, choice and control;*
- *Empowerment and personal development;*
- *Raised expectations about what is possible;*
- *Increased capacity to gain and retain paid work;*
- *Improved health and wellbeing; and*
- *Reduced mental distress.*

*The benefits for the **disability sector** from independent advocacy are substantial. The sector gains:*

- *A long-term view;*
- *Opportunities for people with a disability;*
- *Grass roots support;*
- *Information to help break down stereotypes;*
- *Earlier intervention (reduced use of more intensive services later on);*
- *Reduced need for services to provide more intensive support where issues can be resolved;*
- *before behaviours of concern escalate;*
- *Better communication and relationships between individuals and professionals;*
- *Reduced activities arising from safeguarding concerns about children's welfare;*
- *Quality assurance and diffusion of best practice among providers;*
- *Collection of data to monitor outcomes and promote efficiency; and*
- *Data and research capabilities.*

> *The benefits for the **wider community** from independent advocacy are substantial. The community gains:*
>
> - *Support for all people to participate in democratic processes;*
> - *More diverse workforce;*
> - *By developing strategies for personalised supports and by inclusion of people with disability communities are better enabled to welcome, support and include all people, thereby creating healthier communities;*
> - *Better link the community and people with disability; and*
> - *Awareness by the wider community of both the issues that affect people with a disability, and the advantages of inclusion.*

The UK Advocacy Outcomes Framework (Mercer and Petty, 2016, p.2) states that:

> *In the absence of a common understanding about the transformative role that advocacy can play, there is a danger that we lose out on maximising the potential benefits that advocacy can have for people, the health and social care sector and the wider community.*

The National Disability Strategy acknowledges the importance of advocacy as part of the disability system in numerous places (Commonwealth Government, 2011, p41 for example).

Nationally the NDIS ILC Framework (National Disability Insurance Scheme, 2019) states:

> *People with disability have the same right as other members of Australian society to realise their full potential. They should be supported to participate in and contribute to social and economic life.*

In contributing to those outcomes, the Framework recognises the availability of information, linkages with organisations both inside and outside the sector, and referral ability as important to advocacy:

> *ILC is the component of the NDIS that provides information, linkages and referrals to efficiently and effectively connect people with disability, their families and carers, with appropriate disability, community and mainstream supports. ILC will also ensure the NDIS establishes and facilitates capacity building supports for people with disability, their families, and carers that are not directly tied to a person through an individually funded package (IFP).*

In other words, information, capacity and linkages are fundamental to the system in order to deliver the outcomes sought. The framework recognises that ILC should be broadly scoped, flexible and responsive to the support needs of people with disability, their families and carers because:

> - *People with disability engage both directly and indirectly with a range of informal and formal supports and resources over their lifetime,*

- *Engagement is affected by a range of societal, environmental, demographic and disability-specific factors.*
- *A social insurance model invests in formal, disability-specific support to reduce the lifetime cost of disability, at both the population level and individual level.*
- *ILC can influence the delivery of supports at a systemic level to provide better outcomes for people with disability, their families and carers.*

The National Disability Advocacy Program (NDAP):

> *provides people with disability with access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation. (Department of Social Services, 2018).*

Underlying principles can be based on these human rights models but may also be spelt out as principles that underpin disability advocacy.

A 2017 Consultation Report on the most recent review of NDAP provides a useful description of the program, a summary of findings dealing with models of advocacy, access to advocacy supports, improving the evidence base, the interface with NDIS, conflicts of interest, and legal advocacy/access to justice. There is also a valuable table comparing the purpose, independence and focus of NDAP advocates with a range of other support roles, including NDIS Local Area Coordinators, NDIS Support Coordinators ad the Commonwealth Ombudsman – Disability.

In Victoria The Disability Advocacy Resource Unit has developed its own information booklet *Principles of Disability Advocacy* (Disability Advocacy Resource Unit, 2018(1)). It sets out:

- Best Practice Advocacy
  - Act with integrity
  - Use a Person-directed approach
  - Maximise communication
  - Know the legislative context
- Key Principles:
  - Be responsive
  - Show leadership
  - Be accountable

Models: Types, Mix and Critique

A common taxonomy for any system of disability advocacy is important as soon as we begin to discuss "disability advocacy models".

In the literature "disability advocacy models" can refer to specific models of delivering advocacy (such as individual or family advocacy models); or it can refer to the mix of advocacy types within a system (for example a system may focus primarily on delivering individual and systemic advocacy with a lesser focus on other types of advocacy); or to the funding model. In this review we deal with funding separately.

In relation to individual models of advocacy delivery, in 2009, Jenny Pearson (Pearson, 2009) delivered a report to the Department of Families, Housing, Community Services and Indigenous Affairs (as it was then): *Research of the Models of Advocacy Funded under the National Disability Advocacy Program.* That review included a literature review that contained a search of many definitions of advocacy and advocacy models. She notes (p.3) that there are:

> *A myriad of advocacy models, definitions and classifications in the international research literature.*

Pearson goes on to note that up to 17 different types of advocacy were described in one publication (Advocacy, a Rights Issue, cited by Weafer in 2003).

For her review on the effectiveness of the models, Pearson sticks to the six models that still form the basis of the National Disability Advocacy Program (NDAP) today: Pearson describes each of the models using descriptions of the outcomes sought, sourced from National Disability Program Consultation Work Sheets (FaHCSIA quoted in Pearson at p1)

- **Individual Advocacy** seeks to uphold the rights and interests of people with all types of disabilities on a one-to-one basis by addressing instances of discrimination, abuse and neglect. Individual advocates work with people with disability on a short-term and issue-specific basis. Formal individual advocacy is undertaken by a paid advocate employed by an advocacy agency. Informal individual advocacy is undertaken on a voluntary basis by a family member or a friend.
- **Systemic Advocacy** seeks to influence or secure positive long-term changes that remove discriminatory barriers to ensure the rights and interests of groups of people with disability are upheld. Systemic advocates and policy officers employed by advocacy agencies and peak bodies undertake this advocacy.
- **Self-Advocacy** supports people with disability (predominantly people with an intellectual disability) to advocate on their own behalf or on a one-to-one or group basis. The advocate is paid by the advocacy agency to support people with disability to advocate on their own behalf
- **Citizen Advocacy** seeks to support people with an intellectual disability by matching them with volunteer advocates on a one-to-one basis. Citizen advocates are encouraged to represent the interests of a person with a disability as if they were their own and be free from conflict of interest. Citizen advocates are supported by a paid coordinator who manages the citizen advocacy office. Some of the matches made may last for life.

- **Family Advocacy** works with parents and family members to enable them to act as advocates on behalf of a family member with a disability. Family advocates work with parents and family members on a short-term an issue specific basis. Family advocates work within the fundamental principle that the rights and interests of the person with disability are upheld at all times.
- **Legal Advocacy** seeks to defend the rights and interests of people with disability on a one-to-one basis through the Australian legal system. Legal advocacy is undertaken by a lawyer or individual with appropriate legal knowledge.

Pearson (2009, p33) goes on to state that the consultations pointed to concern that prescriptive categorisation of advocacy models don't reflect actual practices, where models are more mixed to suit the needs of people with a disability.

This is an important consideration when considering the mix of types of advocacy.

Pearson (2009, p17) discussed the effectiveness of the various models of advocacy and the circumstances where each may be useful but goes on to say:

> *A number of authors have concluded that there are advantages in having a range of forms and types of advocacy available and that people will often require more than one type of advocacy.*

One of the purposes of the Pearson review was to answer the question on the effectiveness of disability advocacy models. The consultations noted the following barriers to effectiveness, which are instructive in thinking about the design of an advocacy system for NSW:

- Funding and resourcing, particularly
    - lack of funding both within the sector and for advocacy in the wider sector – linkages with housing, education, transport etc.
    - lack of funding for systemic advocacy
    - lack of funding for rural and remote services
    - underpaid difficult work
- Attitudes to disability and advocacy, including attitudes within the sector that centre around the role of advocacy and how it sits in the system
- Administration:
    - Lack of range and flexibility of models, including geographic differences
    - Governance, including inconsistencies in reporting, regulations, state and federal differences
- Staffing and recruitment difficulties in recruiting, retaining and consistency
    - Lack of professional development and networking opportunities
    - Lack of knowledge of other agencies, of rights, and the high cost associated with public awareness campaigns

- Cultural barriers
- Outreach barriers

It is interesting to note that the more recent review of the Victorian model (State of Victoria, 2016) included some similar findings, particularly in relation to the need to focus on specific groups, and systemic advocacy.

In looking forward Pearson (2009, p.53) said that the consultation highlighted the following factors:

- Be clear around what advocacy is and the language to describe it
- Continued independence of advocacy
- Flexibility in the models
- Individual and systemic advocacy as the primary models
- Adequate resourcing of systemic advocacy
- Collaboration and networking, and sharing of information across the sector
- Longer funding cycles
- Streamlined reporting
- Consistent training

While the National Disability Program recognises six different types of advocacy (as referred to by Pearson above), the NDIS recognises the importance of advocacy, information and capacity building as a part of the NDIS system through the Framework for Information, Linkages and Capacity Building (National Disability Insurance Scheme, 2019). They describe the five "streams" of ILC:

1. **Information, Linkages and Referrals**
2. **Capacity building for mainstream services.** the introduction of NDIS does not shift the responsibilities of mainstream and universal services in ensuring greater accessibility and inclusion, nor is the NDIS a funding source for mainstream services
3. **Community awareness and capacity building.** Governments play a role in fostering the social inclusion of people with disability and their families and carers and that these activities should continue and complement the NDIS
4. **Individual capacity building.** Individual capacity building fosters the principle of choice and control. This funding stream can support courses, groups and organisations to help build capacity, self-advocacy and decision-making, facilitate mentoring and peer support and help provide people with information that will support choice.
5. **Local Area Coordination.** development of relationships between the NDIS, people with disability, their families and carers, and the local community (including informal networks, community groups, disability and mainstream services).

In relation to *Individual Capacity Building*, the framework notes the following about advocacy and types of advocacy:

- Governments acknowledge that advocacy has an important place in the network of supports for people with disability and ILC will be one part of a system of supports for people with disability, their families and carers that will build their capacity.
- The NDIS will fund decision support, safeguard supports and capacity building for participants, including support to approach and interact with disability supports and access mainstream services.
- The NDIS has an important role to play in providing decision-making supports and building individual capacity for people to advocate for themselves (self-advocacy) i.e. NDIS will fund self-advocacy
- Systemic advocacy and legal review and representation will be funded outside of the NDIS; however, ILC will support people with disability to act for themselves and each other, and support families, carers and community members to act for or with people with disability.
- The NDIS will support peer support, where people with disability or their carers share their lived experiences with others on similar journeys.

The Victorian Model

The Victorian Government has developed a disability advocacy plan – *The Victorian Disability Futures Advocacy Plan 2018 – 2020* (State of Victoria, 2018). The vision for the plan is:

> *A thriving independent disability advocacy and self-advocacy sector led by and for people with a disability that reflects their diverse voices and takes action to uphold and promote their rights, wellbeing and interest.*

The plan supports three types of advocacy:

- **Self-advocacy:** undertaken by someone with disability who speaks up and represents themselves. Support and training for self-advocacy is available through community-based groups.
- **Individual advocacy:** a one-on-one approach, undertaken by a professional advocate, relative, friend or volunteer, to prevent or address instances of unfair treatment or abuse.
- **Systemic advocacy:** which involves working for long-term social changes to ensure the collective rights and interests of people with disability are served through legislation, policies and practices.

