The Impact of the NDIS on The Victorian Disability Advocacy Sector

Final Report to the Project Management Group

Paul Ramcharan and Declan Gleeson

30th October 2020

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Executive Summary

The National Disability Insurance Scheme has been described as the "largest reform of disability services in a generation"[1]. It is one of the most significant social policy reforms in Australia since the introduction of Medicare. Throughout the rollout of the NDIS, there has been significant analysis of the scheme's impact on disability service providers, but the scheme's impact on disability advocacy has not received an equivalent focus. This research has been commissioned to ascertain the impact of the NDIS on disability advocacy – specifically, the impact on individual advocacy, self-advocacy, and systemic advocacy provided by Victorian-based organisations that are funded via the Victorian Disability Advocacy Program (VDAP) and the National Disability Advocacy Program (NDAP).

Research insights were elicited through a wide variety of methodologies: a desk review of publicly available data to characterise the advocacy sector in Victoria; analysis of recent data from the Australian Charities and Not-for profits Commission (ACNC), the Department of Social Service's data exchange (DEX), the Office for Disability's (OfD) Quarterly Data Collection (QDC) information, and the Disability Advocacy Network Australia (DANA) to identify trends in advocacy and its funding; semi-structured interviews with Victorian disability advocacy leaders to explore changes in roles and role boundary issues; and focus groups with self-advocates, NDIS workers, Local Area Coordinators (LACs) and Support Coordinators. Throughout the research, FSSI researchers also convened an Action Research Group (ARG) comprised of disability advocates and self-advocates.

The research found that demand for disability advocacy had increased significantly since the introduction of the NDIS, mostly for NDIS related issues. Advocates frequently described these NDIS related issues as more time intensive and complex than other requests for advocacy. Many advocacy organisations also reported that, under present funding arrangements, they lack the resources needed to meet this increased demand.

Overall funding for Victorian disability advocacy organisations has risen since the introduction of the NDIS from a variety of sources. However, for the most part, funding increases - though welcomed - have been time-limited (for example, a two-year 25 per cent increase in VDAP funding, further extended in the context of COVID-19) and, in some cases, relatively modest and tightly prescribed (for example, funding to specifically support engagement with the Disability Royal Commission). While larger organisations received the largest funding increases, small and medium sized organisations particularly highlighted that their funding increases were inadequate. Study data indicated that all parts of the sector lack the necessary funding to keep up with demand.

The introduction of Information, Linkages and Capability Building (ILC) funding with the NDIS has been a boost to capacity given the relatively large size of this funding pool. However, it is important to distinguish between sector capacity and organisation capacity. The time taken for applications is high, leaving smaller organisations struggling to complete applications in a tender process that many talked about as challenging. Smaller organisations also struggle to compete in a competitive application process against organisations with access to specialist grant-writing resources. Moreover, since ILC funding is not recurrent funding, the capacity built over the course of ILC-funded project period cannot be easily sustained. This impacts the organisations concerned and

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[1] Sue Olney & Helen Dickinson (2019) Australia's New National Disability Insurance Scheme: Implications for Policy and Practice, Policy Design and Practice, 2:3, 275-290, DOI: 10.1080/25741292.2019.1586083

disproportionately affects the smaller organisations who cannot absorb reductions in funding and staffing without disruption. This is particularly pronounced for self-advocacy groups, many of whom rely on successful receipt of ILC funding to maintain their existence.

As a consequence of demand outstripping funding, many advocacy organisations have closed services, implemented waiting lists, or shifted their focus to the provision of information and one-off advice instead of providing an advocacy input. This was concerning and stressful for advocates, who felt that they were no longer able to provide advocacy to all of those in need.

Advocacy organisations have also attempted to adapt to a funding shortfall by restructuring their governance arrangements to navigate sustainability challenges and to better align their organisation with the goals of the ILC. For example, some advocacy organisations have recruited new skills to their boards and/or increased their user-leadership. Organisations have also sought to extend and diversify their funding and taken steps to redesign staff roles to meet the challenges of the external policy and funding environment. For example, in some organisations, staff have been required to take on a bigger range of advocacy and non-advocacy roles.

The research has found that the introduction of the NDIS has placed significant demands on disability advocates because people with disability often require the support of an advocate in order to receive an optimal outcome from the system, or there is potential for them to be left without support. In particular, the NDIS is not viewed as user friendly for people with disability, especially people with complex communication support needs, intellectual disabilities, or people from culturally and linguistically diverse communities.

In supporting people to navigate the NDIS, advocates have frequently gone beyond the formal bounds of their funded role and undertaken duties that should be performed by LACs or Support Coordinators. Advocates have taken on a particularly large number of roles during the pre-planning and planning process. This may be a consequence of the lack of understanding amongst LACs about the role of individual advocates, resulting in LACs pushing this work back onto the advocacy sector. The report has also found that the Support Coordinator role is unclear and continues to take shape over time, leading to issues at the boundaries between this role and that of disability advocates. Furthermore, Support Coordinators have often been unable to meet the needs of their clients due to persistently high caseloads and a lack of funding for support coordination in some NDIS plans, sometimes pressuring them to seek solutions and input from disability advocates.

When advocates cross over into work that should be undertaken by LACs or Support Coordinators, the decision is not made lightly. Advocates make these decisions under significant pressure from all parts of the NDIS ecosystem, including pressure from NDIS applicants and participants (and families) who are in distress and may be left unsupported without the assistance of an advocate.

The research found that self-advocates represent a group of predominantly unpaid labour seeking to achieve the NDIS goal on delivering inclusion for Victorians with a disability and building independence. These groups are establishing and maintaining significant networks which act to build confidence and support people with disabilities to learn self-advocacy skills in a safe environment. However, little attention has been paid to these outputs and the associated outcomes are not well known, understood or valued.

This report provides a number of recommendations. They include recommendations targeted to the NDIA that, if enacted, would **reduce** the burden on advocates by making the NDIS easier for people with a disability to navigate. However, these reforms would not completely eliminate the increased pressure that the NDIS has put on disability advocacy organisations and self-advocacy groups. There will be an ongoing role for advocates in supporting people to receive support through the NDIS. Consequently, the research also identifies the need for additional, ongoing advocacy funding to fill gaps and enable advocacy organisations to adequately meet demand, as well as better access to information and training.

The research findings indicate a need for a major rethink around how the ILC funding is applied to ensure that priorities are driven by and for people with disability, and to allow for continued funding and scaling up of successful projects and ideas.

It is recommended that mechanisms are put in place to demonstrate and measure the impact of self-advocacy. There is a huge untapped potential within self-advocacy, and additional funding will be required to use these resources in a way that achieves choice, control and community inclusion.

The disability advocacy sector has been an invaluable actor in protecting and upholding the rights of those with a disability, their families and carers. The sector’s contributions span a range of key areas including the promotion of self-actualisation and agency, improving service access and quality, safeguarding against neglect, exploitation, violence and abuse, and driving systemic reform. The implementation of these recommendations will better ensure that the Victorian disability advocacy sector can continue to play their role effectively and remain strong and sustainable into the future.

Recommendations

1. The Victorian and Commonwealth Governments should provide fair, responsive and ongoing core funding for individual and legal advocacy to meet the clear and evident increases in demand. Future funding arrangements should:
    a. Reflect demand and unmet need
    b. Include an audit of waiting lists
    c. Be based on a new funding formula that recognises the complexity and duration of advocacy cases
    d. Provide comprehensive, timely, quality support for NDIS and non-NDIS issues
    e. Ensure people have access to fair representation and advice to navigate NDIS reviews and appeals.
2. The Victorian and Commonwealth Governments should address the current gaps in systemic advocacy by:
    a. Providing disability advocacy peaks with sustainable funding so that they can fulfil their role as a representative voice for the advocacy sector and a central point of engagement for government
    b. Providing funded disability advocacy organisations with dedicated funding for systemic advocacy, in addition to their core funding for individual and legal advocacy.
3. In recognition of the critical role, unique value and impact of self-advocacy, the Victorian and Commonwealth Governments should provide dedicated, ongoing core funding to support self-advocacy groups to:
    a. deliver individual, group and peer support
    b. undertake assertive outreach activities, community engagement and capacity building work
    c. provide information and advice
    d. build and maintain networks and relationships
    e. protect and promote the safety and rights of people with disability
    f. identify and elevate individual and systemic issues
    g. undertake, participate in and coordinate systemic advocacy.
4. The Commonwealth Department of Social Services should initiate a codesign process with people with disability, advocates and self-advocates to redesign and reorient the ILC grants program to:
    a. ensure priorities are driven by and for people with disability
    b. eradicate the destructive boom-bust cycle of short-term funding
    c. allow capacity to be built, embedded and scaled through sustainable activities and programs

   d. provide the conditions for innovation to flourish – a key priority should be ensuring advocacy and self-advocacy organisations' core operations are sustainably-funded, so that they have the resources to incubate ideas, develop and cost models, and put together funding proposals, including ILC grant applications.

5. To address gaps in the skills, knowledge and confidence of disability advocates in relation to the NDIS, the NDIA should undertake an audit of the training needs of the disability advocacy sector and deliver a comprehensive calendar of targeted and timely training opportunities.
6. To reduce the burden of advocates during the pre-planning and planning stages, the NDIS should identify and address the knowledge needs of:
   a. Adjacent workforces who are being relied upon to support NDIS access, including GP's and medical specialists.
   b. The LAC workforce in relation to potential gaps in their understanding of disability and its impacts.
7. Victorian and Commonwealth Government funding agreements for disability advocacy should adequately resource regular and ongoing provision of external professional supervision, mentoring and support for disability advocates.
8. The sector is continuing to adapt to profound policy and funding reform. The Victorian and Commonwealth Governments should continue to invest in capacity building for disability advocacy and self-advocacy Boards and Executives, with a focus on projects delivering leadership training, mentoring, networking and practical resources.
9. Commonwealth and State Governments, and the NDIA should work at a systemic level to improve provision of information, advice and representation of people with disability. Systemic changes need to include:
   a. Clearly mapping and defining the roles of disability advocates, LAC and support coordinators.
   b. Ensuring all NDIS partners have adequate funding to be able to deliver the defined functions.
   c. Developing a nationally consistent supported decision making policy, and funding supported decision making programs in addition to existing disability advocacy services.
   d. Developing strategies to ensure people from diverse and hard to reach communities have support with preplanning and decision making through assertive outreach strategies.
10. The NDIA should ensure people with disability are well supported to understand and use their NDIS plan by:
    a. Ensuring LACs inform all participants about support coordination during planning
    b. Directing LACs to proactively identify participants who may need assistance to understand, implement and monitor their plan
    c. Providing adequate, ongoing support coordination funding for all participants who need it, including specialist support coordination for people with multiple and complex needs
    d. Developing a model which ensures longer term monitoring of participants who require additional support to confirm that plan implementation has taken place.

11. Mutual understanding and partnerships between LACs and disability advocacy organisations should be encouraged and resources. The NDIS should also work with LAC partners in the community to ensure they are adequately funded to undertake the community engagement aspects of the role.
12. The Commonwealth Department of Social Services and the Victorian Office for Disability should harmonise and expand data collection, data analysis and reporting mechanisms for disability advocacy and self-advocacy to:
    a. capture more high-value information (e.g. unmet demand, the complexity of cases and issues, output and impact)
    b. strengthen reporting capabilities and ensure funding decisions are evidence-based.
    c. build a national understanding of the value of advocacy and self-advocacy by demonstrating the outcome of investment in this work
13. That the Victorian Government fund further research into knowledge and evidence gaps identified in this report, in order to:
    a. form a more comprehensive view of systemic issues affecting access to, experiences of, and the impact of disability advocacy and self-advocacy
    b. use this evidence to make a case for the NDIA, DSS and other parts of the NDIS ecosystem (Planners, LACs and Support Coordinators) to make policy and practice changes and target funding to initiatives that can strengthen the disability advocacy and self-advocacy sectors.
14. Specifically, it is recommended that the Victorian Government fund research into:
    a. The impacts of the NDIS on people with disability in Victoria (eg. trauma and stress experienced by people with disability when engaging with the NDIA)
    b. The DEX database in relation to the hypothesized increase in the range of disability groups receiving advocacy over the NDIS period
    c. Waiting lists to examine who is losing out and what the impacts are
    d. How best to scale supported decision-making, drawing on previous evaluations of supported decision-making projects
    e. The spread of different forms of advocacy and their availability and accessibility in urban, regional and remote areas across Victoria
    f. The development of indicators through which outputs and impacts for self advocacy can be measured
    g. The number of people who fall through the support coordination and advocacy gap, and the impact this has on their lives.

Abbreviations List

ABI – Acquired Brain Injury
ACNC – Australian Charities and Not-For-Profit Commission
CCB – Community Capacity Building
CRU – Community Residential Unit
DARU – Disability Advocacy Resource Unit
DEX – Department of Social Services Data Exchange
DHHS – Department of Health and Human Services
DSP – Disability Support Pension
DSS – Department of Social Services
FSSI – Future Social Service Institute
GP – General Practitioner
ID – Intellectual Disability
ILC – Information, Linkages and Capability Building
LAC – Local Area Coordinator
MS – Multiple Sclerosis
NDAP - National Disability Advocacy Program
NDIA – National Disability Insurance Agency
NDIS – National Disability Insurance Scheme
OfD - Office for Disability
QDC - Quarterly Data Collection, Undertaken by OfD
OT – Occupational Therapist
RMIT – Royal Melbourne Institute of Technology
SARU – Self Advocacy Resource Unit
SDM – Supported Decision-Making
VALID – Victorian Advocacy League for Individuals with Disability
VCOSS – Victorian Council of Social Service
VDAP – Victorian Disability Advocacy Program

1. Project Overview

1.1 Background to the research project

The Victorian Council of Social Service (VCOSS) has been engaged by the Office for Disability to undertake a project that will:

- Provide the Victorian Government with robust evidence of the impact of the NDIS on Victorian disability advocacy and self-advocacy groups.
- Produce recommendations that the NDIA, Commonwealth and Victorian Governments and the Victorian disability advocacy sector can implement to address systemic issues identified in the research (including recommendations to address demand drivers).

VCOSS commissioned the Future Social Service Institute (FSSI) to undertake the research component of the project. This is the final report of the research.

This report aims to document how the advocacy sector has been impacted by the NDIS. As the evidence is presented key findings are identified at the bottom of each section.

A companion version of this report has also been produced in non-technical language for wider circulation. It provides a quick, easy-read version usable by people requiring fast access to essential findings and recommendations, and for those who can better digest summary information.