The Victorian Model delivers self-advocacy, individual advocacy and systemic advocacy via the following framework:

- The Disability Advocacy Resource Unit (DARU), which supports the disability advocacy sector by developing networks, providing information, sourcing professional development opportunities for advocates and strengthening links with broader social policy advocacy.
- The Self Advocacy Resource Unit (SARU) which performs a wide range of roles to support self-advocacy for people with an intellectual disability, people with an acquired brain injury and people with complex communication support needs. This includes networking with key stakeholders, creating and sharing resources, training, providing information on funding and running forums to share information as well as build the capacity of self advocacy groups.
- 24 individual disability advocacy organisations that receive funding (about $3 million in total annually) to deliver the supported types of advocacy.

The first two parts of the model – the advocacy units – are supports for the advocacy system, supporting organisations (the DARU) and individuals or groups where they have intellectual disability, acquired brain injury or communication needs (the SARU). Individual advocacy is then delivered through the individually funded services.

The funded advocacy organisations cover a variety of generalist and specialist organisations including organisations working by region, by disability type, and by population group.

The model also recognised the importance of systemic advocacy.

The model has been reviewed and systemic advocacy was noted as an area for improvement in the review (State of Victoria, 2016). Additional funding was earmarked for systemic advocacy in *The Victorian Disability Futures Advocacy Plan 2018 – 2020* (State of Victoria, 2018) in Outcome 2: Connection (p. 25,26). Systemic advocacy is otherwise delivered through individual groups such as Disability Advocacy Victoria.

Systemic advocacy will also be provided by the newly appointed Victorian Disability Advisory Council which:

> *Provides advice to the Minister … on what the government can do to build a more inclusive Victoria and to increase opportunities for people with a disability (at "Victorian Disability Advisory Council Announced" (Disability Advocacy Resource Unit, 2019)*

It was a strength of the Victorian model that the funded advocacy organisations were independent and resilient (State of Victoria, 2016).

The 2016 review noted areas for improvement in the Victorian model that were important for a well-functioning system:

- Group self-advocacy
- Systemic advocacy to address systemic discrimination
- Tailored advocacy for diverse and isolated groups.

As a result, the review suggested strengthening the disability advocacy framework by:

- Community education
- Centralised access
- Dedicated specialist services for Aboriginal, LGBT and other groups
- Services with specialist advice being available to other services
- Clear referral pathways.

The NSW Model

New South Wales has no specific disability advocacy program as a part of the NDIS rollout but recognises the importance of disability advocacy and has a commitment to continuing to fund disability advocacy organisations to ensure there is no gap in service delivery during the transition to the NDIS. This funding is said to amount to $13 million and is available from 1 July 2018 to 1 July 2020 (National Disability Insurance Scheme, undated).

The funding supplement is available by application to existing organisations who are funded to provide disability advocacy services.

The Federal website has a list of disability advocacy organisations in NSW (Department of Social Services, 2015).

(See also Appendix 6 of this report for more detail about Disability Advocacy in NSW)

The NSW government states that disability advocacy in NSW is currently funded through:

> *individual National Disability Insurance Scheme (NDIS) plans; NDIS Information, Linkages and Capacity Building (ILC) grants program; and the Commonwealth funded National Disability Advocacy Program (NDAP) and Disability Representative Organisation (DRO) program. (New South Wales Government Facts Sheet, undated).*

The NDIS definition of disability advocacy is included in the definitions section above. Disability advocacy is relevant to a population much wider that those that are funded through the NDIS.

The ILC grants program is discussed elsewhere in this document and consists of a policy framework and the investment strategy. The framework is designed to build the capacity of the community, people with a disability, families and carers, and is delivered through a grant program.

That grant program delivers funding through a competitive process still being rolled out, and funding may go to advocacy services as part of that program.

Current NDAP providers have funding until 30 June 2020.

The Disability Representative Organisation Program is a National program that funds specific organisations that represent specific populations. The organisations provide systemic advocacy and are currently funded until 30 June 2020.

The NSW approach to disability advocacy can therefore be said to be largely ad-hoc and historical at this time.

There is a *National Aged Care Advocacy Framework* developed less than 12 months ago by the Commonwealth that may be instructive for the development of an advocacy framework for disability in NSW (Department of Health, 2018)

The program funds nine community-based organisations to provide advocacy, and there is a national helpline. The program includes individual advocacy, the provision of information, and the delivery of education. The role of systemic advocacy isn't clear in the framework, and it is too early yet for any substantial review or critique of the model.

Funding models

In **NSW, disability advocacy** may arise through funding from various sources discussed above, being a mix of state and federal funding, and through current grant processes.

The Victorian disability advocacy model receives a mix of state and federal funding. Federal funding is under review and runs out 1 July 2020. State funding is current until 2021 with a new strategy being developed from 2021. The review of the Victorian model (State of Victoria, 2016) identified the opportunity to make improvements to the advocacy system, and a Disability Advocacy Innovation Fund was created as a result to help fill gaps in the advocacy system.

This type of innovation funding has been prevalent in the National system as well through the ILC program.

The National Mental Health Service Planning Framework (2019) uses population to data to estimate need and, based on need and best practice care models, to estimate funding. It also apportions funding between funding Types. Funder types distinguish between Commonwealth-funded, state-funded, joint Commonwealth and State, private insurer and non-mental health (latter examples being physical health care provided by general practitioners, general hospital beds, family support services etc).

The framework is for the mental health sector as a whole rather than for advocacy services alone, but it has attributes that may be transferrable to disability advocacy. For example, it:

- Is based on clearly articulated assumptions
- Provides national average evidence-based benchmarks for optimal service delivery
- Provides a national agreed language and terminology for mental health services; descriptions of care profiles covering all age groups; a detailed taxonomy and definitions of service types
- Has an accompanying Support Tool (NMHSPF-PST) which allows users to estimate need and expected demand for mental health care and the level and mix of mental health services required for a given population.

The support tool not only estimates need and expected demand, but also funding. The basics of the funding formula include:

- First classification by epidemiology – number of populations with defined mental illness by age and severity
- There is then an agreed taxonomy of the service delivery type needed for each epidemiology group
- There is an agreed estimated percentage of each group that will need services.
- Each service type is then associated with best practice models including staffing profiles,
- The model is also broken into funder to determine what part of the total funding is paid by Commonwealth/States.

If such a framework were to be used as an approach to disability advocacy there are some important notes:

- The development of the model took over five years. There would need to be a staged approach with an interim plan while the model is developed.
- Consultation was wide ranging, including medical professionals, NGOs, peak bodies, academics and others.
- The funding tool requires sufficient population size to work (at least 250,000)
- The model can be used to estimate outputs for best practice models, but it does not appear to measure outcomes.
- The underlying assumption is that all parts of the service system work together and work efficiently. Ensuring capacity building to operate efficiently and ensuring good connections with other parts of the whole system is essential.

The Model for legal advocacy in disability in the United States provides a different type of federated funding model.

- The National Disability Rights Network in the US (National Disability Rights Network, 2011) adopted standards in 2011 to guide the advocacy work of its members. The NDRN is a not for profit Federal peak organisation working for the Federally mandated Protection and Advocacy Systems and Client Assistance Programs – the largest provider of legal advocacy in the USA.
- Each state has a disability advocacy organisation, as well as one for the Native American Population (National Disability Rights Network, 2019).
- The NDRN's main activities are lobbying for Federal funding for all states, advocating for Federal Policy changes, and providing administration and management services to members e.g. database, employee timesheets, sourcing of board members for state services, and insurance. It also provides an online fundraising tool for states to engage donors plus national news and social media monitoring.
- The NDRN provides information exchange networks and education for employees across the US.
- Importantly the NDRN provides the framework to which all state bodies are encouraged to adhere – discussed in the Governance and Oversight section of this Literature Review.

Performance and reporting

It is widely recognised that there is deficiency in the available literature on research into identifying and measuring the outcomes of advocacy. It has long been recognised that measurement of social change should be based on outcomes, although many programs count outputs rather than outcomes. The literature affirms the need to focus on outcomes as a measurement of an effective disability advocacy system.

Pearson (2009, p17) notes the tendency to measure outputs from advocacy based on service contracts, and then summarises the literature at that time, noting the issues with evaluation:

> *The literature describes a number of methodological challenges in evaluating advocacy programs, including:*
>
> - *difficulties in measuring the social justice outcomes of advocacy*
> - *the complexity of public policymaking*
> - *the role of external forces and conditions*
> - *problems of attribution, i.e. determining cause and effect*
> - *the long timeframes needed for systemic changes*
> - *lack of commitment to and resources for evaluation.*

In NSW there are guidelines for evaluation of government programs which set principles and standards for the evaluation of state government programs (NSW Government, 2006).

The guidelines define a program as:

> *A set of activities managed together over a sustained period of time that aim to achieve an outcome for a client or client group.*

The guidelines define program evaluation as:

> *A rigorous, systematic and objective process to assess a program's effectiveness, efficiency, appropriateness and sustainability.*

Evaluation of a disability advocacy system will therefore fall within the guidelines. The guidelines aren't prescriptive, but what they do make clear is that evaluation is an ongoing process that should be built into programs and take place in different forms over the length of the project.

NSW is also moving toward outcome budgeting – measuring effective budgeting through changed outcomes for the NSW population, including a measure for disability inclusion.

The NSW Human Services Outcomes Framework provides a common set of wellbeing measures for human services programs in NSW (FACS, 2017). The framework seeks to measure outcomes across seven domains:

- Education and skills: All people in NSW are able to learn, contribute and achieve
- Economic: All people in NSW are able to contribute to, and benefit from, our community
- Health: All people in NSW are able to live a healthy life
- Home: All people in NSW are able to have a safe and affordable place to live
- Safety: All people in NSW are able to be safe
- Empowerment: All people and communities in NSW are able to contribute.

Nationally, the ILC framework notes that ILC funding mechanisms should have accountability measures linked to outcomes. Some examples may include:

- supporting people with disability to exercise choice and control and navigate systems
- sustaining families and carers in their caring roles
- improving access to the community and mainstream services; and
- increasing the evidence base on effective early intervention and prevention.

ILC is seen as a necessary part of the system leading to achievable outcomes under the umbrella of the National Disability Strategy.

Internationally one recent development has been the Advocacy Outcomes Framework in the United Kingdom.

The *Advocacy Outcomes Framework* was implemented as a response to declining funding in the disability advocacy sector. It is argued that through measuring positive outcome changes a clear case for funding can be made. The measurement of outcomes can also lead to ongoing quality improvement for individual organisations.

The framework provides outcome measurement over four domains:

- Changes for the individual
- Changes in the health and social care sector
- Changes in the wider community
- Changes in the advocacy organisation.

The framework is designed to assist organisations in developing measures around the four outcome domains, as well as identifying current measures and benchmarks for organisations.

In Victoria, opportunities for improvement were identified for measurement and performance outcomes. It was proposed that the following principles apply to performance measures:

- Clear
- Simple reporting, including alignment with the NDAP
- Standardised
- Shared information between services.

The 2018 plan has four overarching outcomes (see Figure 2) with related success criteria. Supporting each outcome are specific actions with themes around:

- Funding
- Other support for organisations
- Access including specific group needs, access at the time and place needed,
- Data and case studies/information sharing
- Partnerships and sharing between organisations, state and commonwealth
- Service guidelines
- Workforce accreditation and capacity.

This performance reporting focuses on the purpose of disability advocacy rather than seeking a neat definition (or KPI) for achievement – in a similar vein to the UK version.

Figure 12: Victorian disability advocacy futures plan outcomes

Victorian disability advocacy futures plan 2018–2020

Vision A thriving independent disability advocacy and self advocacy sector led by and for people with disability that reflects their diverse voices and takes action to uphold and promote their rights, wellbeing and interests

Outcome 1	Outcome 2	Outcome 3	Outcome 4
Inclusion: Disability advocacy is inclusive of everyone	**Connection: Disability advocacy is strong, connected and powerful**	**Responsiveness: Disability advocacy is responsive and timely**	**Sustainability: Disability advocacy grows into the future**
How we can tell if the plan is working – indicators			
Increase self advocacy and access to advocacy for all people with disability Increase support for families and carers who advocate alongside people with disability Increase access to paid employment and leadership opportunities	Increase systemic advocacy that is funded, coordinated and effective Increase support for self advocacy groups Increase partnerships and information sharing between disability advocacy agencies Increase partnerships between disability advocacy agencies and agencies outside the sector	Increase access to disability advocacy that is available where and when it is needed Increase the responsiveness of disability advocacy agencies to increasing demand Increase the necessary knowledge and skills of disability advocacy staff, volunteers and agencies Increase awareness and promotion of disability advocacy	Increase the measurement of the impact of disability advocacy Increase strategic and organisational planning among disability advocacy agencies Increase the evidence base of the Victorian Disability Advocacy Program Increase the participation in and involvement of disability advocates and self advocates in future planning

Absolutely everyone: state disability plan 2017–2020

Four pillars of the state plan:

Inclusive communities – Health, housing and wellbeing – Contributing lives

Fairness and safety

The Pearson review (2009) noted difficulty in describing performance measures, but suggested the following indicators (P.63):

- Client satisfaction measures
- Consumers' experience of services
- Consumer accounts of the difference that advocacy has made - a selection of success stories
- Quality reviews
- External, independent, specialised evaluation of advocacy agencies e.g. Citizen Advocacy Program Evaluation (CAPE)

- Model Coherency Evaluation Tool (John Armstrong)
- Consumer empowerment measured through three indicators: knowledge of rights; how much control; speaking up
- UK Richter Scale which one advocacy agency has modified for people with severe disability – individuals are assessed at intake and then reviewed after advocacy assistance has been provided
- Indicators derived from the United Nations Convention of the Rights of Persons with Disabilities (UN CRPD)
- Qualitative measures like how long cases have been open, waiting lists
- She noted that there was generally concern for the use of numerical counting as a measure of success.

Deloitte Access Economics developed a useful program logic for the ACT Disability, Aged and Carer Advocacy Service (ADACAS) Incorporated in 2013 containing the following elements:

Goals and objectives	Current: Maintain high quality advocacy standards; protect and build ADACAS reputation; best practice governance; ensure ongoing staff support; and match resources, facilities and systems (IT, finance, HR etc.) with future needs. Aspirational: influence changing environment to ensure advocacy is valued; ensure that ADACAS delivers on its promises; seek funding strategically; and develop workforce planning processes and practices.
Outcomes	High client empowerment ratings. Efficient and effective advocacy delivery processes.
Outputs	Statistical measures: number of clients assisted, number of cases.
Inputs	Time of trained staff and volunteer board members. Commonwealth, state and other funding, broken down by key areas of expense.
Contextual factors	Other advocacy organisations in ACT/NSW. The legislative frameworks within which advocates work. Future funding streams and government support. Other barriers faced by clients which are outside ADACAS' control (e.g. employment, income, sustained effort by client). Societal attitudes towards advocacy organisations and clients. Support from target organisations and individuals.

Source: Deloitte Access Economics and ADACAS.

Governance and oversight

Currently in Australia governance and oversight of disability advocacy organisations occurs through service agreements with state and federal funders, and through the Australian Charities and Not for Profit Commission (ACNC). Disability service providers (including Advocacy Services) must adhere to National Disability Service Standards and to the NSW Quality Framework for Disability Services. The frameworks are intended to align.

The National Disability Agreement (NDA) has a potential task in defining advocacy roles - something it isn't currently doing according to the Productivity Commissioner (2019).

> *Roles and responsibilities in the NDA need to be updated to reflect contemporary policy settings, to reduce uncertainty and to address gaps in several areas — including in relation to advocacy, carers, and the interface between the NDIS and mainstream service systems.*

The Productivity Commissioner also notes a "wait and see" attitude, with some states waiting on clarity around funding of disability advocacy from a Federal level through the Nation Disability Advocacy Strategy (Productivity Commissioner, 2019, p14), and notes their vulnerability due to the removal of block funding (ibid, p91).

Recommendation 3.4 at p103:

> *The new National Disability Agreement should set out the responsibilities of the Australian, State and Territory Governments to provide disability services outside the National Disability Insurance Scheme (noting that these could be provided through mainstream systems), in particular where there is lack of clarity including for*
>
> - *services to people with psychosocial disability*
> - *advocacy services, including systemic, individual, legal and self-advocacy*
> - *carer services, in particular respite services*
> - *community access and inclusion programs.*

The US model of legal advocacy through the NDRN has the National Disability Rights Standards (NDRS) setting service standards for advocacy and governance of advocacy agencies – the Protection and Advocacy Standards.

The NDRS states:

> *The Board of Directors of the National Disabilities Rights Network (NDRN) has adopted these [advocacy] standards to guide the advocacy work of its member agencies. These standards address the philosophy, principles and values that provide a foundation for the work of a protection and advocacy system. They also address the policies and practices that are relevant to the governance, management, core activities, and evaluation of a P&A system.*

They address Federal human rights and legislative requirements as well as adopting "accepted norms for an effective protection and advocacy system". The standards are not, however, mandatory. They are a:

- Self-assessment instrument
- Resource for the development of Protection and Advocacy (P&A) systems, policies and procedures
- Basis for peer to peer organisation reviews (which are voluntary)
- Way to demonstrate effectiveness to assist with funding and federal policy making

The standards cover:

- Philosophy, principles and values (including human rights and person-centred values),
- Governance standards,
- Leadership and Management, including financial, personnel and data collection,
- Access, presence, outreach and training (including availability throughout states, telephone systems, physical access),
- Information, referral and intake, including grievance procedures,
- Individual advocacy,
- Monitoring,
- Investigations of abuse and neglect, and
- Systems advocacy.

One potential area for governance consideration is potential conflicts of interest.

The NDIS Practice Standards and Quality Indicators (2018) includes the quality indicator that:

> *Perceived and actual conflicts of interest are proactively managed and documented, including through development and maintenance of organisational policies.*

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Appendix 6: Advocacy in NSW

This report on the history and current status of disability advocacy in NSW has been prepared by the NSW Department of Communities and Justice (DCJ).

Early years of disability advocacy in NSW

In 1986, disability rights advocacy was recognized as a program area to be funded under the Disability Services Act 1986[70]. The first Commonwealth-State Disability Agreement (1991) gave Commonwealth and the states joint responsibility for funding disability advocacy, information and print disability services[71].

In NSW, from 1995-1997 the Ageing and Disability Department (ADD) undertook a consultation process on disability advocacy with the intention of developing an advocacy plan. The process was put on hold while the Commonwealth Government reviewed the National Disability Advocacy Program (NDAP). In the second half of 2000, ADD decided to undertake an EOI process for disability advocacy funding.

Acknowledging that advocacy funding had developed in an “ad hoc” way since responsibility was transferred from the Commonwealth, ADD sought to attain a level of clarity around what was being funded and the basis of its funding.

In March 2001, ADD developed and circulated a Discussion Paper on systemic advocacy titled *Improving and Expanding Disability Advocacy and Information Services in NSW*. At the same time, ADD circulated a package seeking both information about the advocacy sector in NSW, and expressions of interest (EOI) for the provision of advocacy services. This EOI was not progressed.

In July 2001, the Legislative Council Standing Committee No 2 held an inquiry into Disability Advocacy Funding. As a result of the Standing Committee’s findings, the newly created Department of Ageing, Disability and Home Care (DADHC), which superseded ADD, undertook to:

- continue the Government’s commitment to provide $1 million growth funding in 2001-02 through a request for proposal (RFP) process.
- provide all current providers with three-year funding agreements.
- initiate a reform project to develop a State Plan for Disability Advocacy and Information services.

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[70] https://pwd.org.au/about-us/our-history/history-of-disability-rights-movement-in-australia/

[71] From Background Paper 2 1995-96 Commonwealth Disability Policy 1983-1995
https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/Publications_Archive/Background_Papers/bp9596/96bp06

The $1 million growth funding was targeted to areas of high need: regional and remote areas, culturally and linguistically diverse (CALD) and indigenous communities. The RFP was finalised in 2002, and funding allocated for new and expanded advocacy services in Newcastle and Albury, as well as a statewide advocacy service for CALD communities, leading to 40 organisations being funded to deliver advocacy services by the NSW government.

In July 2002, all 40 organisations funded for disability advocacy and information services signed three-year funding agreements. As part of their Funding Agreements, disability advocacy and information services provided DADHC with key performance indicator (KPI) data to assist the NSW Government to better understand and monitor service provision within this sector.

In 2003, DADHC initiated the Disability Advocacy and Information Reform Project. The Project aimed to develop new strategic directions and a policy framework for advocacy services. Discussion papers were developed to form the basis of consultation with the wider community.

Based on this consultation, DADHC developed options for a new policy framework for disability advocacy and specialist information services and consumer peak bodies. An Issues Paper outlining strategic goals for reform, proposing a new service delivery framework for disability advocacy and information services, and articulating an implementation strategy was released in November 2005 for public comment.

Due to delays in the release of the Issues Paper, Funding Agreements were extended until the end of the 2005-06 financial year. Funding was subsequently extended to 2006-07, due to the Evaluation being conducted on the Commonwealth National Disability Advocacy Program. Funding was extended further to 2007-08 and an additional $0.5 million fixed term funding was allocated to fund advocacy services in areas where gaps in service had been identified.

In May 2008, the Minister for Disability Services finalised the Disability Advocacy and Information Reform Project on the understanding that reforms to the advocacy sector would be implemented in a staged manner, with reforms to peak organisations taking precedence. Funding Agreements were rolled over for existing advocacy service providers for a three-year period until 30 June 2011.

NSW - Objectives and Outcomes for Advocacy and Information Advocacy

To assist people with a disability and their families and carers to increase the control they have over their lives through person centred approaches to enable responsiveness and place the client at the centre of decision making and participation in their local community. This program focuses on individual advocacy but recognised the importance of the need to implement systemic advocacy at the local level.

Advocacy objectives:

- facilitate life choices by empowering people with a disability to have their say and make their decisions;
- provide better opportunities for people with a disability to make informed decisions about their lives;
- enhance the rights of people with a disability through advocacy;
- support people with a disability to choose how they want to participate and contribute within their communities;
- increase options for Aboriginal & Torres Strait Islander people with a disability to participate in the community;
- increase options for people with a disability from culturally and linguistically diverse backgrounds to participate in the community;
- include and value families and carers as part of the support system for people with a disability;
- improve access to disability advocacy supports that meet individual requirements/goals; and
- build upon the existing support system to ensure a strong and viable sector and the delivery of high quality services.