2. Methodology and Approach

This research explores the impact of the NDIS on disability advocacy in Victoria. The research methodology comprises five key components:

1. Analysis of secondary data
2. Interviews with advocacy leaders
3. Focus groups with self-advocates
4. Focus groups with Support Coordinators and Local Area Coordinators (LACs)
5. Action research group

2.1 Analysis of secondary data.

The FSSI research team collected data from a range of secondary sources including internet searches[2], Department of Social Service (DSS) DEX (Data Exchange) data, and Office of Disability (OfD) Quarterly Data Collection (QDC).

Internet searches were used to explore:

- The range of advocacy groups across the state and what their websites told us about their advocacy work. We started with the DARU database of advocacy organisations, and DSS and DHHS lists. The research team then reviewed the websites of identified organisations to understand their work in more detail.
- The Information Linkages and Capacity Building (ILC) funding received from the NDIS and from the Office for Disability (OfD) in Victoria.

Commonwealth DEX data provided to us showed the advocacy cases and focus of advocacy between 2016/17 to 2019/20. Data was also provided around the types of issues for which advocacy was performed (e.g. justice, family violence, employment, NDIS, see Appendix 5). The data was analysed to explore the relationship between funding and demand for advocacy over time as reported later.

Analysis of the Victorian Office for Disability (OfD) Quarterly Data Collection (QDC) from advocacy groups (n=24) between 2016/17 and 2019/20 was undertaken. This allowed us to explore trends in the work of the advocacy sector under the Victorian Disability Advocacy Program (VDAP) over a similar period to data extracted from DEX. The data were loaded onto a statistical package to allow analysis of trends and outcomes during the NDIS period 2016/17 to 2919/20. The completion of the QDC data was patchy. Whilst data was complete in the first quarter of 2016/17 (n=24) it varied across time. In 2016/17 the mean response rate over the years was 18.75 responses out of 24. It was 18.25 in 2017/18, 18.75 in 2018/19, but only 13.25 in 2019/20. This made comparison of the growth in advocacy cases over time problematic.

FSSI would like to extend thanks to OfD and DSS for their support in providing relevant data.

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[2] See Appendix 1

2.2 Interviews with Advocacy Leaders.

Working with Disability Advocacy Resource Unit (DARU) and Self-advocacy Resource Unit (SARU), a sample of 20 Victorian Disability Advocacy Organisations was selected from which to recruit interview participants. A maximum variation[3] sampling strategy was used to ensure coverage of a diverse range of advocacy groups and types (Figure 1).

Figure 1: Advocacy types delivered by advocacy leader interviewees

Type of advocacy delivered	Number*
Individual Advocacy	18
Systems advocacy	12
Citizen advocacy	1
Supports to Self-advocacy	7
Self-advocacy	3

*Total number is over 19 as some organisations delivered several forms of advocacy.

A semi-structured interview schedule (Appendix 2a) was employed to explore the nature and activities of each group; their funding experience over the past few years; and their experiences under the NDIS. The data from each interview were transcribed and analysed to identify common issues arising over the NDIS period and assess the impact of the NDIS on the sector over time. Nineteen of twenty planned interviews were completed, with participant circumstances preventing one from taking place. The FSSI researchers assessed that at this stage that the data was 'saturated'. This means very little new information was emerging at the end of each new interview. This gave us confidence that our data accurately reflected the advocacy sector's experience.

2.3 Focus groups with self-advocates

Two focus groups were organised through SARU. Fifteen (15) self-advocates participated in these groups (eight in the first and seven in the second). The data collection[4] was designed to explore the work of self-advocacy and self-advocates, to understand the broader challenges facing individuals engaging with the NDIS, and to explore how self-advocacy might be strengthened in the future.

2.4 Focus Groups with Support Coordinators and Local Area Coordinators (LACs)

Advocates and self-advocates are part of a large and complex eco-system. Since the introduction of the NDIS, this eco-system includes Support Coordinators and Local Area Coordinators (LACs). The FSSI research team identified the importance of engaging with these workforces, to gain insights into

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[3] Using a maximum variation sampling strategy allowed us to cover the widest variety of groups possible: large, medium and small; offering differing forms of advocacy; across city and regional areas; and addressing specific sub-groups (for example, groups relating to ethnicity, age, and LGBTIQ communities.

[4] See Appendix 2b: Focus group questions for self-advocates.

their experience and knowledge of advocacy, including their perceptions of the role of disability advocates.

The FSSI research team made a successful *External Research Request* to the NDIS to undertake two focus groups, one with Support Coordinators and one with LACs. The themes for exploration with these groups are shown in Appendix 2c and 2d.

2.5 Action Research Group.

This research is part of a larger project that seeks to understand the impact of the NDIS on disability advocacy and take steps to moderate those impacts where they constrain the sector's capacity and participant outcomes. VCOSS has commissioned the Disability Advocacy Resource Unit (DARU) and the Self-advocacy Resource Unit (SARU) to develop resources and tools for the advocacy sector that are informed by insights from the FSSI research and which would have most impact on sector change.

The FSSI researchers convened an Action Research Group with representatives selected by SARU and DARU through an Expression of Interest process promoted to the sector. All nominees were subsequently invited to join the group to consider the emergent findings of the project. Leaders from 10 advocacy organisations participated across the five meetings alongside representatives from DARU, SARU and the research team (Appendix 2e). Feedback from advocacy leaders enabled DARU and SARU to identify and prioritise ideas for resource development, and discuss the framework for their design, including selection of the right medium to deliver these resources.

2.6 Research Ethics

FSSI obtained approval from the RMIT Human Research Ethics Committee to meet the requirements of the National Health and Medical Research Council's, *National Statement on the Conduct of Human Research*.

3. The transition to the NDIS

The transition to the NDIS caused significant disruption across the disability advocacy sector, both for people with disability, and for the advocacy agencies that seek to improve their lives. Advocacy organisations have invested considerable time and resources in learning how to navigate this new and complex system:

> *'And what we found really quickly was it was complex. The issues were complex. And we had no resources like training in NDIS policies and legislation. And if you had a look at the NDIS legislation it's pretty extensive'.*

Advocates learned about the NDIS through experience and engagement. They did not receive any formal support from the NDIS to assist with the transition, such as NDIS training, resources to support their learning, or the establishment of a community of practice:

> *'We had to learn it by going to hundreds of planning meetings.'*

There was a common view among research participants that the NDIS continues to evolve, placing advocates under ongoing pressure to adapt to changes.

Since the introduction of the NDIS, new roles such as Local Area Coordinator, Support Coordinator, and NDIS Appeals Officer have emerged. Enquiry lines to address NDIS queries have also been established. These structural shifts within the sector have changed the contacts and relationships of advocates. One participant observed:

> *'…we had to rebuild all of the context for NDIS relationships…we've had… to try and rebuild an understanding of our role and all of the jurisdictional issues as they happen alongside helping people get on board.'*

NDIS processes have also changed the way advocates engage with disability service providers, resulting in increased administration requirements.

> *'…the NDIS itself has created a whole bunch of work … So the block-funded type work before meant you were only dealing with…service provider, usually the Victorian Government or individuals. But now you've got this whole extra layer of admin and bureaucracy and issues that you have to deal with, which is the NDIS.'*

The experience of people with disability has changed how advocates work. Research participants spoke of people with disability struggling to understand the system and to have sufficient knowledge to be able to advocate for themselves. Individual advocates report that they are providing more information and advice to support people to advocate for themselves.

> *'…disabled people are still learning the skills that they need to be able to represent themselves. What that means for us is that there is additional time that advocates need to ensure that people do have the capacity to be able to self-advocate'.*

The NDIS has also increased eligibility to disability services. Advocates report that the range of people for whom they provide advocacy has changed significantly since its introduction:

> *‘We’re now dealing with a greater range of disability than we were. A lot of our work prior to NDIS was the engagement with DHHS around people with ID, people with cognitive impairment … Now we’re much more engaging with people who have ABI, people who have neurological impairments…’*
>
> And,
>
> *’So now, with NDIS, there is a whole bunch of people who would never have been eligible for support except maybe for DSP, but now there’s a huge population of people who are eligible.’*

They are having to learn about a wider range of disabilities, including psychosocial disabilities, ABI and neurological impairments, and support more people than ever before.

Changes to advocacy funding, organisational governance and reporting structures

The funding environment for advocacy organisations in Victoria has also changed since the implementation of the NDIS[5]. Victorian Disability Advocacy Program funding of $3.1 million is committed annually to 23 advocacy organisations in Victoria. In 2016-17 an additional $1.5 million was committed through the Disability Advocacy Innovation Fund for self-advocacy, place-based initiatives, rural and regional areas, as well as amongst Aboriginal and LGBTIQ communities. This was supplemented in 2017-18 by $1.57 million to 15 funded projects focused on people with Acquired Brian Injury (ABI), women with disability, LGBTIQ and culturally diverse groups as well as those in rural and regional areas.

The Victorian Government, through the Office for Disability, has more recently implemented the Victorian Disability Advocacy Futures Plan 2018-20 offering a 25% increase in funding to 23 advocacy agencies over the two years. An additional $3.1 million was then added to the Victorian Disability Advocacy Futures Grants Program[6] committed to a number of programs[7] designed to achieve four outcomes: Inclusion, Connection, Responsiveness and Sustainability.

Additionally, over the period since the introduction of the NDIS, DSS funding, as reported below, has provided the following funding - advocacy support under the National Disability Advocacy Program (NDAP); Appeals funding, which includes advocacy supports and legal assistance; Disability Representative Organisations funding, largely for systems advocacy; and, in the past year, funding to support people with disability to make submissions to the Disability Royal Commission. A further tier of temporary, project-specific funding can also be accessed through the ILC grants program.

There is now a complexity to funding that did not exist prior to the introduction of the NDIS. But these new, multiple avenues for temporary funding of disability advocacy have not led to confidence in a sector which is in need of stable and ongoing funding.

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[5] https://www.statedisabilityplan.vic.gov.au/advocacy-futures#:~:text=The%20Victorian%20disability%20advocacy%20futures,will%20guide%20the%20government%20to%3A&text=respond%20to%20the%20community's%20call,advocacy%20in%20Victoria%20from%202021.Victorian_disability_advocacy_futures_plan_2018_2020_word_version

[6] https://providers.dhhs.vic.gov.au/victorian-disability-advocacy-futures-grants-program-summary-funded-initiatives for 2019 funded initiatives.

[7] See, https://providers.dhhs.vic.gov.au/victorian-disability-advocacy-futures-grants-program-summary-funded-initiatives

As a consequence, advocacy organisations are establishing new Board, Executive and management groups to reflect the challenges of NDIS-related demand pressures and concerns about their funding. These groups are making strategic decisions and adapting staff working practices to provide efficiencies which can ensure their sustainability, and to provide greater impact.

Other changes

Advocacy leaders reported a growing awareness of advocacy services amongst people with disability in Victoria. This is reflected in increased demand for their services. Our research did not provide an opportunity to collect and analyse data about **where** awareness has increased (which cohorts) or **how** awareness increased at a time when many advocacy organisations are not proactively marketing their services given waiting lists. However, we did elicit insights into a key driver (the ‘why’). Many interviewees reported increased stress amongst people with disability around accessing the NDIS and the processes that are involved:

> *‘…we're seeing people who are navigating the NDIS quite stressed, which is new for us.’*

It is not the focus of this report to explore the impact of the NDIS on people with disability, but much of our data indicates that this area could be a useful focus for further research.

Key Finding 1

Advocates learned about the NDIS by experience and engagement. This was a significant undertaking and continues to be so as the NDIS itself is still evolving. They did not receive formal NDIS training, nor any resources to support their learning, nor a community of practice.

4. The state of the Victorian advocacy sector.

The demand for advocacy has risen over recent years. OfD QDC data shows a significant increase in demand for advocacy services relating to the NDIS over the years 2016/17 to 2019/20. Of particular note is the threefold increase in the provision of one-off information and advice provided by advocacy organisations since 2016/17. Whilst the overall funding to advocacy groups has increased, its distribution has not fallen evenly, with larger organisations tending to benefit the most. Some smaller organisations have experienced moderate increases to funding as well as spikes in funding through ILC grants, but upon completion of the grant, funding tends to fall back to previous levels.

Additionally, there has been a diversification of funding amongst larger organisations, with not all work focusing on advocacy. This has the potential to lead to mission drift.

4.1 Characterising the Victorian disability advocacy sector over the NDIS period.

The data and findings in this section were collected from secondary data sources as outlined in 2.1.

4.1.1 Type of disability advocacy provided

The research team identified 62 organisations providing disability advocacy in Victoria. The most cited form was systemic advocacy followed by individual advocacy. However, the majority of organisations engage in multiple types of advocacy (Figure 2). Most self-advocacy groups were linked to SARU and VALID, but we also found some larger organisations also supported self-advocacy. This is shown as ‘Supports self-advocacy’ in Figure 2. For example, SARU alone supports 18 independent self-advocacy groups across the state whilst VALID supports the North, South East and West self-advocacy networks comprising around 200 members.

Figure 2: Types of advocacy performed by Victorian disability advocacy groups.
(Numbers add up to more than 62 because some organisations deliver more than one form of advocacy).