Advocacy outcomes:

- people with a disability and their families and carers are supported to self-advocate, advocate on behalf of other people, or access and advocate so that their rights are upheld in the community;
- people with a disability choose to participate in activities in which they are welcomed and supported;
- a person’s participation and contribution to the local community is determined by that individual;
- people have improved access to appropriate and responsive advocacy including people from Aboriginal & Torres Strait Islander backgrounds;
- people have improved access to appropriate and responsive advocacy including people from culturally and linguistically diverse backgrounds; and
- there is greater acknowledgment and awareness of disability in the community.

Information

Information services assist people with a disability and their families and carers to increase the control they have over their own lives. This will contribute to an understanding about what is available in the community and through mainstream services, as well as, where appropriate, more specialist support. Information services will enable people with a disability to make informed choices regarding their contribution to and participation in the local and broader community

Information objectives:

- empower people with a disability to communicate their own preferences to enable informed planning and decision making;
- facilitate inclusion for people with a disability, their family and carers, in the community;
- increase ease of access and timeliness to relevant, local and other information;
- respond to identified information and communication modes/needs that contribute to improving outcomes for people with a disability, their families and carers;
- improve the cultural appropriateness of format and content of information for Aboriginal & Torres Strait Islander people with a disability so that they have greater choice in community participation;
- improve the cultural appropriateness of format and content of information for people with a disability from a culturally and linguistically diverse background so that they have greater choice in community participation;
- include and value families and carers as part of the support system for people with a disability;
- provide information to the broader community to assist in knowledge and understanding of issues affecting people with a disability, their families and carers; and
- ensure the delivery of high quality information services.

Information outcomes:

- people with a disability can make informed decisions about their lives;
- information services are provided responsively to meet the needs and interests of people with a disability from Aboriginal and Torres Strait Islander people with a disability;
- information services are provided responsively to meet the needs and interests of people with a disability from culturally and linguistically diverse backgrounds;
- people with a disability have access to information that facilitates their choice of contribution and participation in the community; and
- there is greater acknowledgement and awareness of disability in the community.

Disability Reform in NSW

NSW introduced the *Stronger Together – a new direction for disability services in NSW 2006-2016* reforms in two phases (ST1: 2006-07 to 2010-11 and ST2: 2011-12 to 2015-16).

The first phase of Stronger Together (ST1) set out plans to increase capacity by 40 per cent. This involved a record investment of $1.3 billion (in 2006/07 dollar terms) focussed on capacity expansion around three areas of effort: strengthening families; promoting community inclusion; and improving the system's capacity and accountability.

The second phase of Stronger Together (ST2) involved the continuation of the service expansions and reforms of ST1 at a cost of $2.02 billion and a second round of service expansions and additional reforms at a cost of $2.02 billion. ST2 focussed on lifespan and person-centred approaches and included (among other things) expansion in decision support resources such as information, planning, advocacy, case management, service brokers and support coordination ($141.2 million over 5 years).

ST2 acknowledged significant changes at an international and national level since 2006 that impacted on disability administration, including Australia's ratification of the United Nations Conventiononthe Rights of Persons with Disabilities (UNCRPD), the development of the National Disability Agreement (2009) and National Disability Strategy (2010), and the Productivity Commission report on Disability Care and Support (2011).

In October 2010 the NSW Advocacy Program Guidelines (Disability) and the NSW Information Program (Disability) were released[72]. The guidelines outlined the objectives of these programs and provided a platform for improved quality, accountability and Minimum Data Set reporting.

From 2011, advocacy and information service providers were required to develop and submit an annual work plan by 31 May each year that demonstrated how the service would use its funding to meet the purpose, objectives and outcomes for its service type (refer to **'NSW - Objectives and Outcomes for advocacy and information'**).

Work plans were then assessed to ensure that they were fit for purpose and reflected the requirements of each organisation's Service Description Schedule for that service. A progress report against the work plan was also submitted by 30 September each year.

All funded organisations were also required to report against the Disability Services NSW Minimum Data Set Collection Data Guide, issued by the Department of Ageing, Disability and Home Care in conjunction with the Australian Institute of Health and Welfare (refer to **'The Disability Services National Minimum Data Set'**).

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[72] https://web.archive.org/web/20101226040723/http:/www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Advocacy+and+Information+Services.htm

MDS data was collected nationally and has been used for a wide range of purposes, such as for planning, national program evaluation and to monitor achievement of program objectives and agreed priorities, including:

- provide data for Productivity Commission's Report on Government Services
- provide data for National Disability Agreement Performance Indicators presented in the *COAG Reform Council National Disability Agreement: Baseline performance report*
- provide national comparisons of numbers of service users living in institutional versus community-based settings
- inform decisions on possible increases in the level of service user contributions by measuring the proportion of CSTDA service users who have benefits or pensions as their main income source
- indicate whether certain groups of people (e.g. those of Aboriginal and Torres Strait Islander origin) are accessing services in proportion to their assessed level of need
- support planning for future service delivery
- support budget submissions for increased funding or changing funding emphasis.

Data was collected quarterly. Providers that were funded to provide a service in the 'advocacy, information or alternative forms of communication' service group were not asked to provide any service user details but were required to indicate how many service users they supported in each quarterly reporting period.

Funded providers were also required to acquit their funding each year. They did this by completing a statement of expenditure and providing a number of financial documents, including profit and loss statements and audited financial statements. Providers could request to retain unexpended funding to deliver additional services.

While the sector was preparing for the introduction of the NDIS and capacity-building funding was being rolled out to support this, three-year contracts were issued to advocacy and information services for the period July 2012-June 2015.

Ready Together launched in December 2013 to continue ST2 reforms and prepare people with disability and the disability sector for the transition to the NDIS. Funding for all disability service providers, including disability advocacy, was renewed under a new three-year Funding Agreement from 1 July 2015 to 30 June 2018[73].

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[73] https://www.parliament.nsw.gov.au/la/papers/Pages/qaprofiles/non-government-disability-advocacy-fundi_188906.aspx

The Disability Services National Minimum Data Set[75]

The Disability Services National Minimum Data Set (DS NMDS) is a national collection that has a set of nationally significant data items that are collected in all Australian jurisdictions and an agreed method of collection and transmission. The purpose of the DS NMDS collection is to facilitate the annual collation of nationally comparable data about services provided under the National Disability Agreement (NDA), and to obtain reliable, consistent data with minimal load on the disability services sector. MDS items most relevant for the advocacy sector include:

6.01 Advocacy

Services designed to enable people with disability to increase the control they have over their lives through the representation of their interests and views in the community. Examples include:

- self-advocacy/individual advocacy
- citizen advocacy
- group advocacy
- system/systematic advocacy

6.02 Information/referral

Information services provide accessible information to people with disability, their carers, families and related professionals. This service type provides specific information about disability-specific and generic services, equipment, and promotes the development of community awareness. Information includes contact by phone, print or e-mail that recommends a person to another service.

6.03 Combined information/advocacy

Services that offer both information and advocacy services to individuals where these two components cannot reasonably be separated.

6.05 Alternative formats of communication

Includes alternative formats of communication for people who by reason of their disabilities are unable to access information provided in the standard format and may include interpreter services, radio and alternative formats of print medium, for example, TTY, Braille and so forth.

7.03 Peak bodies

Peak bodies are generally funded to support non-government disability funded-agencies in achieving positive outcomes for people with disability.

7.04 Other support services

Services that are completely outside any of the defined service types. This service type also includes the provision of one-off funding for a defined event (for example, for promotional activities) or for the purchase of aids and equipment for a community facility (not for an individual).

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[75] https://www.aihw.gov.au/getmedia/1026f60a-cc97-40fb-a6ef-46c25ec006a6/ds-nmds-data-guide-2016-17.pdf.aspx

NDIS readiness activity

In 2016-17, the initial NDIS Information, Linkages and Capacity Building (ILC) grants rounds were allocated. Grants totalling $6.8m went to 13 organisations to support NDIS readiness activities in NSW, including:

- continuing funding for NSW Council for Intellectual Disability: *My Choice Matters* Information workshops, online learning and leadership courses, and peer networks; Expanding the *My Choice Matters* capacity building program, enabling people with disability, families, carers and supports to develop skills to identify and choose services and supports, preparing them for first contact with NDIS.
- grants to nine providers to support information and NDIS readiness activities for hard-to-reach cohorts and locations, such as people in remote locations, Aboriginal and CALD communities.

From 2016 to 2018 the *Skilled to Thrive* Project was a $1.5 million two-year project funded by FACS focused on building the capacity of the 40 eligible NSW Advocacy and Information providers. NSW established the *Skilled to Thrive* project to support disability advocacy and information services to be ready to make the most of the NDIS, and to continue to provide services under the NDIS to their clients.

The project delivered a number of resources and supports for service providers, including a Service Alignment Resource for Advocacy and Information Providers. This was a table that mapped correlations and interfaces between traditional advocacy and information activities and NDIS support categories - primarily Capacity Building in NDIS Individual Funding Packages – to assist advocacy providers to consider how best to adjust their service offerings to reflect the NDIS landscape.

Transitional Advocacy Funding Supplement 2018-19 to 2019-20

During the period of transition to the NDIS and in the early stages of full scheme, the Transitional Advocacy Funding Supplement (TAFS) was introduced to ensure that people with disability had access to all necessary information and supports. TAFS addressed potential shortfalls for advocacy groups with funding set aside of up to $26 million for advocacy services until 2020.

TAFS also enabled in-scope providers to identify and resolve issues with how the NDIS was working on the ground during the early years of full scheme. It also allowed organisations to continue systemic and representative advocacy services related to broader inclusion and support for individuals with disability.

Disability advocacy, information and representative organisations were only eligible for TAFS funding if they had applied for ILC grants. The outcomes of the *NDIS ILC National Readiness and NSW Jurisdictional Grants Rounds* was taken into account to ensure that there was no duplication of funded services between the Commonwealth and NSW Government.

In 2018-19, FACS funding was used to ensure that advocacy providers received a total quantum of funding equal to what was previously funded per annum by the NSW Government. In 2019-20, FACS funding was rolled over from the previous year, as ILC grants rounds were not complete in time to be taken into account.

Organisations which received more or equal funding than previously through the ILC program were only considered for NSW Government funding if they could demonstrate a gap in the range of services they were previously funded to provide to people with disability.

Other Sources of Advocacy Funding

National Disability Advocacy Program

The Commonwealth-funded National Disability Advocacy Program (NDAP) provides people with disability with access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation. NDAP agencies receive funding under the Disability Services Act 1986 (DSA). All disability advocacy agencies funded under the NDAP must comply with the DSA and the applicable standards[76].

The creation of an independent disability advocacy program arose from the Review of the *Handicapped Persons' Assistance Act* (1983). In 1991, the Commonwealth/State Disability Agreement restructured Commonwealth and state program responsibilities, with the Advocacy and Information Services remaining as the only service type that was a dual responsibility of both state and Commonwealth governments[77]. All people with disability are eligible to receive **individual advocacy** from NDAP-funded services.

Agencies are funded to provide disability advocacy support:

- delivered from specified locations;
- covering a specified service area – either state-wide or a collection of Australian Bureau of Statistics Statistical Areas (SAs); and
- using the specified model or models of disability advocacy support.