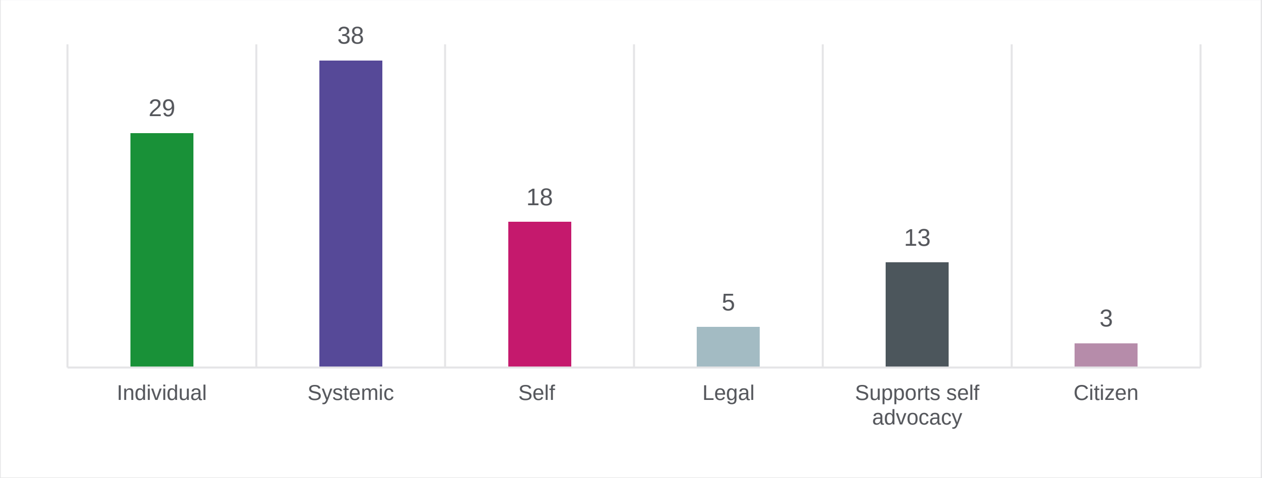


Figure 3: Website findings of disability groups that were the focus for Victorian advocacy organisations

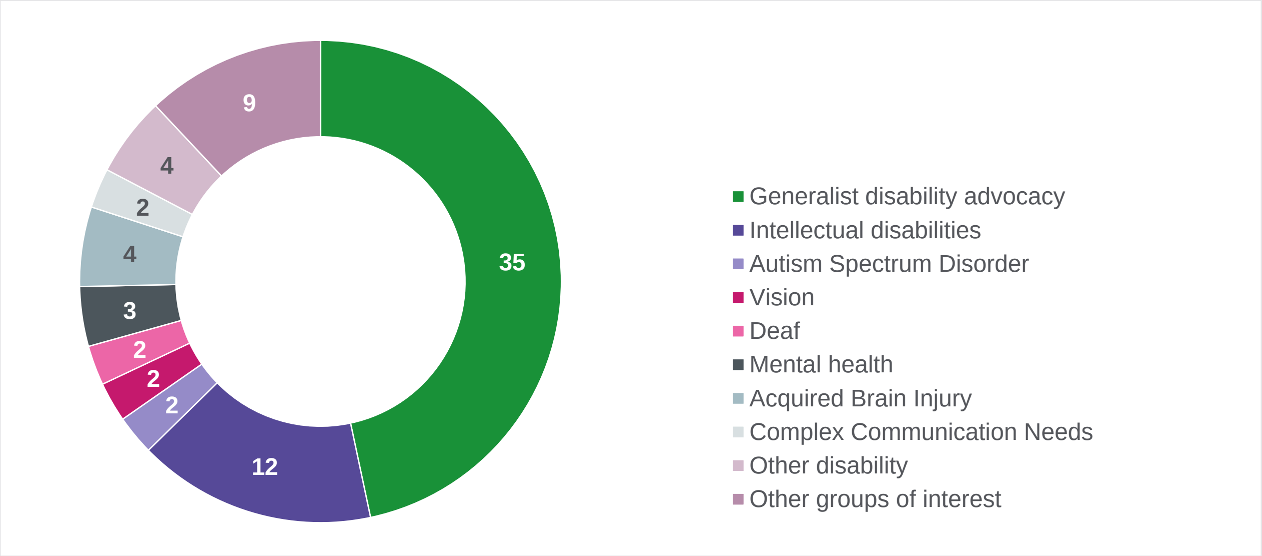


Figure 3 shows that over a third of advocacy groups are generalist, while 12 groups focus their support for people with intellectual disability and nine other groups provide specialised support for people with other specific needs (for example, organisations that have a key focus on people with disabilities from culturally and linguistically diverse backgrounds).

Some advocacy leaders interviewed for the study suggested that certain groups and areas, particularly in regional Victoria, are underserviced by advocacy. Conversations in the Action Research Group indicate that the present range of Victorian advocacy organisations has more to do with historical legacy rather than strategic planning. More research could be undertaken to explore whether all forms of advocacy are equally accessible to all across Victoria. It would also be useful to know how accessible advocacy is for people with varying disabilities to enable a strategic approach which accomplishes equality of accessibility to all groups.

Key Finding 2

Not enough is known about what forms of advocacy (individual, systemic, citizen, self, systemic and legal) are available to the range of disability groups across Victoria. It would also be useful to know how accessible advocacy is for people with varying disabilities to enable a strategic approach which accomplishes equality of accessibility to all groups.

4.2 Overall funding for the disability advocacy sector over the NDIS years

Funding varies widely across the Victorian disability advocacy sector.

Most organisations that solely deliver disability advocacy have only limited funding.

Highly funded organisations tend to deliver other services (in addition to advocacy), such as education and training.

Government funding has increased disproportionately for larger organisations whilst most organisations have had marginal increases in funding since 2015, in addition to temporary funding spikes (examples of which were described earlier in this report). Some Victorian disability advocacy organisations have also been able to access ILC funding to support their work. In some instances, ILC funding has enabled them to respond to existing clients in new ways or to expand their services to work with new client groups. However, the one-off nature of these payments may not positively affect organisational sustainability.

To explore how the overall financial health of the advocacy sector in Victoria has changed since the introduction of the NDIS, Australian Charities and Not-for-profits Commission (ACNC) data for the period 2015 to 2019 was examined. This data includes *all* government and non-government funding received by Victorian disability advocacy organisations who submitted data to ACNC.

It was difficult to draw clear conclusions from this data for the following reasons:

- Some self-advocacy groups may have submitted their financial information to the ACNC under the umbrella of a larger advocacy organisation, meaning their revenue for a given year cannot be clearly identified.
- It was also difficult to discern what proportion of an organisation's revenue is allocated to disability advocacy, as some advocacy organisations engage in activities other than advocacy.
- Only 28 advocacy organisations were found to have consistent data across all years.

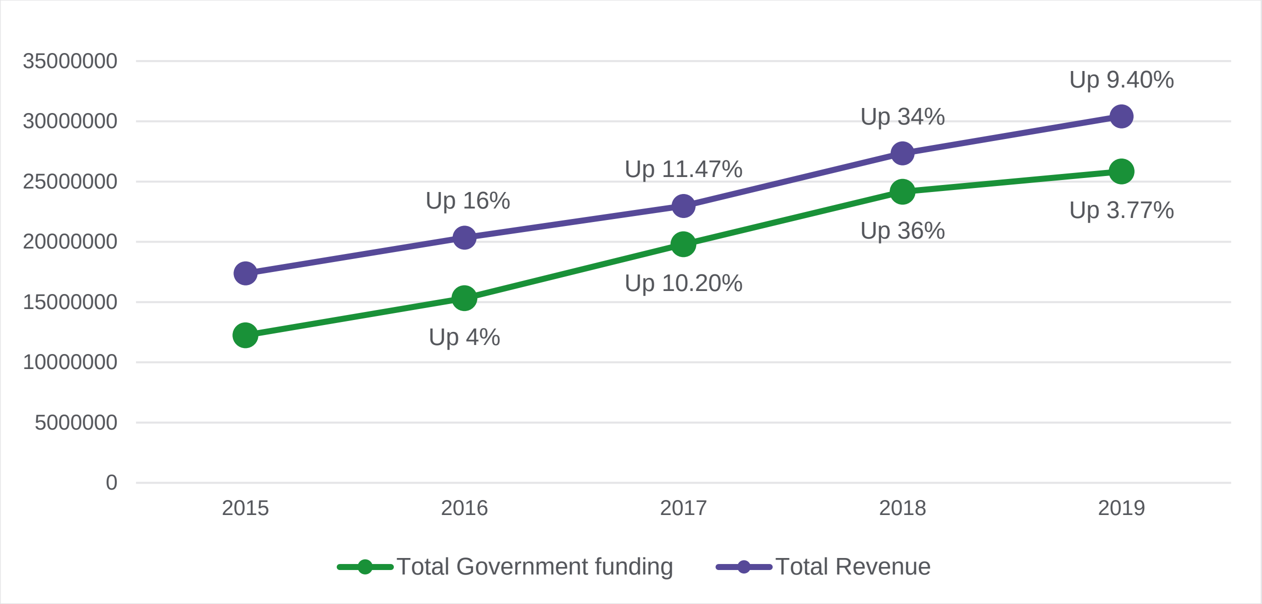
Notwithstanding these constraints, we identified that:

- Total revenue and government funding to advocacy organisations both increased across this period for this sample of 28 organisations.
- The majority of advocacy organisations had an income less than $500,000, with a significant number below $200,000 per annum. There were a few outliers – for example, some of the larger advocacy organisations listed operate nationwide, receiving revenue of up to $10 million per year

and engaging in systemic advocacy campaigns to change community attitudes and legislation. These organisations also engage in activities additional to advocacy, such as providing education and training services or running community events.

- There is a significant reliance on government funding within the sector (Figure 4).

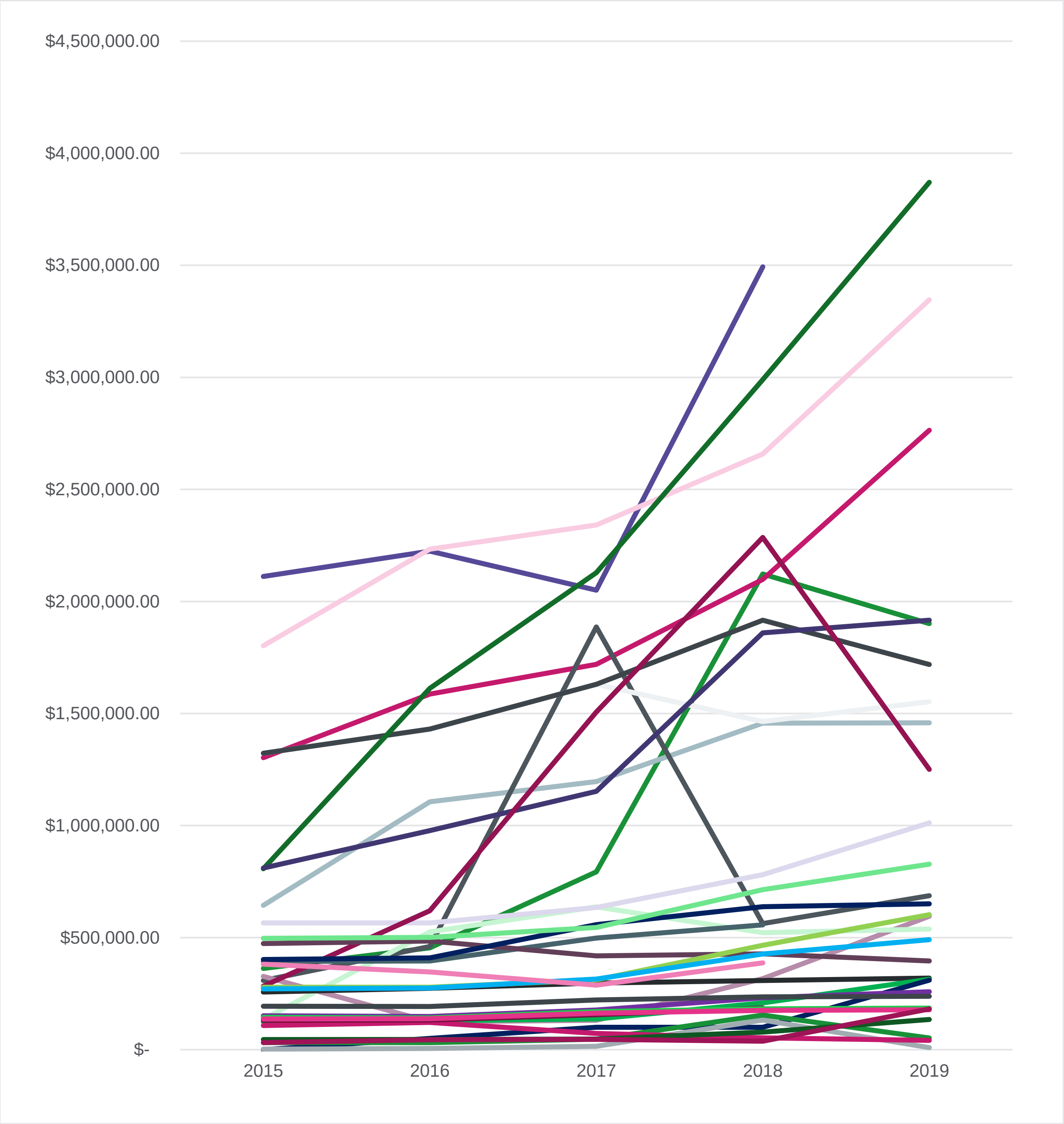
Figure 4: Total government funding and revenue to the advocacy sector 2015-2019



A breakdown of the total government grants for each advocacy organisation over the 2015-2019 period was then undertaken. Data for 33 organisations - for whom the ACNC had at least one year of funding data - was analysed to identify individual trends across five financial years as shown in in Figure 5.

Figure 5 demonstrates that most of the grant increases over the five-year period are attributable to larger advocacy organisations. Small (revenue up to $500,000 income) and medium sized (revenue under $1 million) received very little of the overall increases in government grants. It is noticeable that 22 of the 33 organisations displayed in Figure 5 are small or medium sized. Spikes in funding for several organisations are mostly attributable to ILC grants.

Figure 5: Changes in Government (VDAP and NDAP) funding for 33 Victorian disability advocacy organisations 2015-2019.



As described earlier in this report, the ILC grants program has emerged as one of the new potential sources of funding for disability advocacy and self-advocacy groups. To date, these grants have been administered by the NDIS but will be administered by DSS[8] in future. The Victorian

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[8] https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability/information-linkages-and-capacity-building-ilc-program

Government also provided time limited funding for ILC-type activities with National Disability Insurance Agency (NDIA) funding under four areas of investment as part of transition to the NDIS[9]. This funding has now ceased with this activity having moved to the ILC.

Our analysis of the categories of all Commonwealth and Victorian ILC grants is shown in Appendix 3. There are clearly some ILC grants which lead to an increase and strengthening of the advocacy sector such as ‘creating new or supporting existing self-advocacy groups’, ‘supporting people to build self-advocacy skills’ and ‘supporting systemic advocacy projects’. There is also funding for capacity building to strengthen organisations, disability advocacy groups included.

Some grants sought to capacity build the self-advocacy sector. But it is not clear how capacity building can gain long term traction and sustainability via these time-limited grants. This is discussed later in the section on self-advocacy. It can be seen that ‘teaching leadership and employment skills’ has also been funded. This is in some ways a departure from advocacy funding but is associated more closely to building systems of community inclusion. This is important because it shifts attention away from disability services and more to the engagement of people with disability in their own communities. Supporting people with disability to become employed and to have a stronger say in local communities has the potential to benefit those communities through community capacity building (CCB) for diversity and inclusion. Since the NDIS sees community inclusion as a significant outcome of the policy, this is an important role additional to supporting people to access disability support services.