Agencies may also be funded to specialise in providing advocacy support to groups such as:

- Aboriginal and Torres Strait Islanders;
- people from diverse cultural and linguistic backgrounds; or
- people with a particular disability type e.g. acquired brain injury.[78]

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[76] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap

[77] Adapted from the Family Advocacy Submission in response to the Productivity Commission Draft Report into Disability Care and Support at: https://www.pc.gov.au/inquiries/completed/disability-support/submissions/subdr0712.rtf

[78] https://www.dss.gov.au/sites/default/files/documents/03_2018/ndap_operational_guidelines_february_2018.pdf p3

The Australian Government has extended the NDAP to include individual advocacy support for people who need extra support to engage with the Disability Royal Commission. Advocacy support is for people with disability (or family members or carers acting on their behalf) who cannot advocate for themselves because they have difficulty in communicating or understanding how to engage with the Disability Royal Commission. An advocate will be able to help people with disability to understand how to tell their story to the Disability Royal Commission, how to work out problems or avoid discriminatory issues, find communication supports such as interpreters, and access other supports such as legal or financial services[79].

National Disability Representative Organisations

A number of organisations are currently funded under the Disability Representative Organisations program to provide systemic advocacy and representation for Australians with disability. The program provides funding, from 1 January 2018 – 30 June 2020, to:

- Children and Young People with Disability Australia
- Disability Australia Consortium
- Disabled People's Organisations Australia
- Mental Health Australia
- National Disability Services.

The funding is to enable organisations to provide **systemic advocacy** for Australians with disability.

The disability peak bodies are currently funded at over $2 million per year. These peak bodies provide advice to the Commonwealth Government on breaking down barriers and improving social and economic participation; they engage with a range of ministers and portfolios[79].

NDIS Information, Linkages and Capacity Building[80]

The objective of the Information, Linkages and Capacity Building (ILC) Program is to increase social and community participation for people with disability. The ILC Program seeks to do this by:

1. building the capacity of people with disability to participate in their community; and
2. creating opportunities for people with disability to participate by creating more inclusive services and communities.

The ILC Framework (2015) states that "Systemic advocacy and legal review and representation will be funded outside of the NDIS. ILC will support people with disability to act for themselves and each other, and support families, carers and community members to act for or with people with disability"[81].

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[79] From: https://www.dss.gov.au/disability-and-carers/disability-royal-commission-support-services

[79] Adapted from: https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/national-disability-peak-bodies

[80] Adapted from the ILC Investment Strategy at https://www.ndis.gov.au/media/1665/download

[81] ILC Policy Framework p 6: https://www.ndis.gov.au/media/241/download

There are four specific, complementary programs outlined in the ILC Investment Strategy:

1) Individual Capacity Building Program;
2) National Information Program;
3) Economic and Community Participation Program; and
4) Mainstream Capacity Building Program.

ILC grants can be used, among other activities, to help people with disability to build capacity to self-advocate and participate in mainstream community life, and to fund information services for all people with disability, both of which form part of the traditional advocacy, information and referral program.

NDIS-funded Local Area Coordinators also provide referrals and linkages to the community for all people with disability, which are functions that advocacy providers can perform.

Advocacy in the NDIS Participant Individual Funding Plans

An NDIS funding package may include advocacy related supports, such as:

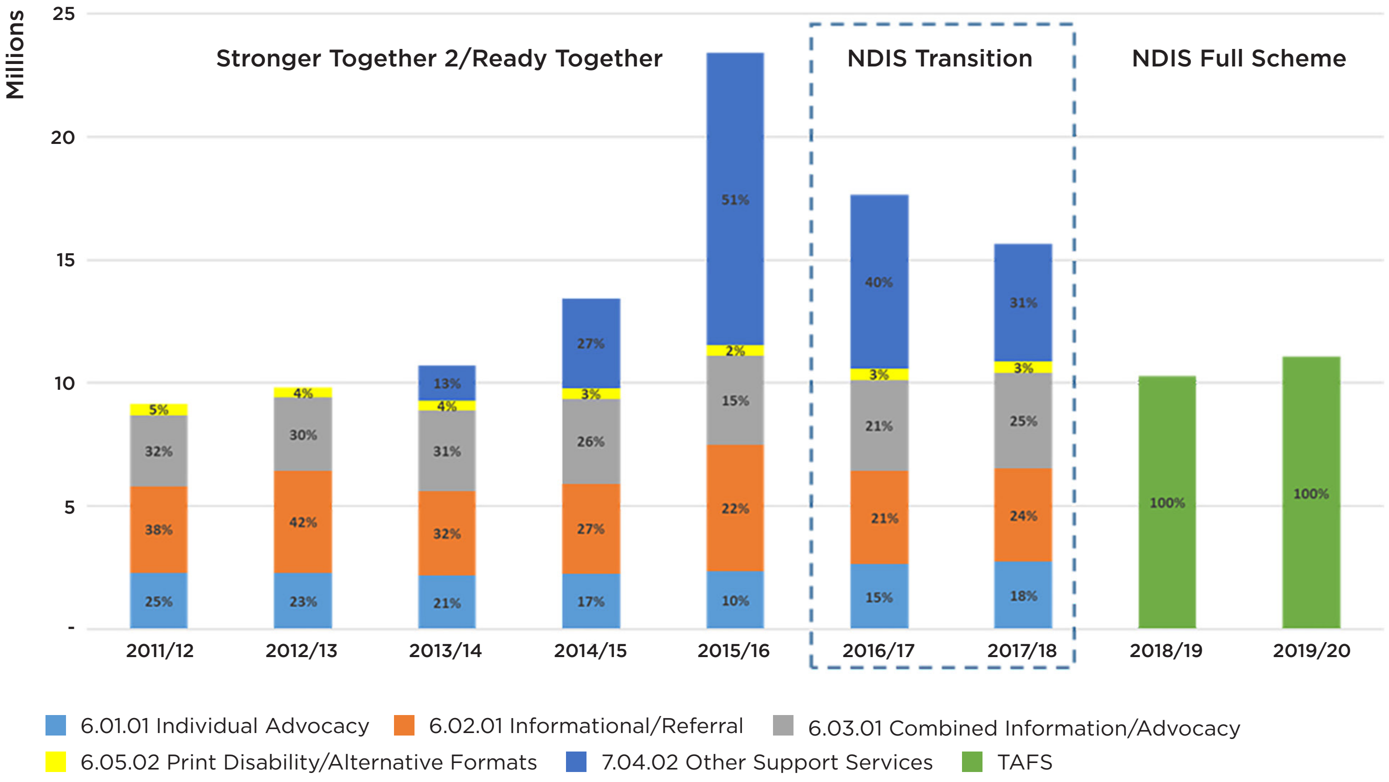
- assistance to strengthen a person's ability to coordinate their supports and to participate in the community
- advice and assistance to develop resilience and resolve points of crisis
- training in planning and plan management
- specialist support coordination
- developing life skills
- life transition planning, including mentoring, peer support and skill development
- assistance with decision making, including daily planning and budgeting.

Once individuals receive their NDIS Individual Funding Package, they are able to choose how this funding will be spent, and who they spend it with (as long as it is 'reasonable and necessary' expenditure against the broad areas agreed in their plan). The NDIS will help them to build the capacity to make those choices, through support coordination and local area coordination assistance.

Summary of NSW funding for advocacy organisations

Figure 13 and Table 12 below show the growth in advocacy funding by NSW across MDS service types since disability reform significantly ramped up from ST2 in 2011/12 to full scheme NDIS.

Figure 13 – NSW Government funded disability advocacy 2011-12 to 2019-20



Whilst most of the advocacy service types were consistently funded over time, the significant increase in 7.04.02 Other Support Services prior to and during transition to the NDIS reflected the NSW investment in building capacity for individuals and the system. The vast majority of this funding went to person centred planning and NDIS transition support (excluding peaks) activity.

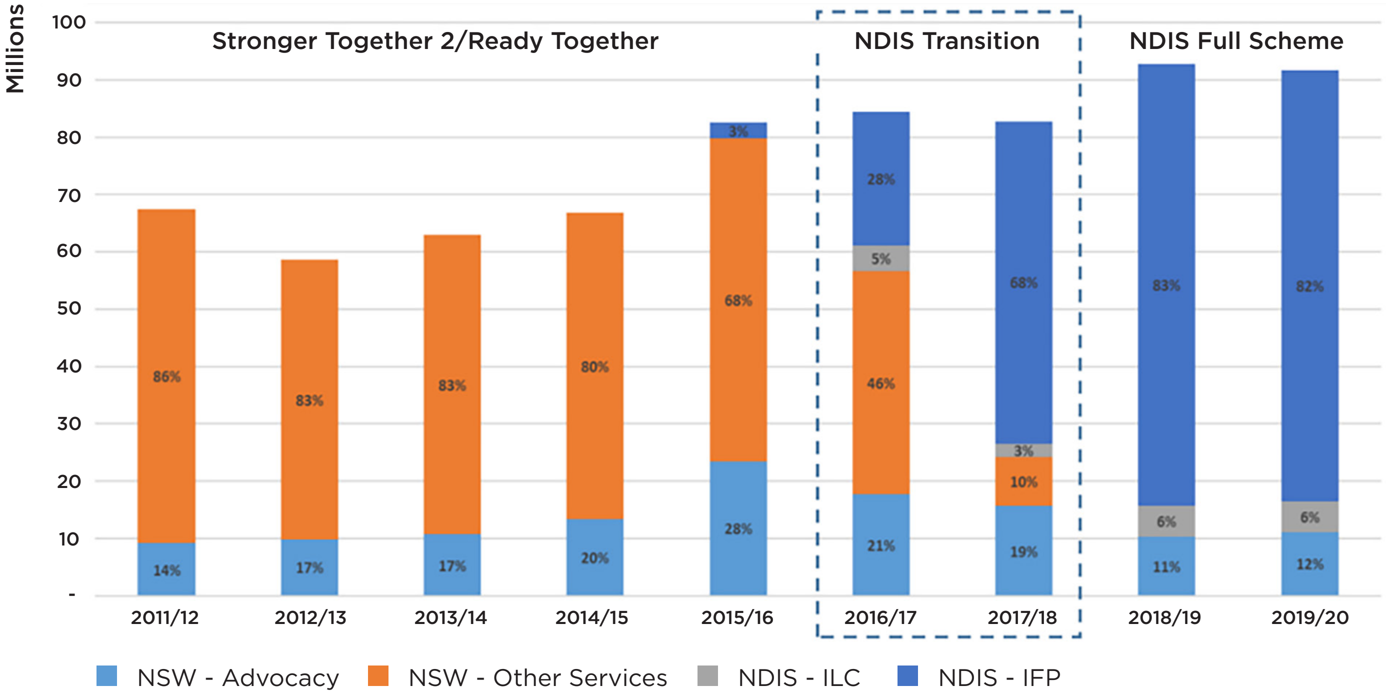
Table 12 - NSW Government funded disability advocacy 2011-12 to 2019-20

Service Model	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20
6.01.01 Individual Advocacy	2,301,922	2,278,312	2,195,473	2,272,001	2,367,620	2,656,208	2,749,707	-	-
6.02.01 Information/Referral	3,497,713	4,155,062	3,402,256	3,638,822	5,140,466	3,768,309	3,788,274	-	-
6.03.01 Combined Information/Advocacy	2,886,220	2,977,602	3,271,731	3,454,184	3,601,324	3,704,015	3,871,177	-	-
6.05.02 Print Disability/Alternative Formats	475,090	401,392	413,350	425,699	439,931	453,760	467,369	-	-
7.04.02 Other Support Services	-	-	1,417,123	3,632,428	11,847,464	7,048,047	4,778,228	-	-
TAFS	-	-	-	-	-	-	-	10,291,540	11,057,102
Sub-total	**9,160,946**	**9,812,368**	**10,699,932**	**13,423,134**	**23,396,805**	**17,630,340**	**15,654,754**	**10,291,540**	**11,057,102**
Other sevice models	58,329,010	48,739,214	52,209,957	53,318,366	56,401,900	39,048,681	8,502,574	-	-
Total	**67,489,955**	**58,551,582**	**62,909,888**	**66,741,500**	**79,798,706**	**56,679,021**	**24,157,327**	**10,291,540**	**11,057,102**

It should be noted that advocacy organisations were also funded by the NSW Government for other disability related services. For example, in 2015/16, of the 44 organisations funded for advocacy services by the NSW Government, 18 organisations also received funding for other disability services to the value of $56.4 million.