Key Findings 3

3.1 Funding varies widely across the disability advocacy sector. Most Victorian disability advocacy organisations that solely deliver advocacy have limited funding. Most organisations seem to have had only marginal increases in funding since 2015, with larger organisations receiving disproportionately large Government funding increases in this period.

3.2 Some Victorian disability advocacy organisations have been able to access ILC funding to support their work in some instances. ILC grants have enabled them to respond to existing clients in new ways or to expand their services to work with new client groups. However, the one-off nature of these payments may not positively affect organisational sustainability.

4.3 The data from DSS Data Exchange

Data analysed in this section was extracted from the Commonwealth Department of Social Services - Data Exchange (DEX), which was current as of 8 September 2020.

The data provided to the research team displays the various National Disability Advocacy Program (NDAP) funded activities (services) performed by all 17 NDAP funded Victorian advocacy organisations, and the total number of times (sessions) that each service was performed across three financial years, from 2017 to 2020.

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[9] See https://www.vic.gov.au/disability-information-linkages-and-capacity-building, which identifies organisations receiving funding in 2019.

Funding from DSS can be broken down into a number of areas. First, funding for Disability Representative Organisations (between 2017/18 and 2020/21) which largely fund systemic advocacy, has increased marginally over these years. Significant DSS funds for advocacy support in relation to the Disability Royal Commission has been provided in 2019/20 and are projected to continue at the same level in 2020/21.[10]

The more important data related to NDAP funding for Advocacy Support between 2016/17 and 2019/20 which shows a marginal increase.

There has been some additional funding provided under NDAP from 2018/19 in relation to supported decision-making.

Funding increases have taken place in the NDIS Appeals Program Funding. Between 2016/17 and 2019/20 advocacy support in relation to Appeals has risen by 1.8 times its level in 2016/17. Funding for legal advocacy over the same period has started from a very low base but has more than trebled in that time. The increase in this funding is not surprising given the continuing enrolment of people into the NDIS.

DSS funding for systemic advocacy and NDAP advocacy support have seen only marginal increases since 2016/17. Reflecting increasing numbers of NDIS participants, funding for appeals and reviews has nearly doubled. Whilst legal advocacy funding has trebled it has done so from a very low baseline.

The DEX data provided in relation to NDAP advocacy support were analysed to find whether the number of sessions being performed by these Victorian advocacy organisations over this three-year period had increased.

The analysis found that the total number of sessions performed for all advocacy services increased across the three-year period, with the most significant increase in advocacy sessions occurring from 2017-18 to 2018-19 as shown in Figure 6. Also evidenced is an increase in NDIS related sessions performed by advocacy organisations, and an increase in these sessions as a proportion of their total work, from 18% in 2017-18 to 37% in 2018-19 and 2019-20.

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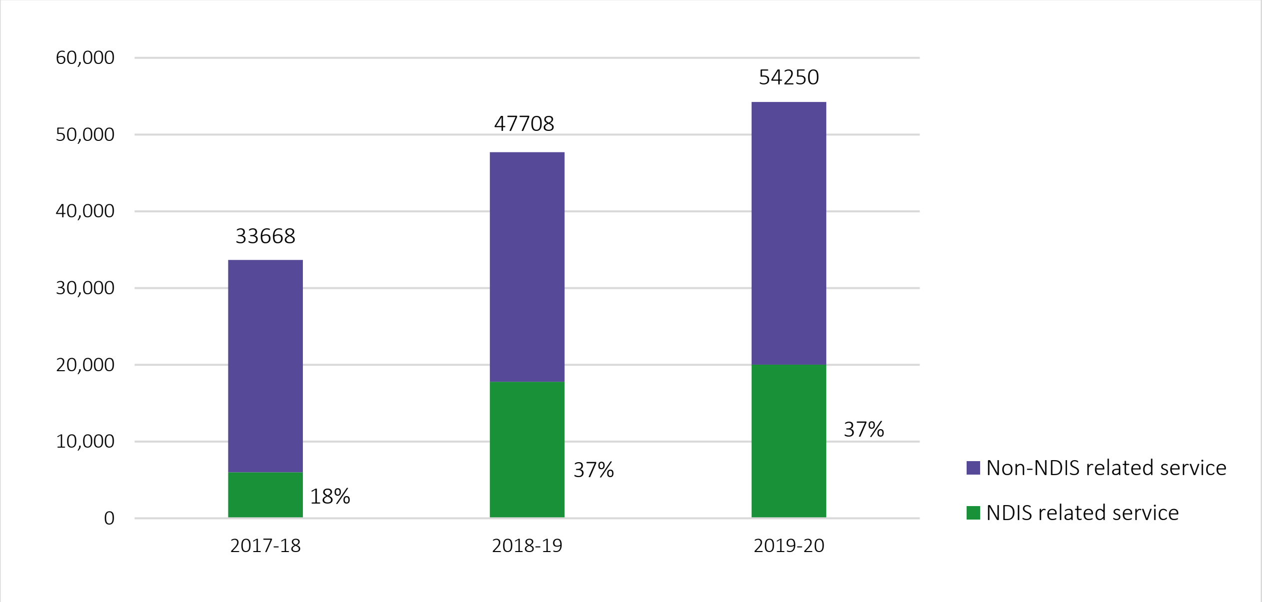
[10] The State Government via the Office for Disability has also delivered a separate stream of funding to support engagement with the Disability Royal Commission

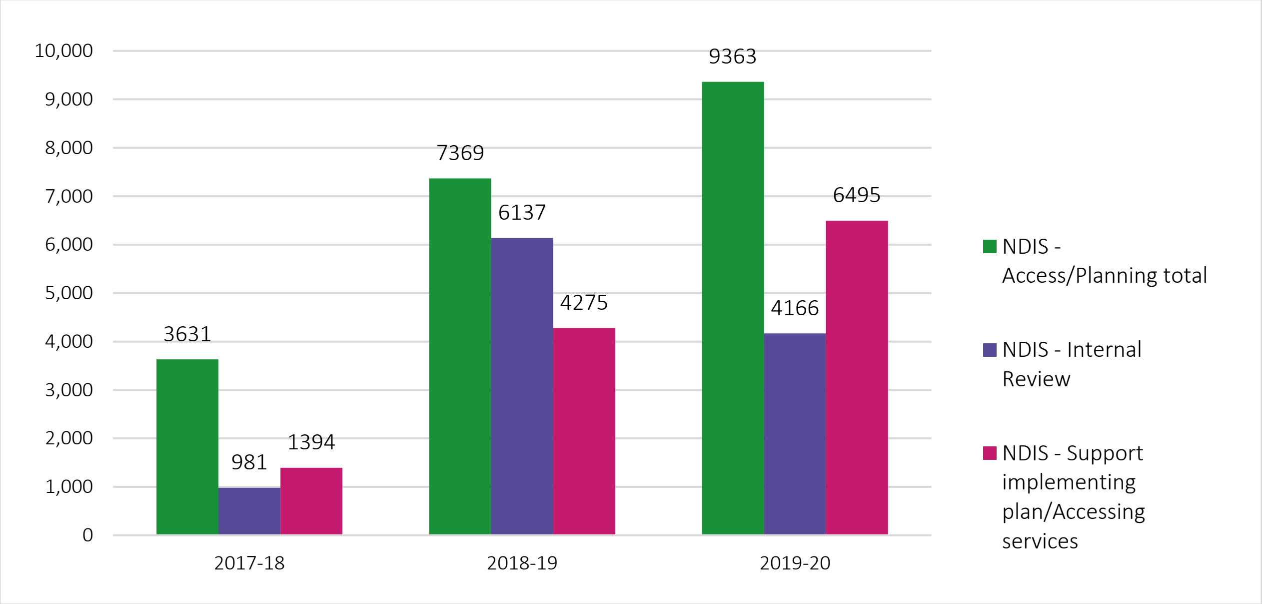
Figure 6: The change in advocacy sessions performed by NDAP funded Victorian advocacy organisations from 2017-20, and the proportion of these sessions that are NDIS related.



The DEX data also broke down NDIS related service into three separate categories; (1) NDIS – Support implementing plan/Accessing services; (2) NDIS – Internal Review, and (3) NDIS – Access/Planning. This showed what NDIS advocacy work contributed to the biggest growth in sessions performed by advocacy organisations over this period (Figure 7).

Notably, case number have increased by 1.6 times over three years. The analysis found most significant growth in the number of sessions devoted to NDIS internal review related work and work involving support to implement a plan or to access services.

Figure 7: The number of NDIS related sessions performed by advocacy organisations from 2017-20



The DEX data helps us to see in more detail how advocacy has been applied to different parts of the NDIS process. All areas of activity have increased over the years data has been collected.

Important observations can be made about the data between 2017/18 and 2019/20:

- Advocacy relating to access and planning has increased more *than 2 and a half* times – this period is notable in that the NDIS rollout schedule, as documented in the bilateral agreements, required the NDIS to be fully implemented by 2020 for all those eligible.[11]
- Internal reviews have increased by a factor of *four and a quarter* although they have fallen between 2018-19 and 2019-20. This possibly reflects the fact that as people have moved through and reviews completed where necessary, there are fewer new plans requiring review.
- Advocacy relating to implementing plans and accessing services has multiplied over *four and a half times*. This probably reflects that as plans turn into services for more people there is a proportionate increase in services in the lives of people with disability and, as a result, more advocacy issues arising as a result.

These increases are far greater than any funding increase to the sector over the same period.

Key Findings 4

4.1 DSS funding for systemic advocacy and NDAP advocacy support have seen only marginal increases since 2016/17. Reflecting increasing numbers of NDIS participants, funding for Appeals and reviews has nearly doubled. Whilst legal advocacy funding has trebled, it has done so from a very low baseline.

4.2 For agencies funded under NDAP, the number of NDIS-related sessions has increased by a greater percentage than has the funding provided to advocacy across the period 2016/17 to 2019/20. Support for access and planning has increased sharply given the aim to complete the roll out of the NDIS to all parts of Australia by 2020. Support for plan reviews increased quickly and is likely to remain a significant component of advocates' work. Supporting plan implementation has and continues to increase, raising issues around the role of individual advocates in this area (*see* Section 8.2 in particular).

4.4 QDC data from the Office for Disability, DHHS

The QDC data was collected from up to 24 advocacy organisations each quarter between 2016/17 and 2019/20. Analysis of the data shows varying response rates, with one organisation having left the VDAP in 2019, and data from quarter 3 2019/20 being particularly low because of the COVID-19 crisis.

The distribution of areas addressed by advocacy are shown in Appendix 4 between 2016/17 and 2019/20.

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[11] https://www.vic.gov.au/about-ndis-victoria

This data shows that of the 24 organisations submitting returns, individual advocacy was the most performed advocacy (mean number of organisations per quarter between 2016/17 and 2019/20 being 15.3). This was followed by systems advocacy with a mean of 13 and then self-advocacy with a mean of 12.5 organisations per quarter. Over the period it was found that a mean of 7.37 organisations provided two forms of advocacy in any quarter and a mean of 5.5 organisations provided three or more forms of advocacy. The results demonstrate a significant range of advocacy taking place consistently since data collection started in 2016/17.

All numbers relating to cases and their focus were placed into a statistical package for analysis. Our analysis is principally focused on the quantitative data, rather than the open-ended qualitative data.

QDC data do not seem to indicate significant changes to the proportion of cases undertaken across different disability groups (Appendix 5). Two explanations may account for this. First, the majority of increases in the range of people with disability may have been delivered through NDAP funding which DEX data did not allow us to explore. Alternately it may be that the focus of advocacy groups has changed, with less of a focus on one disability type such as, for example, intellectual disability, and a widening of the groups for whom they provide advocacy,

As shown in Appendix 5, between 2016/17 and 2019/20 the proportion of NDIS cases rose sharply as a proportion of overall cases from 7.1% in 2016/17 to 33.5% in 2019/20 This data was similar to the change reported in DEX. There was a corresponding decrease in advocacy relating to non-NDIS disability cases over the same period.

Since 2016/17 the proportion of NDIS cases has increased from 7% of all advocacy cases to around 33.5%, a similar change to that reported in DEX data.

QDC data also showed that short, medium and long-term cases were relatively stable over time. In contrast, the number of responses to information and advice had tripled from the start of data collection (2016/17) to its high point in Quarter 4 2018/19.

The increase in provision of information and advice is important in a number of ways. If repeated, it suggests that information and advice is, and will be, as important as the provision of advocacy in the future. It highlights that resources would be useful around key areas in which that information and advice were sought. It also may represent a way that advocacy organisations could manage demand.

With the significant increase in the provision of advice and information since the NDIS was introduced, it may be that advocacy organisations see this as an efficient approach which allows them to focus on priority cases. However, it also suggests the need for both resources which provide such information and advice, or an organisation specifically funded to deliver this to people with disability, in addition to those systems presently in place.

The data set out in the two previous sections demonstrate significant changes that have been taking place in the advocacy sector since the introduction of the NDIS. The data shows for smaller advocacy organisations a limited increase in core funding (except where ILC funding has been accessed). It has demonstrated funding increases from DSS in relation to NDAP Appeals funding and for legal advocacy. Whilst no evidence was found in QDC data of a wider range of disability groups receiving advocacy, the data has clearly shown a rapidly expanding advocacy provision in relation to NDIS-related issues. DSS data indicates the increase in cases has not been matched by a proportionate increase in funding. It has also been shown that advocacy organisations in Victoria have been providing advice and information to a greater degree, by a factor of over 3 since 2016/17.

Key Findings 5

5.1 Since 2016/17 the proportion of NDIS cases has increased from 7% of all advocacy cases to around 33.5%, a similar change to that reported in DEX data. There was a corresponding decrease in advocacy relating to non-NDIS issues over the same period. This decrease in advocacy relating to non-NDIS issues requires further investigation, as it is not clear whether the decrease relates to a reduction in demand or whether it is because urgent NDIS cases have been accorded higher priority than non-NDIS issues.

5.2 There has also been a significant increase in the provision of advice and information since the NDIS was introduced. Given the increased demand for advocacy and the sector's constrained resources, the proliferation of advice and information may be seen as an adaptation that enables disability advocacy organisations to target advocacy to the highest priority cases while providing a form of response to others.

5.3 While the sector should be adequately resourced so that all clients **requiring** advocacy get access to advocacy, the data does indicate that there is a market for information and advice (as a pre-cursor to advocacy). It suggests the need for expanded investment in information and advice across the system or an organisation specifically funded to deliver this to people with disability (alongside other system-wide investment).

5. Victorian Disability Advocacy Sector Perspectives

In the previous section we used secondary data to explore the impact of the NDIS on disability advocacy in Victoria. In this section we look at advocates' perspectives on that impact.

5.1 Setting the Scene – What you will find in this section

Interviews with 20 Victorian disability advocates revealed the significant impact the NDIS has had upon the sector. Whilst the demand for advocacy has grown significantly since its introduction, core funding to the sector has not increased at a commensurate level. Interviewees reported the demand for advocacy now outstrips the capacity within existing funding systems to deliver comprehensive, high-quality advocacy to those in need.

Most interviewees felt their confidence in the future funding of the sector has reduced over recent years, and none were confident of their own future funding. Self-advocacy groups were found to have the lowest core funding on average.

Whilst many advocacy organisations are struggling with insufficient funding, evidence suggests there is a growing awareness of disability advocacy services across the Victorian community. Advocates report that a wider range of people are seeking advocacy support than ever before, with growing numbers being referred by NDIS personnel or through a range of community service organisations. Anecdotal evidence suggests a rise in the complexity of cases is also contributing to increased staff workloads.

Advocacy organisations have been trying to adapt to these changes. Many have made changes to governance and strategy and have adopted new staff practices to be more efficient. In an attempt to manage workloads, some advocacy organisations have adopted waiting lists and others have closed their intake. QDC data showed an average of 122 people were on a waiting list in Victoria for three of the quarters in 2019/20 for which data were available.

Given that demand is currently outstripping capacity, it is important to consider who is losing out under the NDIS. Interview and focus group data revealed that those more likely to lose out are: people with complex communication needs; people who experience culture or language barriers to accessing advocacy or services; and those who are isolated. People with complex life situations were also identified as being likely to lose under the NDIS. The danger for people who do not have access to advocacy is that they may miss out on the chance to achieve procedural fairness when moving through the NDIS pathway.

5.2 Managing changes in funding and demand.

Advocacy organisations have made significant changes through the transition to the NDIS to balance income with demand whilst maintaining service quality.

5.2.1 Governance and staffing

Since the introduction of the NDIS, many advocacy organisations have made changes to governance and staffing. Some have reformed their Boards by increasing user-leadership and moving to more skills-based boards. Others have devised new strategies and operational practices to better meet the demands of the new system. ILC funding has driven some of this change, with high levels of funding and a capacity building element to deliver new initiatives.

Advocacy organisation Boards have a key role to play in the work of advocates, overseeing key decisions regarding organisational direction and approach:

> *'…when our Board said… if people with disabilities are struggling with any system… we needed to do advocacy in that space… we started to take on some clients'.*

Boards and management teams have also made adaptations to the way their staff operate. It is important to see the perceived change in both the number of paid staff and the total number of paid hours to have a clearer picture of the extent to which the organisation's capacity has increased or reduced over the previous five years. The data around staffing shows that limited funding increases were mirrored in similar increases in the number of paid staff and paid staff hours (Figures 8 and 9).

Figure 8: The number of paid staff over the last five years has…

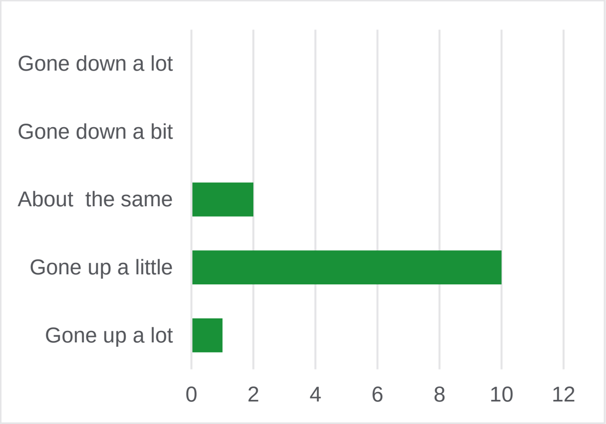
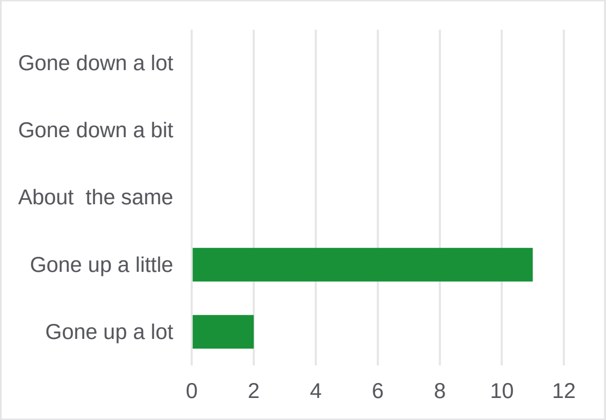


Figure 9: The number of paid staff *hours* over the past five years



The data from interviews suggests many advocacy organisations have adopted innovative practices and made adaptations to employee roles since the introduction of the NDIS. Some organisations have implemented 'blended roles', with employees working across DSS and OfD funding.

> *'if we can get a $5000 or $10,000 Council grant…we could…apportion some of that into our service delivery'.*
>
> And,
>
> *'At the moment we are in negotiations to try and cover some of these wages, and some of that is by redistributing project funds… It's a bit of an ad hoc system, but we are constantly searching for additional funding to ensure that we're able to cover staffing costs moving into the future'.*

In other organisations, advocates have diversified their duties and taken on work not associated with advocacy. New roles have also been introduced such as managing waiting lists. Managers are having to balance the benefits of diversifying roles against the losses to knowledge and experience through specialisation. Advocacy organisations are showing innovation and adaptation to the challenges they have faced during the NDIS years.

Key Findings 6

6.1 There have been a lot of changes to the Boards of advocacy organisations and to efforts to create new strategies in recent times. Much of this appears to be a response to the new NDIS environment. It would be useful for Boards to have access to training and resources as they and advocacy itself transforms over time.

6.2 Good management practice requires decisions to be made about the allocation of staff time and strategic decision-making about how to prioritise work. Managers are having to balance the benefits of diversifying roles against the losses to knowledge and experience through specialisation. Advocacy organisations are showing innovation and adaptation to the challenges they have faced during the NDIS years.

5.2.2 Approaches to managing demand

Advocacy organisations have employed a range of strategies to manage the increase in consumer demand. Some have identified new referral pathways, directing people to seek assistance from other advocacy organisations with greater available resources. This does not always work since other advocacy organisations are doing the same:

> *‘We've got now some referral pathways that we've identified. Organisations who have had funding - NDAP funding - we try and refer people there if we can’.*

Others have employed an ‘intake officer’ to better manage excess demand.

> *‘Well, we are quite fortunate that we do have an intake officer and they work tirelessly seeking information to be able to refer people on to other organisations. However, the sad case is that many other advocacy organisations are in the same boat as us; their wait list is closed as well. So our intake officer sometimes is able to give them small amounts of information that does help to support them.’*

Whilst this may be useful for managing excess demand in the short-term, there is a danger that this approach may be shifting significant resources away from the delivery of focused advocacy. More needs to be known about how information and advice are delivered and about what referral pathways to other organisations have been adopted.

Some advocacy groups have established waiting lists to manage excess demand:

> *‘I think for us the demand is just never ending. It's huge. There are so many people who miss out purely because we can't - we get our waitlist full and we have to turn people away. And so the worry for us is what's happening to these people’.*

Recognising that waiting lists were being implemented in the advocacy sector, DHHS added a number of questions to their QDC data collection from quarter 2, 2019/20: “Has your service had to close due to increased demand?”; “Does your service currently have a waiting list?”; “How many people are on the waiting list?”; and “How does the service manage the waiting list?”

Responses for Quarter 3 2019/20 were lower than usual, skewing the figures. The results are shown in Figure 10 below:

Figure 10: QDC waiting list data

	Quarter 2 2019/20 N=17	Quarter 3 2019/20 N=9	Quarter 4 2019/20 N=11
Waiting list closed because of demand?	2	4	2
Is there a current waiting list?	9	9	6
How many are on the waiting list?	136	96	133

Data returns for quarter 3 reflect the impact of COVID-19 and are likely to be an understatement of the true level of demand. However, even without taking the pandemic into account, the average number of people in Victoria on a waiting list over the three quarters is 122. It is not known how many of these transfer between data points. Irrespective of whether there is a degree of transfer, it is clear that a significant number of people are not receiving the advocacy they need. Additionally, a waiting list mean that is derived by simply counting cases does not capture the true level of demand as it does not factor in ‘unmet need’ within the Victorian community.

It is also interesting to note that some organisations have made the decision to close their waiting lists altogether, further reducing the accessibility of advocacy for people in need of support.

Another important point needs to be made here. If there are waiting lists of people requiring advocacy; if there are people receiving information and advice instead of advocacy; if advocacy waiting lists close – then the numbers in the QDC data do not and cannot reflect demand. Demand is higher than just the current caseloads reported in the data.

Advocates report that waiting lists do not always operate on a first come first served basis. Issues relating to NDIS Plans, Appeals, and Reviews are often prioritised to adhere to timetables set by the NDIA. This means many other urgent cases may face long delays before receiving crucial advocacy services: *‘We have to prioritise need for the wait list…we review that weekly…there are some situations…[that] can't be wait-listed and it might be an NDIS Appeal which needs to be done within 28 days’.*

Discussions in the Action Research Group also pointed to some organisations becoming more particular about who and what issues they choose to address. It was reported that some people with disability place themselves on several waiting lists, with some ultimately receiving advocacy from more than one source. It was reported that some may manufacture an ‘artificial emergency’ to receive faster service. Where there are waiting lists, there is the danger that those who complain the loudest may be seen first. Additionally, it was observed that regional areas are not widely served by a range of advocacy groups, making waiting lists and referrals even more problematic.

Waiting lists establish barriers which have potential to undermine some of the key principles designed to make the NDIS fair, comprehensive, and responsive.

Key Findings 7

7.1 A waiting list averaging 122 people per quarter indicates high ‘unmet need’ for advocacy. Waiting lists seem to reduce the comprehensiveness and responsiveness of the sector and to raise issues of fairness and social justice. This is another huge stress on the sector. It is important to count the unmet advocacy needs in case data to get a true reflection of demand for advocacy.

7.2 Some advocacy organisations have had to close their waiting lists. The big question is what effect this is having on the people who are not receiving an advocacy input when required. This would be an informative subject for future research.

7.3 Waiting lists may not work on a first come first served basis with issues to do with NDIS. Plans, Appeals, and reviews are often being prioritised because of timetables set by the NDIA. This means many crucial cases may not be seen until much later.

5.2.3 The impact on people and communities.

The introduction of the NDIS has had a significant impact on all Victorians with disability and the advocates who support them. The NDIS system is complex and difficult to navigate, particularly for people with complex communication needs, intellectual disability, or people from culturally and linguistically diverse communities. Some Victorians have struggled to access the system at all.

In interviews and focus groups, advocacy leaders, self-advocates and Support Coordinators identified the groups they believed were most likely to need additional advocacy support to successfully engage with the NDIS. The group considered to be at highest risk of losing out under the NDIS were people who could not speak for themselves, such those with an acquired brain injury, intellectual disability, or a communication disability.

> *‘… a difficult process I think, especially for people that don't have the communication abilities. A lot of [people with] brain injury … become aphasic or speak slowly’*

Young people were also identified as being at high risk of falling through the safety net and failing to receive the support they need. In particular, children and young people with limited support networks and complex needs who do not have an independent voice.

This research also suggests that Deaf people and culturally and linguistically diverse (CALD) communities experience significant difficultly in engaging with the NDIS due to a lack of targeted information resources. This issue is often compounded by challenges associated with the translation of information.

> *‘… Deaf people rely upon information in Auslan…the NDIS may rollout in their local area, but it's confusing because information in Auslan is not available…that's the same issue that many CALD people face’.*

Other factors identified by participants as impacting people’s ability to speak up were cultural and language barriers. People from cultural backgrounds where individuals are less likely to engage or speak up may struggle to access the system, as are those for whom English is a second language.

In short, the more disadvantaged a person is, the more they need advocacy, and the greater the potential for them to miss out on the support they need. The NDIS was founded on the principles of choice and control. If people who experience multiple forms of disadvantage are not getting the support needed to make their own choices across the NDIS pathway, it raises key issues about how such groups and individuals achieve procedural fairness across that pathway. Some attempt needs to be made to ensure that everyone has a voice in their engagements with the NDIS.

5.3 Funding Changes and Challenges

The interviews sought to explore the funding for each of the 20 organisations interviewed. However, despite the research team having signalled this as one area for the interview, for a range of factors many interviewees were unable to provide an accurate picture of their organisation's financial situation.

As a result, following interviews, we asked participants about their perceptions of funding using a mini-survey.

Figure 11: Since last year my organisations core funding has…

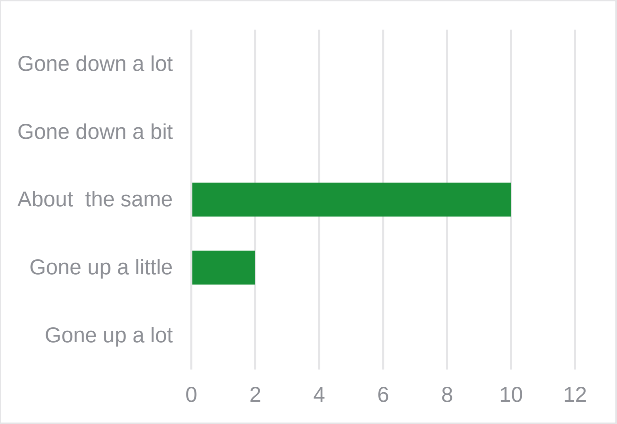
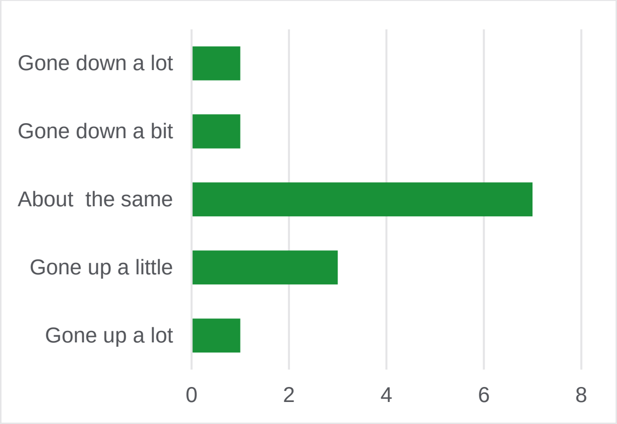


Figure 11 shows that 12 of 14 participants saw core funding since last year as staying the same with two saying it had gone up a little or had stayed the same.