As NSW direct service delivery funding stepped down during the transition to full scheme NDIS (2016-17 to 2017-18), the funding mix changed such that in first year of full scheme NDIS 21 of the organisations received $77.1 million from NDIS Individual Funding Packages and 24 organisations received $5.4 million in NDIS ILC funding. Figure 14 and Table 13 below show how the funding pool has continued to grow and the mix changes from the Stronger Together 2 reforms to full scheme NDIS. It should be noted that this does not include other Commonwealth advocacy funding (for example NDAP) which would be additional revenue. It should also be noted that 17 NSW TAFS funded advocacy organisations do not access funds from NDIS Individual Funding Packages.

Figure 14 – NSW Government and NDIS funding for disability advocacy organisations 2011-12 to 2019-20[81]



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[81] Note: FY 2019-20 NDIS – IFP values annualized based on YTD September (Q1).

Table 13 - NSW Government and NDIS funding for disability advocacy organisations 2011-12 to 2019-20[82]

Program	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20
NSW - Advocacy	9,160,946	9812,368	10,699,932	13,423,134	23,396,805	17,630,340	15,654,754	10,291,540	11,057,102
NSW - Other services	58,329,010	48,739,214	52,209,957	53,318,366	56,401,900	39,048,681	8,502,574	-	-
NDIS - ILC	-	-	-	-	-	4,465,000	2,381,730	5,368,629	5,358,682
NDIS - IFP	-	-	-	-	2,695,409	23,299,237	56,228,604	77,112,401	75,261,693
Total	**67,489,955**	**58,551,582**	**62,909,888**	**66,741,500**	**82,494,114**	**84,443,258**	**82,767,662**	**92,772,570**	**91,677,478**

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[82] Note: FY 2019-20 NDIS – IFP values annualized based on YTD September (Q1).

Timeline - Advocacy in NSW 1999-2019

Date	Event
1999	Commonwealth Review of Disability Advocacy Services recommended that a distinction be made between individual and systemic advocacy.[83]
2001	NSW Disability Council discussion paper: Improving and Expanding Disability Advocacy and Information Services in NSW
July 2001	NSW Legislative Council Standing Committee review of disability advocacy funding[84]
2001-02	$1m growth funding for advocacy services targeted to areas of high need: remote and regional communities; CALD and Aboriginal communities
July 2002	40 organisations funded for disability advocacy and information services signed three-year funding agreements that required them to provide key performance indicator data to assist the Government to better understand and monitor service provision within the sector.
2003	Disability Advocacy and Information Reform Project (DAIRP) initiated. The project aimed to develop a new framework and [policy for these services. Thirty-one public consultations took place, with 525 people taking part.
2004	NSW and Commonwealth jointly fund the Indigenous Disability Advocacy Service (IDAS)
November 2005	DAIRP Issues paper released for consultation. Funding Agreements with advocacy and information providers extended to 30 June 2006.
June 2006	DADHC releases: *Stronger Together: A new direction for disability services 2006–2016*
July 2006	Funding Agreements with advocacy and information providers extended to 30 June 2007. DAIRP process to focus first on consumer peaks, then individual advocacy and information services
July 2006	Report released: Australian Government Department of Families, Community Services and Indigenous Affairs *Evaluation of the National Disability Advocacy Program*
2007	NSW funded advocacy and information services have their funding agreements extended until 30 June 2008. An additional $0.5 million fixed term funding in 2007-08 to fund advocacy services in areas where gaps in service had been identified.
May 2008	Minister for Disability Services approved the finalisation of the Disability Advocacy and Information Reform Project[85] Extensions of funding agreements to existing service providers for a three-year period until 30 June 2011.
2008-09 financial year	Additional $0.5 million for disability advocacy services.

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[83] https://www.aph.gov.au/-/media/wopapub/senate/committee/clac_ctte/completed_inquiries/2004_07/cstda/submissions/sub116f_pdf.ashx
[84] https://www.parliament.nsw.gov.au/committees/inquiries/Pages/inquiry-details.aspx?pk=1697
[85] https://www.parliament.nsw.gov.au/lcdocs/other/9405/081111%20QON%20Ageing,%20Disability%20Services%20-%20written%20questions.pdf p48

Date	Event
October 2010	ADHC released the NSW Advocacy Program Guidelines and NSW Information Program Guidelines. The guidelines outlined the objectives of these programs and provided a platform for improved quality, accountability and reporting. Advocacy Services were required to submit an annual work plan by 31 May each year that highlighted priorities for the coming year and described how to achieve them. Additionally services were required to submit an annual progress report against the work plan by 30 September.
2011	ADHC releases: *Stronger Together: The second phase 2011–2016* New investment of $141.2 million over five years in decision support services, including information, planning, advocacy, case management, service brokerage and support coordination.
June 2011	Minister announced that Advocacy services would continue to receive funding for a further 12 months to July 2012.
August 2011	Productivity Commission Report into Disability Care and Support released. Foundation for the introduction of the NDIS
2011-12	An additional $3.1 million was allocated to a broad range of activities that support people with a disability to participate in the community, through providing information, knowledge, advocacy and community capacity building.
2012	Three year contracts were issued to advocacy and information services for the period July 2012 – June 2015.
December 2013	*Ready Together launches. Continued Stronger Together 2* reforms and prepares people with disability and the disability sector for the transition to the NDIS.
2014-15	DAIRP Issues paper released for consultation. Funding Agreements with advocacy and information providers extended to 30 June 2006.
June 2006	The Government extended all contracts for service providers, including advocacy and information services until 30 June 2016[86].
2015-16	Funding for all disability service providers was renewed under a new three year Funding Agreement from 1 July 2015 to 30 June 2018[87].
2018	NSW Legislative Council Inquiry: *Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales.* Recommendation 15: That the NSW Government provide ongoing funding and support to advocacy organisations beyond 2020.
2018-19 2019-20	Transitional Advocacy Funding Supplement (TAFS) was introduced to ensure that people with disability had access to all necessary information and supports. TAFS addressed potential shortfalls for advocacy groups with funding set aside of up to $26 million for advocacy services until 2020.
2019	NSW Ageing and Disability Commissioner to report on Disability Advocacy funding in NSW

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[86] https://www.parliament.nsw.gov.au/la/papers/Pages/qaprofiles/non-government-disability-advocacy-fundi_188906.aspx

[87] https://www.parliament.nsw.gov.au/la/papers/Pages/qaprofiles/non-government-disability-advocacy-fundi_188906.aspx

Table 14: Organisations that received Transitional Advocacy Funding Supplement

	RECEIVED TRANSITIONAL ADVOCACY FUNDING FYE **2018/19**	RECEIVED TRANSITIONAL ADVOCACY FUNDING FYE **2019/20**
Ability Advocacy	✓	✓
Action for People with Disability Inc.	✓	✓
Advocacy Law Alliance Incorporated	✓	✓
Assistive Technology Australia	✓	✓
Better Hearing Australia NSW State Council Inc.	✓	✓
Blind Citizens NSW	✓	✓
Broken Hill & District Hearing Resource Centre	✓	✓
Central Coast Disability Network Inc.	✓	
Citizen Advocacy Western Sydney Inc.	✓	✓
Disability and Aged Information Service Inc.	✓	✓
Disability South West Limited	✓	✓
Epilepsy Action Australia	✓	✓
Ethnic Community Services Co-operative Ltd	✓	✓
First Peoples Disability Network (Australia) Limited	✓	✓
IDEAS - Information on Disability Education and Awareness Services Inc.	✓	✓
Italian Social Welfare Organisation	✓	✓
Intellectual Disability Rights Service		✓
Macarthur Disability Services Ltd	✓	✓
Motor Neuron Disease Association of NSW Inc.	✓	✓
Multicultural Disability Advocacy Association of NSW	✓	✓
Muscular Dystrophy Association of NSW	✓	✓
NADO Inc.	✓	✓
NSW Council for Intellectual Disability	✓	✓
Parents of Deaf Children Incorporated	✓	✓
PATH Inc.	✓	✓
Penrith Disabilities Resource Centre Inc.	✓	✓
People with Disability Australia Incorporated	✓	✓
Radio for the Print Handicapped of NSW Co-op Ltd	✓	✓

	RECEIVED TRANSITIONAL ADVOCACY FUNDING FYE **2018/19**	RECEIVED TRANSITIONAL ADVOCACY FUNDING FYE **2019/20**
Regional Disability Advocacy Service	✓	✓
Royal Institute for Deaf & Blind Children	✓	✓
Spinal Cord Injuries Australia Limited	✓	✓
Stroke Recovery Association Inc.	✓	✓
Sydney Region Aboriginal Corporation	✓	✓
Synapse Australia Ltd	✓	✓
The Deaf Society of NSW	✓	✓
The Institute for Family Advocacy & Leadership Development	✓	✓
The Paraplegic & Quadriplegic Association of NSW - T/A Para quad-NSW	✓	✓
The Physical Disability Council of NSW Inc.	✓	✓
The Trustee for Catholic Care Sydney Trust	✓	✓
Vision Australia Limited	✓	✓

Appendix 7: Population estimates of people with disability in NSW

Introduction

The NSW Department of Communities and Justice (DCJ) is working towards establishing a baseline profile of people with disability in NSW. This will help with understanding the service needs of those with a reported disability, which in turn supports decision making by DCJ about funding.

The disability sector has changed significantly

The disability sector has undergone significant change since the introduction of the NDIS in NSW; from the Hunter trial (2013/14-2015/16), the Nepean Blue Mountains early roll-out (2015/16), the transition for the remainder of the state (2016/17-2017/18), through to full scheme NDIS (2018/19+).

The NDIS is only one component of the disability support system and is expected to provide support for up to 140,000 people with individual funding plans in NSW. There are other people living with disability who will not be eligible for NDIS plans and who will require assistance. Their needs vary depending on their level of disability and activity limitations. It is the intention of this section of the report to quantify the respective need groups.

The main source of data is the Survey of Disability Ageing and Carers

The main source of data to describe the broader disability population is the Australian Bureau of Statistics' (ABS) Survey of Disability Ageing and Carers (SDAC). This report uses analysis of the SDAC 2015. [88] It is noted that the Summary Findings for SDAC 2018[89] was released on 24 October 2019; however, the detailed data tables were not be available in time for analysis and publication of this report.

The SDAC estimates of people with disability in NSW are based on a survey of 75,000 people across Australia (around 63,500 people from over 25,500 private dwellings, and a further 11,700 people from 1,000 establishments).

According to SDAC 2015, approximately 1.4 million people in NSW have a disability[90]. This represents 18.1% of the NSW population and is very similar to the national estimates.

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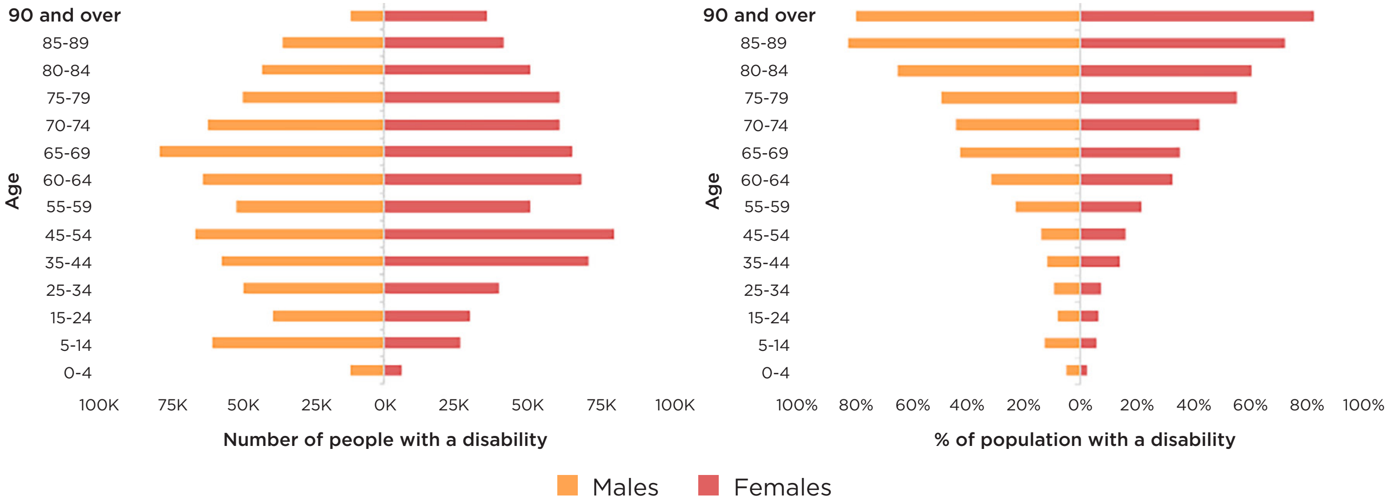
[88] 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015 (released 18/10/2016) https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4430.0main+features12015 Pearson (2009)

[89] 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2018 (released 24/10/2019) https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

[90] The 2018 SDAC has the estimation slightly less at 1.3 million people.

Figure 15 – Number and proportion of NSW population with a reported disability (SDAC 2015)



In summary, SDAC 2015 shows:

- The total number of people with a reported disability in NSW is similar between males and females (680,000 vs 693,000 respectively).
- Of the 1.4 million people with a reported disability, approximately 105,000 (or 7.6%) were aged 14 and under, with approximately 600,000 (or 43.8%) aged 65 and over.
- However, the number of people with disability varies by gender for certain age groups:
  - Notably, there are more younger males reported with a disability (in particular aged 5-14 years old), whereas there are more females aged 35 to 54 with a reported disability.
  - These features are similar between the NSW and overall Australian population.
- As expected, the proportion of people with disability increases by age band for both genders. This is because older Australians are more likely to have a long-term health condition that limits activities.

There are limitations to the SDAC data

As with all data sources, there are limitations. In this case, SDAC 2015 is now four years old and was conducted before the transition to the NDIS in NSW, and therefore may not be fully reflective of the current disability landscape. Additionally, it is survey data from a population sample that is then generalised to the broader population. Sampling itself may lead to bias; for example, the sample chosen from households and other institutions may not capture more transient populations who may experience a higher prevalence of disability. It is important, therefore, to acknowledge early that these are not exact figures; they are estimates and they should only be used as a guide to the size of particular need groups for strategic planning purposes only.

Definitions of disability are important in understanding need

SDAC defines a disability as: ‘limitations, restrictions or impairments that last or are likely to last for at least six months’. There are four levels of limitation based on a person’s ability to carry out the core activities of communication, mobility and self-care. These levels are defined as:

- Profound – the person ***is unable to do, or always needs help with***, a core activity task.
- Severe – the person:
    - ***sometimes needs help*** with a core activity task, and/or
    - has difficulty understanding or being understood by family or friends, or
    - can communicate more easily using sign language or other non-spoken forms of communication.
- **Moderate** – the person ***needs no help***, but has difficulty with a core activity task.
- **Mild** – the person ***needs no help*** and ***has no difficulty*** with any of the core activity tasks, but:
    - uses aids or equipment, or has one or more of the following limitations
    - cannot easily walk 200 metres
    - cannot walk up and down stairs without a handrail
    - cannot easily bend to pick up an object from the floor
    - cannot use public transport
    - can use public transport, but needs help or supervision
    - needs no help or supervision, but has difficulty using public transport.

In addition to these levels of activity limitation, respondents with disability may also have a schooling or employment restriction only.

Figure 16 – Proportion of population by disability level (SDAC 2015)

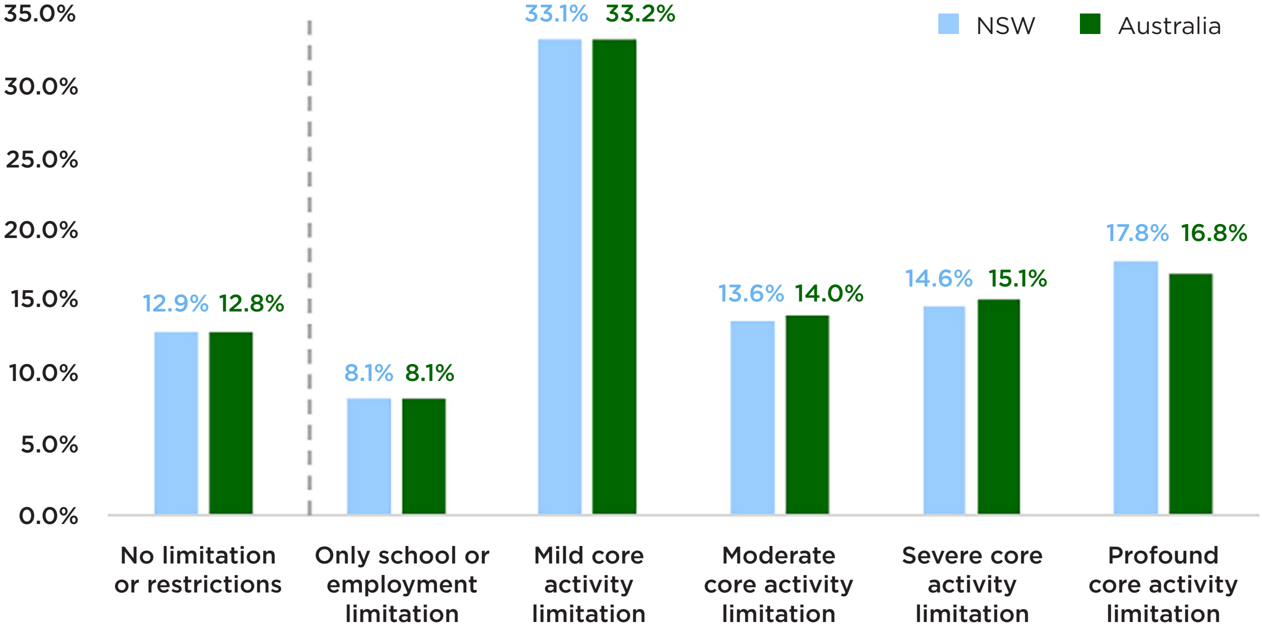
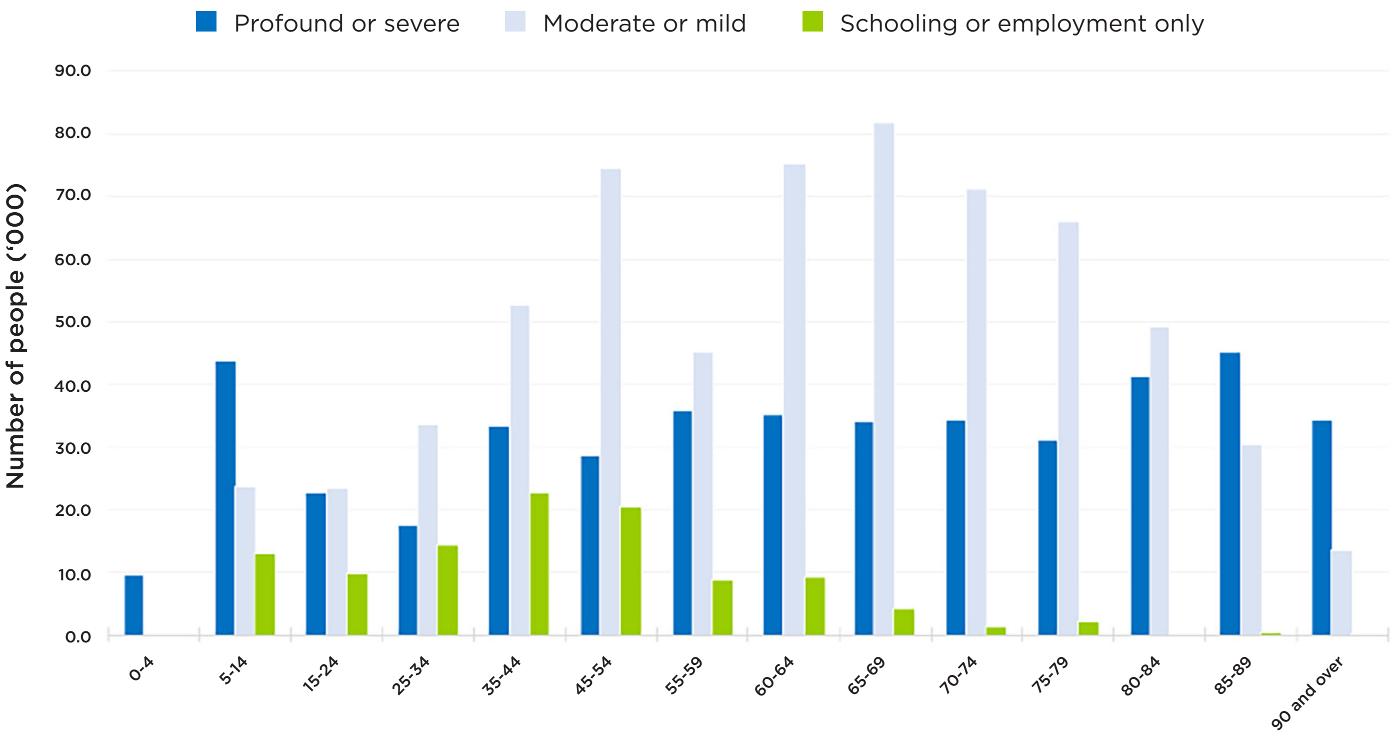


Figure 16 shows that:

- approximately 13% of respondents with a disability had no specific limitations
- eight percent had only a school or employment limitation
- approximately 33% of the population with disability (~455,000) had a mild core activity limitation, while almost 18% (~244,000) had a profound core activity limitation
- the distributions for NSW were very similar to Australia overall.

Figure 17 – Distribution of age group and level of disability (SDAC 2015)



Taking into consideration that the mild and moderate limitation groups (by definition) need no help, it is the expectation that specialist disability funding would be targeted towards people with severe or profound limitation.