Confirming the earlier findings from the ACNC data, we found some organisations describing that their 'overall' funding (including non-advocacy funding) as increasing (Figure 12) though, as can be seen, some saw a reduction in overall funding.

Figure 12: Since last year our organisations overall **funding has…**



We also explored the extent to which organisations' saw their core and overall funding as having changed over the past five years i.e. over the majority of the NDIS period (Figures 13 and 14). As can be seen the majority of respondents felt funding had gone up 'a little' and this reflected the Victorian Disability Advocacy Futures Program, 2018-20, funding and confirmed early ACNC data findings.

Figure 13: Between now and five years ago our organisations core funding has …

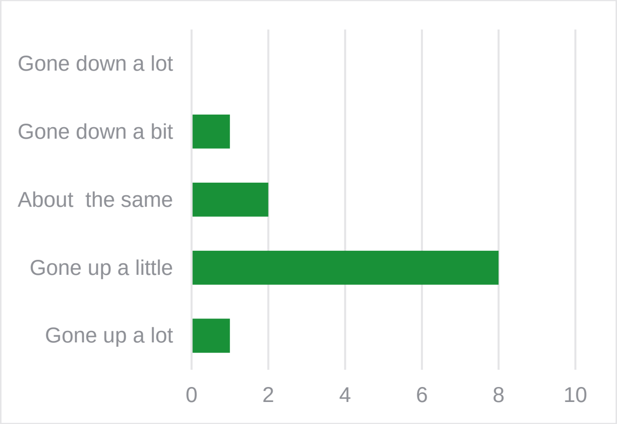
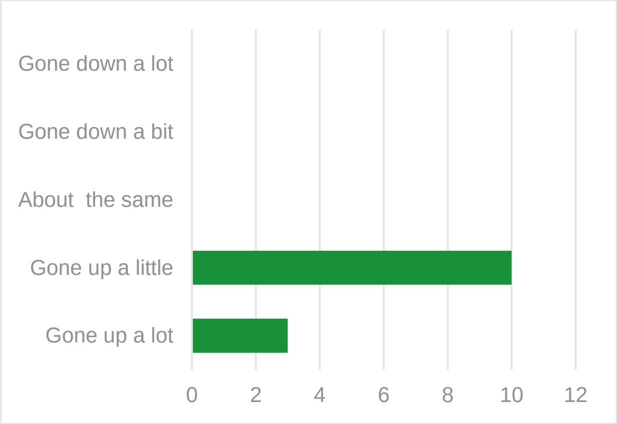
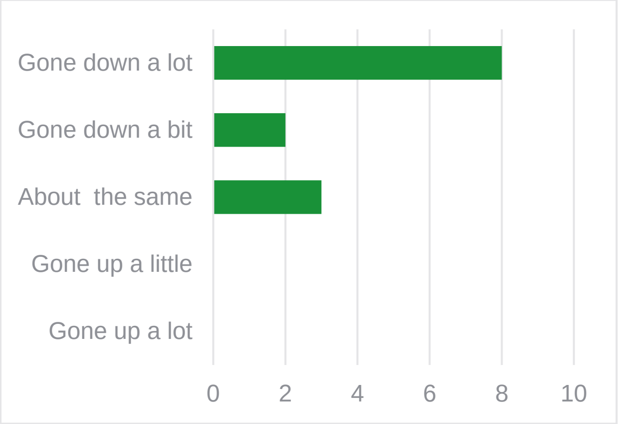


Figure 14: Between now and five years ago our organisations overall funding has …



Several respondents again pointed to temporary, project specific funding boosts including Disability Royal Commission submissions funding, as the source of the increase in overall funding between now and five years ago. Others talked about the Victorian Disability Advocacy Futures program funding, but none specifically mentioned the 25% increase in core funding under the Victorian Disability Advocacy Futures Plan 2018-20.

Figure 15: My confidence in future funding for our organisation has…



Advocates' perceptions of funding and statistical data therefore reinforce one another. However, it is very important to note that respondents had mostly lost either some or a lot of confidence in the future funding of their organisation (Figure 15).

In explaining this lack of confidence in future funding, agencies had expressed that stretching back even to before the NDIS, they have operated on a year-by-year basis with no security of longer-term funding. This means that resources are being consumed in making bids to secure funding merely to sustain operations, something which has a disproportionate effect on smaller advocacy organisations which are less able to commit resources to generating funding.

Larger organisations seem to maintain their funding and resist stresses associated with 'staying afloat' more easily than smaller organisations. Significant diversification of funding is taking place, the larger the organisation the more likely diversification will be. There are some smaller advocacy organisations that continue to struggle year-on-year.

It was also found that self-advocacy groups seem to be the least well-funded with the exception of those which have received ILC funding, either Victorian or NDIS. As one self-advocate put it:

> *'…hope they change the way that they issue funding out for self-advocates [unclear]. You know because if you think about it, it's a bit unfair'.*

On the whole, self-advocacy groups have lower core funding and overall funding, unless funded through an additional ILC grant either state or national. It might also be observed that, with support, they act largely through the efforts of their unpaid members, people with disability. The experience of self-advocacy groups with ILC funding is discussed further in Section 6.3.

Perceptions of the ILC funding process and grants:

ILC funding had the potential to be transformational for advocacy organisations facing growing demand for services:

> *'Earlier this year, we got a huge grant from the ILC, an information linkages and capacity building grant. And we got $1.4 million for three years. So that's by far the biggest amount of money we've ever got. Absolutely. So that's been a bit of a game changer.'*

Whilst project specific, ILC funding could free up resources, or fund projects that could alleviate the demand from NDIS-related advocacy requests, such as peer support groups that assisted persons with accessing the NDIS:

> *'…We're running this peer support project and it's absolutely fantastic and that project was about getting groups together who were applying - people who were applying for the NDIS, so we got them right at the start. So what we were making sure of was that their original application, their initial application, their application for access it's called was right, so that they more often than not, unless they just weren't eligible, that they actually got it. And then that saved us a lot of work with appeals, you got in right on the ground floor with them.'*

However, organisations participating in this research shared much frustration in regard to the competitive ILC application process and ILC grant administration, reporting that the tender process had:

> *'…obscure rules about who can and can't be involved, this whole thing about them being disability organisations but they had to be corporate entities.'*

Furthermore, interviewees spoke of feedback on bids that was not helpful nor informative. This can potentially lead to more resources wasted in putting together future bids without a proper understanding of why a previous application was unsuccessful:

> *'they wouldn't enter into any conversation about it…they basically said, "well it takes away the competitiveness if we tell you why, what you could do better". They make it so hard for us.'*

The time-consuming, onerous nature of the application process meant that unsuccessful organisations were extremely disheartened after diverting a significant level of resources to complete the application:

> *'On the ILC form, it asked how many hours had been used for that form and I worked out…I'd used over 100 just for this application'.*
>
> And,
>
> *'It's traumatic…I could spent two, three weeks. I spent my entire holidays…writing one of those applications. And then you get knocked back… It's really…disheartening.'*

A major issue for all parties involved with ILC projects was that it was felt to be a 'boom and bust' approach that led to improved income and organisational capacity building followed by issues in maintaining the expanded capacity once the time-limited grant was exhausted. In in many cases it was felt that it was not possible to deliver on the ambitious promise of ILC funding with grants of time-limited duration:

> *'And if they are only short grants, they're one or two years, it's really hard to make effective training, to build relationships, build trust, your capacity in such a short time. You're talking about a grant that is one or two years' time.'*
>
> And,

> *‘…the short term nature of the way that the funding works. Most good projects that are rooted in communities take three or five years to get started, to get going, to be known, to be visible, to start to become an entity that people trust and work with… it's being structured as a short term project.’*

Key Findings 8

8.1 The data from the mini-survey were broadly in line with the findings from the ACNC data presented earlier. Core funding has increased slightly and overall funding has increased significantly for some, but stayed the same or fallen for others. The perceptions and statistical data therefore reinforce one another. But it is very important to note the lack of confidence the advocacy sector has in relation to future funding.

8.2 Larger organisations seem to maintain their funding and resist stresses associated with ’staying afloat’ more easily than smaller organisations. Significant diversification of funding is taking place, the larger the organisation the more likely diversification will be. There are some smaller advocacy organisations that continue to struggle year-on-year.

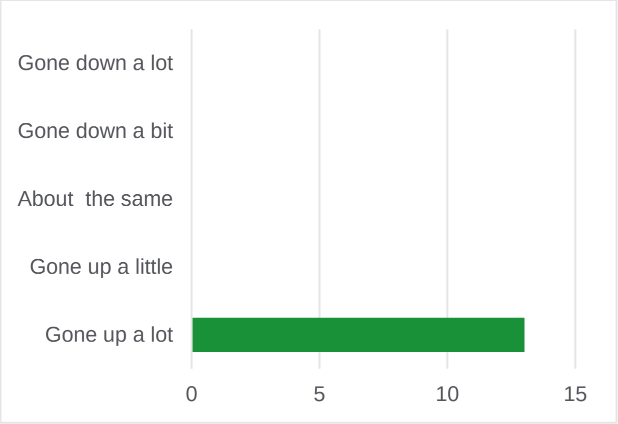
8.3 On the whole, self-advocacy groups have lower core funding and overall funding, unless funded through an additional ILC grant either state or national. It might also be observed that with support they act largely through the efforts of their unpaid members, people with disability.

8.4 Advocacy organisations have viewed the successful receipt of an ILC grant as an unprecedented boost to capacity. Yet time taken for applications is high leaving smaller organisations struggling to complete applications in a tender process that many talked about as challenging. Moreover, since ILC funding is not recurrent funding, the capacity built over the course of ILC-funded project period cannot be easily sustained. This impacts the organisations concerned and disproportionately the smaller organisations who cannot absorb reductions in funding. .and staffing without disruption.

5.4 Perceptions of Demand for Advocacy

Data from our interviews supports previous findings that the demand for advocacy has increased significantly since the introduction of the NDIS. This was confirmed in the mini survey (Figure 16).

Figure 16: The demand for advocacy in the past five years has

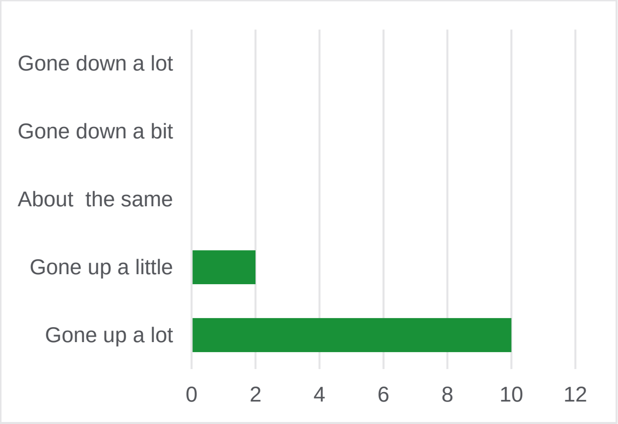


Participants suggested that this was due to more people requiring an advocacy input to access and navigate the NDIS, that there was a growing awareness of advocacy within the Victorian community.

> *'…advocacy is… the flavour of the month'.*

There is also a perception that this was due to the complexity of cases increasing significantly. This was confirmed in data collection subsequent to interviews (Figure 17).

Figure 17: The complexity of cases we are supporting over the last five years has



In the QDC data, information was collected about short-term, medium-term and long-term cases. The time spent on cases is an indicator of complexity. However, analysis of this data showed no major differences across time. This may suggest the indicator is not sufficient to measure complexity but it may be that perceptions of complexity are about the pressures of a clearly increasing workload. This remains open to debate. It should also be observed that the complexity of cases often makes it almost impossible to know when the individual advocate is applying NDAP or VDAP funding in delivering their advocacy and this has a real impact in relation to how judgements are made around who funds what.

Interview data supports the previous finding in the statistical data that there have been significant increases in NDIS-related advocacy over the past five years. Two participants estimated 75% and 80% of their work now relates to the NDIS, whilst others observed:

> *'…Since the NDIS has came in, it's now… between 55% and 60% of our work, when initially… it was… probably 15 and 20%...'*

Many organisations report that the increases in demand for NDIS related advocacy support have placed them under significant pressure. This has led to stress and emotional discomfort for advocates as they are not always able to provide services to those in need.

Though not the focus of this project, further research to investigate the trauma and stress experienced by people with disability when engaging with the NDIS would be useful in providing better understanding of how to organise appropriate supports and improve access.

Given the demand for advocacy, one participant observed:

> *'I think we still provide tremendous value, probably too good value for money given the amount of people we get coming through, and the amount of funding we get.'*

Advocates' perceptions of demand correspond with quantitative data provided in earlier sections of this report.

Key Findings 9

9.1 The demand for advocacy is outstripping the sector's capacity to deliver comprehensive quality services to all people who require advocacy. Statistical data shows an increase in advocacy, particularly in relation to the NDIS. However, core and overall funding has risen more slowly than demand over the NDIS period.

5.5 A Voice for Advocacy

One final issue raised by a number of participant interviewees was who speaks up for advocacy itself. Many spoke of the great work of SARU and DARU alongside the advocacy peaks:

> *'…it's (auspice agency) a huge organisation and has plenty of contacts, plenty of networks… plenty of opportunities to… lobby other organisations and try and get some philanthropic funding through, so we're very fortunate. We would – I would – not have the time or potential to do that.'*
>
> And,
>
> *'…your relationships with your peaks are imperative. They can get into areas of government that that we don't get into. They've got they've got access to ministers.'*

The roles of DARU, SARU and the advocacy peak organisations is central to advocacy being able to bring its own issues to the table at state and federal levels as well as to highlight systemic issues for people with disability.