In NSW, there are estimated to be 440,000 people with profound or severe core activity limitation. There is a high number of people with a profound or severe core activity limitation aged 5 to 14 years (~44,000) with approximately 220,000 people aged 65 years and over (refer Figure 17).

NDIS participants are likely to be a subset of the profound/severe need group

It was estimated in NSW at full scheme (2018/19) that there would be approximately 140,000 people supported by IFPs under the NDIS (NDIS participants), with the whole disability population supported through NDIS Information, Linkages and Capacity Building (ILC) funding.

A person meets the disability requirements of the NDIS if:

- they have a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition, and
- the impairment or impairments are, or are likely to be, permanent, and

- the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:
    - communication
    - social interaction
    - learning
    - mobility
    - self-care
- self-management, and
- the impairment or impairments affect the person's capacity for social and economic participation, and
- the person is likely to require support under the NDIS for their lifetime.[91]

It is also noted that a person must be under the age of 65 at the time of the access request.

The numbers in each of the segmented need groups can be estimated

The 1.4 million people with a disability in NSW (as at 2015) can be segmented into need groups, as outlined in Figure 18.

In very rounded terms, there are 440,000 people with profound or severe core activity limitation in NSW; 220,000 of them are over the age of 65; 224,000 of them are under the age of 65, of whom 140,000 are expected to be supported by the NDIS and 84,000 who are not. All people with disability should be able to receive supports through mainstream service systems, such as health, education and transport.

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[91] National Disability Insurance Scheme Act 2013; Cl 24 Disability requirements.

Figure 18 – Estimates of segmented need groups (SDAC 2015)

People with disability living in households

Age band	Profound		Severe	Moderate	Mild		No core limitation	All with disability
0 to 14	19.5	6.8	20.3	3.7	13.5	5.4	35.2	104.5
15 to 34	15.7		22.9	14.2	43.5		66.4	162.7
35 to 64	46.3		82.1	89.2	156.9		130.1	504.6
65 to 79	41.0		47.5	57.8	163.3		59.7	369.3
80+	7.6	39.6	26.2	23.8	34.7	36.0	4.1	172.0
Total	**176.5**		**199.1**	**188.7**	**453.4**		**295.4**	**1313.1**

People with disability living in cared accomodation

15 to 64	3.4	0.7	0.2	0.0	0.2	4.5
65 to 79	9.9	1.2	0.1	0.1	0.2	11.5
80+	43.3	3.8	0.4	0.5	0	48.0
Cared accomodation (all ages)	56.5	5.7	0.7	0.6	0.5	64.0
Total	**233.0**	**204.8**	**189.4**	**454.0**	**295.9**	**1377.1**

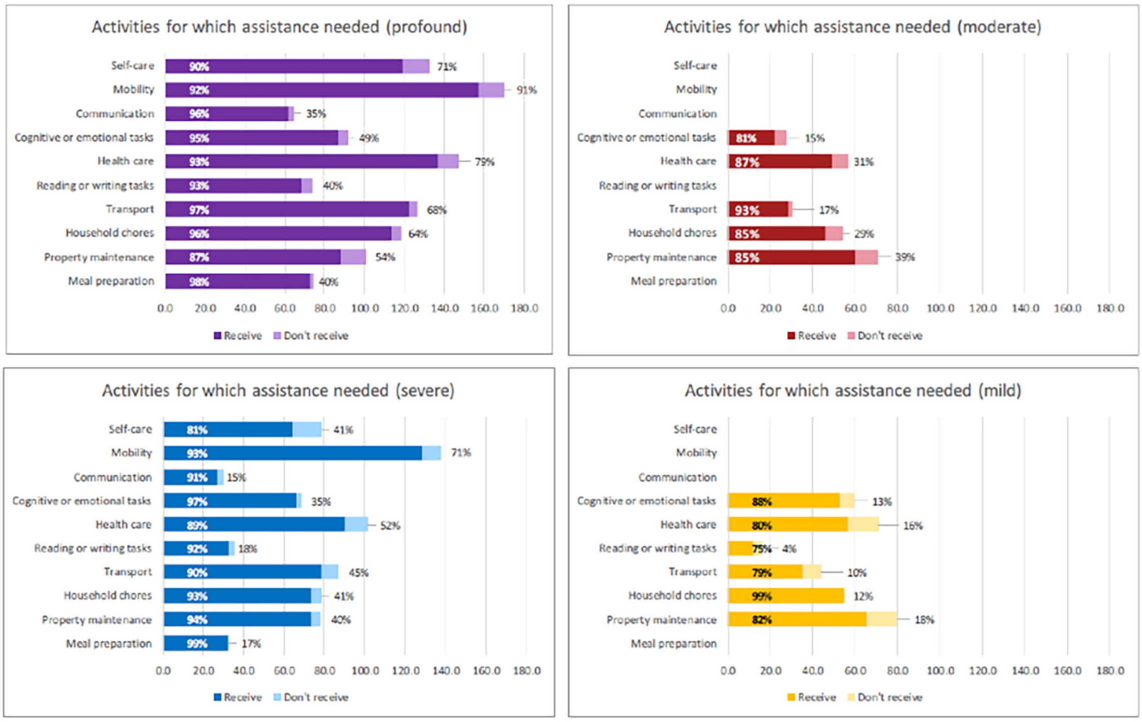
The assistance needed and received varies by need group

SDAC 2015 gathers responses on 10 broad activity groups where assistance is needed. These are classified into two groups:

- Core activities
    - Self care
    - Mobility
    - Communication
- Non-core activities
    - Cognitive or emotional tasks
    - Health care
    - Reading or writing tasks
    - Transport
    - Household chores
    - Property maintenance
    - Meal preparation

Figure 19 shows the assistance needed and received by need group. As expected, higher severity levels have a higher number of people needing assistance. The exception for this is for health care and property maintenance, where numbers with a mild core activity limitation are similar to other groups.

Figure 19 – Assistance needed and received- all NSW (SDAC 2015)



Activities for which assistance needed (profound)

Activities for which assistance needed (moderate)

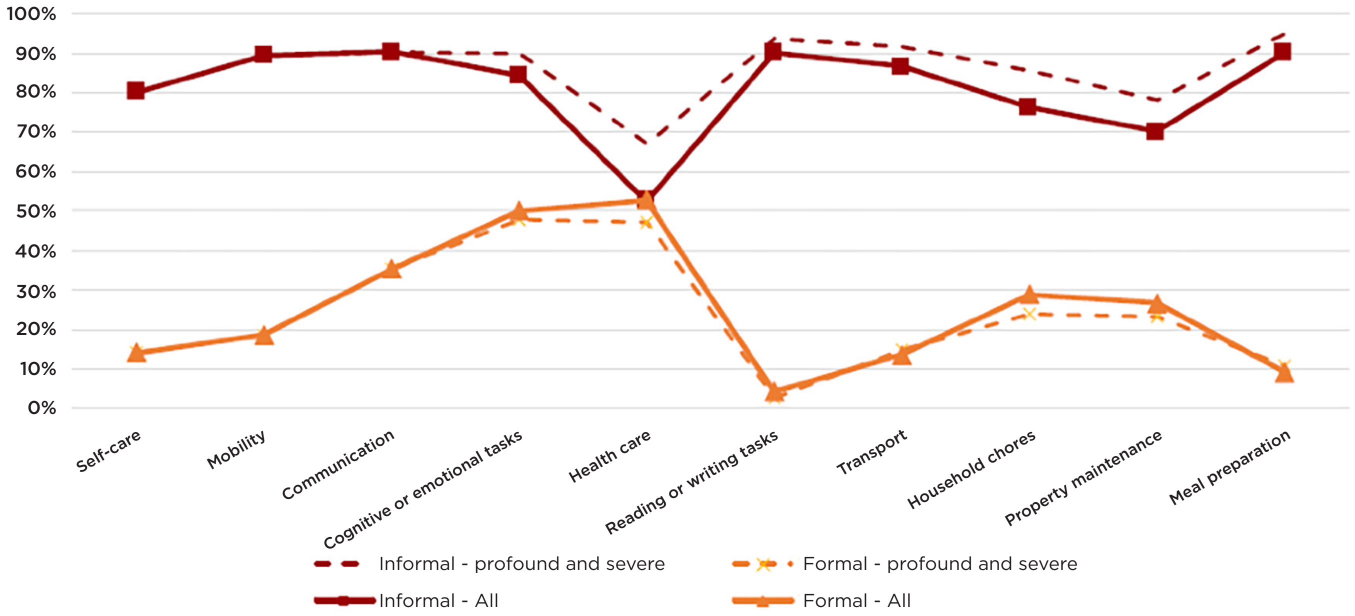
Activities for which assistance needed (severe)

Activities for which assistance needed (mild)

Assistance is provided both formally and informally

People with disability can receive assistance from both formal sources such as government or private not-for-profit organisations, as well as informal sources such as from family members or friends. The SDAC captures the source of assistance from respondents with disability, split by the 10 activity groupings. Apart from health care, 70% to 90% of those who needed assistance for an activity had informal support. For health care, communication and cognitive or emotional tasks, respondents were more likely to receive formal support. The trends were similar for the profound or severe group (dotted line) and for all people with disability.

Figure 20 – Proportion of people accessing formal and informal assistance (SDAC 2015)[93]



The disability population is growing

The ABS estimates the NSW population will grow by 25%, from 7.6 million in 2015 to 9.5 million in 2030. The population aged 64 years and under is forecast to grow by 22%; however, the 65+ population is expected to grow at a much faster pace (41% for 65-79; 60% for 80+). Age related disability will therefore become a more prevalent feature of the demand for services.

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[93] Note: the two sources of assistance are not mutually exclusive. For example, a person can receive help from a partner as well as from friends or government.

When these growth rates are applied to the age and disability segments of SDAC 2015, the following estimate of need groups arises.

Figure 21 – Estimate of need groups – 2030 projection (based on SDAC 2015)

People with disability living in households

Age band	Profound		Severe	Moderate	Mild		No core limitation	All with disability
0 to 14	23.8	8.4	24.9	4.6	16.5	6.7	43.1	128.0
15 to 34	19.3		28.1	17.4	53.4		81.5	199.7
35 to 64	55.6		98.7	107.2	188.6		156.3	606.4
65 to 79	57.8		67.1	81.6	230.4		84.2	521.1
80+	13.3	59.2	42.1	38.1	61.3	53.9	6.6	274.5
Total	**237.4**		**260.9**	**248.9**	**610.8**		**371.8**	**1,729.8**

People with disability living in cared accomodation

15 to 64	4.1	0.8	0.2	0.0	0.2	5.4
65 to 79	14.0	1.7	0.1	0.1	0.3	16.2
80+	69.5	6.1	0.6	0.8	0.0	77.0
Cared accomodation (all ages)	87.5	8.6	1.0	0.9	0.5	98.7
Total	**325.0**	**269.5**	**249.9**	**611.7**	**372.3**	**1828.4**

Again in very rounded terms, in 2030 there will be 590,000 people with profound or severe core activity limitation in NSW (440,000 in 2015); 330,000 of them will be over the age of 65 (220,000 in 2015); 260,000 of them will be under the age of 65 (224,000 in 2015), of whom 170,000[94] are expected to be supported by the NDIS (140,000 in 2015) and 90,000 who are not (84,000 in 2015). All 1.8 million people estimated with disability should be able to receive supports through mainstream service systems such as health, education and transport.

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[94] Unpublished actuarial estimate of NDIS participants aged 0-64. A further 15,000 NDIS participants are expected to be in the 65+ category.