6. Self-advocacy Experiences

Our research found:

- Self-advocates have: disability specific networking roles; wider networking roles across the community; a collective voice around the experiences of people with disability; and roles developing projects, training and resources to inform the work of the NDIS. The relevance of these roles to the NDIS is highlighted in the following sections of this report.
- Self-advocacy is poorly funded and the majority of self-advocates give their time for free.
- ILC funds have provided some self-advocacy groups with unprecedented levels of temporary funding, but self-advocates struggle with the application process and in maintaining their increased capacity once the funding is depleted.
- Much of self-advocacy work goes unseen. Self-advocacy groups and networks contribute what would seem to be substantial – but largely u]nquantified – value and impact.
  For example:
  - Self-advocates provide advice, support and referrals to formal advocacy organisations.
  - Self-advocates have built stronger inclusive community links and can speak on behalf of a huge range of people with disability. They need more opportunities to have their voice heard under the NDIS.
- More needs to be done to get a measure of the outputs and impact of self-advocacy.

6.1 Self-advocates and their work

Figure 18: How self-advocates describe their role - summary of findings from research focus groups.

Roles identified by self-advocates.

Disability specific networking:

- Talk to other people and make sure they're happy
- Talking to people in community residential units (CRUs) and day centres
- Developing relationships and building confidence
- Teaching people to speak up for themselves
- Running peer to peer support groups

Wider networking:

- Help people with disability get the same human rights as others in the community
- Network and communicate with people with other disabilities
- Educating the general community to change attitudes to people with disability
- Give people with other disabilities information about where to go for help in their local community

A collective voice for people with disability:

- Engaging with government and organisations and lobbying
- Talking at forums and campaigning
- Sitting on Committees

Project work:

- Making and updating resources (e.g. How to do Zoom meetings) and problem solving
- Applying for grants

6.2 Exploring the contribution of self-advocacy

As outlined above, self-advocates play several vital roles in supporting Victorians with a disability to access the NDIS and to realise the goals of the NDIS. These roles are described in more detail below.

Disability specific networking roles

Through a range of disability specific networking activities, self-advocates help people with disability to develop relationships, build confidence, and speak up for themselves. They run peer to peer support groups and liaise with other people with disability to monitor their wellbeing. In addition, they provide an important route for the referral of NDIS and non-NDIS issues to individual advocacy groups. For example, one member of the project's Action Research Group reported that 30 people had recently come to their organisation for individual advocacy support via referrals from self-advocates.

Their work in this area also helps to highlight emerging systemic issues, build a community of mutual support, deliver updated information about things that are important, act as a sounding board amongst members in relation to their rights, and serve as an informal referral pathway. In doing so, they are creating more inclusive communities, one of the focuses of the NDIS, and providing mutual support for people with disability. Further, their work also contributes to the Victorian Disability Advocacy Futures Plan 2018-20 and its aim for advocacy to be 'responsive'.

One Victorian self-advocacy group maintains a database of over 200 people, keeping them connected via emails, information resources, informal chats, and community activities. Whilst it was not clear from the data collected how much of this work is NDIS specific, it is likely that some relates to NDIS issues.

Self-advocates also support people to speak for themselves, assisting them to better navigate the NDIS system.

> *'…one of the main successes I've seen in community based advocacy… is where they do community development, they actually go out and train self-advocates to then train other self-advocates, and I'd say that's where we see the greatest level of success is where we see, you know, not reactive advocacy.'*

Their networks allow relationships of support, information, exchange and friendship to flourish. These create mutual support, community connectedness and a system of referral within the broader advocacy sector. Much of this goes unnoticed but has an impact in relation to engagement with the NDIS and achieving community inclusion potentially.

Finally, self-advocacy helps people to speak up collectively. In terms of the NDIS focus on choice and control these are valuable activities. Crucially, this type of capacity building also strengthens safety and safe guarding.

In the focus groups, self-advocates reported a number of issues experienced by people with disability when attempting to navigate the NDIS (Appendix 7). These included the impact of transport funding criteria; new rules for access to assistive technology; understanding how much of their plan funds were left to use and how to invoice; practical help to get to NDIS meetings; and NDIS staff not listening or making decisions for the person despite their own feelings. There was a feeling that many NDIS staff needed more training around giving people a voice and about not judging people simply on appearance as some disabilities are 'not obvious'.

Self-advocates possess unparalleled knowledge about the lives and struggles of people with disability based on lived experience. This knowledge should be seen as a primary resource which allows systems such as the NDIS to adapt to improve the life quality of people with disability they serve. This depends on supporting self-advocacy to have a voice and to be supported to participate in ways that drive change.

As discussed previously, the self-advocates identified similar groups who were losing out under the NDIS, broadly those people who could not speak up by virtue of their impairment, their spoken language, background or culture or those who are isolated or are living in rural areas. Their strongly held view was that without self-advocacy, the NDIS cannot maximise its response to people's choices (see also Smith, Cocchiarella and Shaper, 2020[12]). Effectively, self-advocates are pointing to ways in which they 'level the playing field' for people with disability and therefore contribute to 'procedural fairness' in the NDIS. More is said of this later in the discussion section of this report.

It is important to seek to get a measure of the impact of self-advocacy in data returns. One way of doing this is to identify the size of the network of contacts. Another approach could be to undertake a survey of groups and networks to identify impacts in a number of key areas so as to build a metric that can be applied in calculations of impact dependent upon size and activity of the groups and networks. Sources of referral data at individual and legal advocacy organisations could also demonstrate the impact of self-advocacy. It is also vital to listen to what issues are arising in a recurrent way from these contacts and self-advocacy groups can report on those too.

The history of self-advocacy provides ample examples of how self-advocacy has built networks with other self-advocacy groups to share experiences and build strategies for action; modelled inclusion to the wider community through their actions; and strengthened locality networks (e.g. Walmsley and the Central England People First History Project Team; Henderson and Bigby 2016; Ramcharan, David & Marx[13]). The latter point is vital to the intention of the NDIS in building models of community inclusion in which services and supports are generic and non-disability-related.

The third area of activity outlined above is the contribution of self-advocates to bringing a collective voice to public duties on committees, campaigning and lobbying.

Under the NDIS there seems to be less participation from the point of view of self-advocacy groups. For example, one self-advocacy leader pointed out that the NDIA Advisory Committee had been varied in its approach to self-advocates and to listening to the points they raised and responding to them. Self-advocacy groups bring the voice of **collective** lived experience to systemic conversations. The self-advocacy sector's perceptions that the NDIA's engagement of self-advocacy groups is neither consistent nor comprehensive, and there has been a reduction in opportunities to participate in formal decision-making structures, appears to relegate the representative voice of the self-advocacy sector.

Further, system advocacy leaders also mentioned that the burden of their individual advocacy was so great as to blunt their ability to pursue systemic issues:

> *'…we need to invest much more as a sector in systemic advocacy'.*

This is concerning because it means that the ability to raise common issues for the sector and to advocate for systemic change is reduced.

Self-advocates, too, need space to run campaigns, to lobby and protest. The NDIS would not have become a reality without over 3000 voices of people with disability that featured in the Shut Out report, nor in the massive Every Australian Counts campaign that followed. An independent voice for

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[12] Smith, J.G., Cocchiarella, N.P. and Schaper, A.D. 2020). Reflections on Choice: The Stories of self-advocates. In R.J. Stancliffe, M.L. Wehmeyer, K.A. Shogren & B.H Abery (Eds) Choice: Prefeence and Disability: Promoting self determination across the lifespan. Cham, Switzerland: Springer. pp.67-84.

[13] Walmsley, J. & The Central England People First History Team (2013) Journal of Applied Research in Intellectual Disabilities, 27,1, https://doi.org/10.1111/jar.12086; Henderson, D. & Bigby, C. (2016). 'We were more radical back then: Victoria's First Self-advocacy Organisation for People with Intellectual Disability, Health and History, 18,1, pp42-66. ; Ramcharan, P, David, C., & Marx, K. (2020) . You are Here! Negotiating liminality in place in the context of the National Disability Insurance Sceme, Qualitative Social Work, 19,3, pp359-379.

self-advocates is vital in the context of building continuous improvement into the NDIS. This underlines the importance of ensuring the self-advocacy sector has a strong, independent voice.

Measuring and auditing the contributions of self-advocates in committees and other forums where they can bring their independent voice is a reflection not just of their contribution, but also the success of government in listening and responding to the voice of people with disability. This may be one area for data collection in the QDC or by DEX in relation to self-advocacy.

There are significant outputs from self-advocates around resources, training and capacity-building. Once again, these activities would provide a useful way to collect QDC and DEX data and for government to use that data to assess not just the contribution of self-advocacy but, also, how to plan with self-advocates to adopt new work that aligns with the interests of government and those of people with disability.

Key Findings 10

10.1 Self-advocates' networks allow relationships of support, information, exchange and friendship to flourish. These create mutual support, community connectedness and a system of referral to the broader advocacy sector. Given their contact with other people with disability, self-advocates have an unparalleled knowledge about the lives and struggles of people with disability. Much of this goes unnoticed but has an impact in relation to engagement with the NDIS and achieving community inclusion.

10.2 An independent voice for self-advocates is very important to maintain in the context of building continuous improvement into the NDIS. The strength of that independent voice should not in any way be diluted.

10.3 It is important to seek to get a measure of the impact of self-advocacy in data returns. One way of doing this is to identify the size of the network of contacts. Another approach could be to undertake a survey of networks to identify impacts in a number of key areas. Sources of referral data at individual and legal advocacy organisations could also demonstrate the impact of self-advocacy. Self-advocacy groups could also report on what issues are arising from these contacts.

10.4 Measuring and auditing the contributions of self-advocates in committees and other forums where they can bring their independent voice may be one area for data collection in the QDC or by DEX.

6.3 Self-advocates perceptions of the ILC process and grants

A significant level of funding has been provided to self-advocacy groups over recent years via the provision of ILC grants, though its distribution has been uneven. Victorian self-advocacy groups and their support network expressed a mixed reaction to the process for accessing ILC funds and the impact of the funding on improving outcomes. There was a strong feeling that the application process does not cater for self-advocates, especially those with an intellectual disability. While plain language versions have been produced, the lived experience of self-advocates is that the language in key documents remains inaccessible. Further, the medium for application submission is limited to a written form, and this presents a barrier for some people. The process is seen as difficult and time consuming, with lengthy applications unable to be completed by groups without the assistance of a support worker:

> *‘Yes, just the application and there's no kind of friendly face to them at all. Like there's already so many barriers that have been there most of their lives and then it's like another barrier to get over, to get paid for their expertise.’*
>
> *‘You know, why don't they just allow video submissions? Like, oh, you know, their motto is choice and control the NDIA, well their choice would be to speak to camera to what they're going to do.’*

One self-advocate expressed that it was unfair that small self-advocacy groups were competing for ILC funding in the same category as larger advocacy organisations who had a greater capacity to put in a more detailed, more competitive application. There was also a frustrating lack of flexibility in the application process which was felt to not accommodate those with an intellectual disability:

> *‘You ring, and there's no flexibility on lead up times planning, where's your plan, haven't got it, you know, it's often not allowed. And so there's a lack of flexibility and start and finish times, which I think goes back to that issue of lack of understanding of intellectual disability.’*

Much like the application forms, self-advocacy groups who were successful in receiving ILC funding found completing the regular ILC funding reporting tasks to be onerous and difficult to understand. Assistance from an external person was often required to complete these tasks, taking away the self-advocacy group’s independence, choice and control:

> *‘The reporting arrangements for the bigger projects are complex. And if they could be, they need to be simplified in a way. And they need to make it more accessible for people. Because otherwise, you know, it's not ideal for self-advocates to be completely dependent on others to do that.’*

That ILC grant materials and processes are largely inaccessible for self-advocates has fed concerns that those who are administering ILC grants and assessing the applications have little knowledge of the self-advocacy sector, their work or history. There is a view amongst self-advocacy networks that this is unlikely to improve with the shift of ILC grants administration to DSS:

> *‘I just think there's a real lack of knowledge (of self-advocacy). So they'll just be judging it on the quality of the submission writer that the big organisations have paid to write.’*

Should an organisation be successful in their application, the impact of their ILC grant funded project often became dependent on the existing expertise at the organisation, or the ability of a self-advocacy group to successfully recruit a capable project manager. Rural organisations have tended to have greater difficulty in recruiting people with the expertise to successfully manage ILC funded projects. It is particularly difficult when these are time-limited projects that offer temporary employment, which can further limit the pool of capable and interested candidates.

> *‘In rural areas there are issues around running small projects, particularly around finding good project workers or support workers to support if they get successful. Because there's just not a great choice for workers in the rural areas as much as they would be inside Melbourne.’*

ILC funded projects delivered by self-advocacy groups varied hugely in nature, from resource development to the creation of networks which aimed to produce systemic changes that would improve lives of people with disability. ILC funding has also been used to establish new self-advocacy groups. One self-advocacy group had built a substantial advocacy and state-wide support network with ILC funding:

> *'to inform policies or start to get policies changed in terms of how things have been worked for parents with ID having their children taken for no other reason… they've produced quite a lot of resources, as well as a stronger network throughout Victoria. And I think that they had some connections nationally as well.'*

A significant benefit of ILC grants for the self-advocacy sector has been the ability for some groups to provide their members with paid employment for the duration of the project, finally giving self-advocates the prospect of remuneration for their expertise and many hours of previously unpaid work undertaken:

> *'And so… one of the things… that's important that they get the self-advocates employed as part of the project, because what ______ was saying is that most of lack the opportunity for proper employment, and they can't get real jobs. And it's an opportunity to develop their own skills or to go anywhere…. It's the fact that people are employed, that people feel that they've ownership, that matters.'*

Yet concerns were raised that self-advocacy groups were at times being overburdened in receiving large injections of funds to deliver substantial projects within short time frames that distract from the group's core work. The suggestion was put forward that smaller levels of ongoing funding could present a more effective means of funding for self-advocacy:

> *'It's a big burden, _______got something like an $800,000 grant that's going to go over three years, and everything becomes about that. And they're really rapt, but it's a massive amount of work. And what we were talking about, what would be ideal if there's only 32 self-advocacy groups around Australia. If one of those 32 self-advocacy groups got just $50,000 ongoing a year.'*

Much as with the impact of ILC funding on larger advocacy organisations discussed earlier, the self-advocacy sector could also face the prospect of a 'boom and bust' cycle from the receipt of ILC grants. Knowledge, expertise and networks built throughout the lifespan of a project can also disappear once a grant is finished and several self-advocacy groups are relying on the continued receipt of ILC funding to maintain their very existence:

> *'But I think self-advocacy groups are just constantly at risk. And the boom-bust could be that you get this great lot of funding, and then you don't get it again. And because the majority of groups have no funding, that's an issue.'*

> *'So really from that source you live year on year. So you're not secure in your funding at all and you have to battle and you have to put in applications…'*

6.4 Some final points relating to self-advocacy

The research suggests that self-advocacy is vital to the success of the NDIS and achieving better lives for people with disability in Victoria. Self-advocates perform a range of crucial roles including:

- Supporting people to (have the confidence) to speak up, contributing to the driving NDIS principles of choice and control.
- 'Journeying with people' through their relationships and acting as both a source of information and an early warning system for potential problems.
- Supporting people experiencing disadvantage and additional barriers in our community to access the NDIS.
- Contributing to targeted support and the delivery of procedural fairness.
- Undertaking independent campaigning and lobbying.
- Establishing a vital dialogue between rights holders (people with disability) and duty bearers (the NDIS and other service providers) that seek to achieve human rights.

Much of the work they perform is *relational* as opposed to *transactional*. They tend to know the person with whom they have contact. Their work is based upon deep and lasting relationships rather than short term interventions. Their contributions to the NDIS system are indirect and not always easily visible. They nonetheless play a key role in supporting the system.

Key Findings 11

11.1 Self-advocates are more likely than others in the advocacy sector to be unwaged, to give their time for free or to be paid for expenses or through gift vouchers. Consideration should be given to this issue.

11.2 ILC funds have provided some self-advocacy groups with unprecedented levels of funding to deliver ambitious projects, and have also been used to formally establish new self-advocacy groups. These grants have also made possible remuneration to a workforce that has long been unpaid.

11.3 ILC applications and reporting documentation are inaccessible for many self-advocates. Small self-advocacy groups are particularly impacted by the lengthy, competitive application process wherein they struggle to compete with larger, well-resourced organisations

11.4 Some self-advocacy groups have faced difficulty in using the time-limited ILC funds effectively or have been distracted from their core work when receiving the large injection of funds. Self-advocacy groups also face the prospect of a boom-and-bust cycle after receiving an ILC grant, with the likely loss of knowledge, expertise, networks or their very existence which had been built throughout the lifespan of a project.

7. Working with the NDIS

7.1 Context: What you will find in this section

- Advocates, particularly individual and legal advocates, are engaged across each part of the NDIS Pathway.
- We identify key experiences and examine issues for advocates across the following components of the NDIS pathway: Pre-planning; The planning meeting and NDIS Plan; Post LAC Planning meeting: Support Coordination; Reviews and Appeals. The issues in relation to boundaries and roles are presented in Appendix 6.
- This section reinforces the case for improved role clarity across advocates and NDIA personnel, especially Local Area Coordinators (LACs) and Support Coordinators. Definitions of role and criteria for engaging in activity are as important for the advocacy sector to clarify, as it is for NDIA workers. Improved accountability is also another important consideration.
- The importance of increasing supported decision-making is highlighted.
- Questions around advocates acting as Plan Nominees are raised, given it was found that many had taken this role. It is not clear whether this should be an individual advocate's role.

7.2 Exploring perceptions of the NDIS pathway

Insights from research participants establish a picture of the NDIS as a deeply bureaucratic system which is difficult for users to navigate. Each stage across the cycle has its own bureaucracy. This creates 'staged compliance systems' that have a significant impact upon the work of advocates. Many research participants spoke of issues across the NDIS Pathway, with one describing it as a *'very unwieldy system'* and *'not user friendly for people with disability'*. Another observed:

> *'…from people wanting help with the actual application process…if they get knocked back … there's an appeal process. And we also help with that… if that still fails, at that point, we help them go to the Administrative Appeals Tribunal.'*

The NDIS involves multiple stages encompassing pre-planning, the planning meeting with the LAC, plan implementation including support coordination and, if required, reviews and appeals. It is important that the early stages are successfully completed. If not, significant work is created for individual and legal advocacy further down the line. This is inefficient for both advocates and the NDIS. Many advocates interviewed identified the importance of having 'properly resourced advocacy' involved from the beginning.

Key Findings 12

12.1 The NDIS has created a deeply bureaucratic system which is difficult for users to navigate. Each stage across the cycle has its own bureaucracy. This creates ‘staged compliance systems’ that have a significant impact upon the work of advocates.

12.2 The NDIS can be seen as a number of processes moving from pre-planning, the planning meeting with the LAC, plan implementation including support coordination and, if required, reviews and appeals. It is important to make sure the early stages are successfully completed. If they are not then it creates significant work for individual and legal advocacy down the line and is inefficient for advocates as well as for the NDIS.

7.2.1 Issues with pre-planning

Prior to a person having a meeting with a NDIA Planner or LAC, a considerable amount of work is needed to collect evidence and supporting documentation in readiness for the planning meeting.

Most service provider organisations can offer very limited time to support people with disability in this process, yet it involves a significant amount of work (see Appendix 6). People with disability entering the NDIS for the first time must complete the NDIS application form and prove their eligibility by collecting information confirming their disability to be significant and enduring. This means bringing together documentation from doctors and other health professionals. This information is considered by the LAC, who assists in the development of a plan that is then reviewed and approved by an NDIA delegate. Some participants will develop their plan with an NDIA representative.

The plan determines what services a person can access and their quality of life. It is not the responsibility of advocates to support each NDIS applicant in the development of their plan, nor to complete all the necessary documentation on their behalf. Despite such tasks not falling within their domain, the research suggests some LACs seem to have this expectation. In some cases, interviewees reported that LACs sent people to them to seek support with the planning process and completion of forms.

> *‘…people would come here and say, “I want to apply for the NDIS”. We'd send them around to the LAC … And they turn up back here and say… “the LAC told me to come to you”…Is it appropriate to be doing someone else's job for them?’*

Agreed rules driven by advocacy peaks in consultation with the sector, OfD, and the NDIA are needed to clearly define the advocate’s role in the pre-planning stage of the NDIS process.

The availability of supported decision-makers (SDM) within the NDIS system was another issue raised by participants:

> *‘the NDIS…does tend to position people as either people for whom they've presumed capacity or people who need a plan nominee. One or the other’.*

This suggests that there may be some participants who have the capacity to make decisions in regards to parts of the NDIS pathway, who are unnecessarily being asked to always have a plan nominee present.

One organisation reported having received two years' worth of project funding to investigate areas where supported decision-making could ease the burden on advocacy. DSS is also funding a supported decision-making trial. More research is required around how to implement supported decision-making at scale.

Work on establishing supported decision-making is essential to ensure that advocates can focus on their role of speaking for and with people when they cannot do so for themselves.

The data also found that advocates have taken roles in working with medical professionals and health specialists to collect the 'right' information and to have it included in the planning process in a way that is likely to get a positive response from the LAC. One participant went so far as to provide a customised letter that could be adapted by the GP to supply evidence for the NDIS. There is no doubt that 'getting the right information submitted to LACs' is important, but where the responsibility lies for this is unclear. It would be useful to determine whose role this should be and whether it is best managed by advocates in their areas, or via a resource.

Key Findings 13

13.1 It is not the responsibility of advocates to support each NDIS applicant to develop their plan nor to complete all the documentation necessary. Yet in some cases LACs seem to have this expectation. Agreed rules driven by advocacy peaks in consultation with the sector, OfD, and the NDIA are needed for advocates around their role in this respect.

13.2 Work on establishing the role of supported decision-making as opposed to the advocacy role is essential to ensure that advocates can focus on speaking up for and with people who cannot do so for themselves.

13.3 Those providing information or evidence to support NDIS access should know what is required to be written and what impact that will have. Who takes responsibility for ensuring the right information is submitted to LACs is an important issue that should be determined.

7.2.2 The Planning Meeting and NDIS Plan

According to research participants, some LACs expect that advocates will attend the planning meeting as a matter of course. Generally speaking, advocates report that this happens only where the advocate has had previous contact with the person applying to the NDIS. However, they are not required to attend all plan meetings. They are most likely to attend when they have had previous contact with the person applying for NDIS access. This is a good boundary to maintain.

Advocates report that there is a gap in knowledge and expertise amongst LACs in relation to disability and its impacts. Many LACs are considered to have 'little experience of disability'; are 'not…able to understand the impact of disability and particularly complex disability'; are unable to understand what the applicant might want without it being converted to plain language; and, are 'badly trained'. This situation is exacerbated by the high turnover of LACs. As a result, advocates have found themselves fielding a huge number of queries from LACs and having to spend time educating them rather than fulfilling their advocacy duties.

Whilst providing additional training for LACs may address this issue, other options such as an enquiry hotline may also be useful. It is important that LACs are provided opportunities to build their expertise without feeling that they are being judged.

Our earlier analysis of data from advocacy leaders (see Section 5.4) and the LAC focus group suggests that advocates have been drawn into tasks that should be carried out by LACs themselves, see Figure 19 below:

Figure 19: Tasks being undertaken by disability advocates that are the role of Local Area Coordinators

- Assisting people to access and navigate the NDIS
- Completing forms and chasing medical and other reports
- Helping people to establish their goals and prepare for their planning meeting
- Linking people who are ineligible for the NDIS to community services and support
- Continuing to engage with participants following plan implementation

Key Findings 14

14.1 Generally advocates have been clear that they are not required to attend all plan meetings. They are most likely to attend when they have had previous contact with the person applying for NDIS access. This is a good boundary to maintain.

14.2 From the perspective of advocates, there is a gap in knowledge and expertise amongst LACs in relation to disability and its impacts. Advocates are currently having to spend time educating LACs. Whilst training may assuage this shortfall there may be other options, for example, an enquiry hotline. It is important that LACs are provided opportunities to build their expertise without feeling that they are being judged.

7.2.3 Post LAC Planning Meeting

After a Plan is approved by the NDIS Planner or delegate, it is supposed to be implemented so the right services are purchased to reflect the Plan contents. However, some interviewees reported that they had been “inundated” with requests for support from people whose plans had lain dormant after approval:

> *‘So we are being inundated with a lot of that sort of work...people whose plans are sitting dormant because no one's actually supporting them to engage with any services.’*

When a plan is left to lie dormant, it has significant repercussions at the Plan review stage as unspent funds are considered ‘un-needed’ funds, and funding is generally reduced as a result.

Two potential ways of managing this issue are the appointment of a Plan Nominee or the allocation of funding within the package for a Support Coordinator. Many people have NDIS plans in place without a Plan Nominee or Support Coordinator to help monitor if they are meeting their goals. This creates a potential gap. Without follow-up, an effective system of case management, or a way for people to be identified as ‘needing additional support’, many may fall through the net.

A second issue is the ‘consent’ to plan and service implementation which is required of the person with disability. One interviewee reported that there is often no Plan Nominee in place for people who might need one, leaving advocacy organisations to support “hundreds” of people. This work then reduces the time available for other advocacy work.

Key Finding 15

Many people have NDIS plans in place without a Plan Nominee to help monitor if the person is meeting their goals. This role has been picked up by advocates and is taking up a significant proportion of their time which could be spent undertaking advocacy. It is unclear who should be undertaking this role and how it should be funded.

7.2.4 Support Coordination

The research identified multiple issues in relation to support coordination[14]. These include:

- Inappropriate referrals to advocates and ‘off-loading’ of work
- Lack of knowledge among Support Coordinators
- Clarity of roles
- Limited funding for Support Coordinator hours

One of the key factors impacting effective support coordination was found to be insufficient funding. Support Coordinators are funded for their role, but many reported that the funding received does not cover the amount of work required. In response to this, they often seek to refer on aspects of their role to advocates. In their interviews, advocates reported sometimes having to set boundaries to ensure they were not undertaking the Support Coordinator role. (see Figure 20)

Lack of clarity over roles is a common issue within the NDIS system. Much of this arises because NDIA personnel see advocates doing a multitude of jobs in each pathway area. They then mistakenly assume that because they have seen them performing these jobs, they are responsible for their delivery. They miss the key thing advocates do – speak for a person where that person is unable to do so for themselves.

Like the LACs, Support Coordinator focus group data as well as data from interviews with advocates showed that Support Coordinators had asked advocates to undertake roles that were not advocacy roles, see Figure 20 below:

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[14] See Appendix 6 for further detail.

Figure 20: Tasks being undertaken by disability advocates that are the role of Support Coordinators

- Explaining service agreements to participants
- Educating participants and their families about the NDIS system and roles
- Attending planning meetings on request
- Advocating for the rights of a participant to get the most benefit from their plan
- Supporting participants to identify and access services, and engage with them long term
- Playing a broader case management role, especially around crises
- Assisting participants to prepare for a plan review

There are times advocates may be involved in speaking up for people, but they do not always have a role in the areas identified in Figure 16. Nor are they required to play a role upon request by Support Coordinators or LACs. This highlights the importance of a clear role definition.

Key Finding 16

NDIA personnel often see advocates working across multiple areas of the NDIS pathway and assume the advocates therefore have responsibility for these areas. They do not understand sufficiently well that advocates will only work in these areas to the extent the person with disability cannot do so themselves. It is important that all sector roles be clearly defined.

7.2.5 NDIS Reviews

Reviews and appeals are resource intensive and time-limited. The appeals process has set time frames, which has an impact on the capacity of advocates to respond. Preparation for reviews and appeals can be time consuming as advocates are required to follow up new information. However, our sample did not include a legal advocacy organisation, so less is said below about this area then about reviews.

As discussed in Section 5.2.2, the time limited nature of NDIS reviews and appeals also means that these issues are often prioritised above other urgent advocacy issues by advocacy organisations.

In relation to reviews, there is a narrative amongst some of those working in, or advocating in, the disability sector that funds not spent under a Plan are almost inevitably withdrawn following a review on the grounds they were not needed in the first place. This narrative was contested by LACs (see Section 8.3). Some interviewees pointed out that is of particular impact where the need for services and support are unpredictable year on year, such as for people with a psychosocial disability. It should additionally be noted that if the correct support from Plan Nominees and Support Coordinators is not forthcoming, those least able to speak for themselves are more likely to miss out.

Key Finding 17

Reviews and appeals are resource intensive and time-limited. The emergent role of advocates in the review process, and in upcoming reassessments of NDIS Plans, may have a huge impact on the advocacy sector moving forward. Once again clarity over roles is required alongside identifiable funding streams to ensure advocacy has the resources necessary to support people with disability to successfully access the NDIS system.

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8. NDIS Perspectives on Advocacy

8.1 NDIS delivery partners' perspective on advocacy

As part of this research, focus groups were run with a group of eight Support Coordinators and a group of seven Local Area Coordinators (LACs). These were designed to understand more about the perceptions of advocacy held by these groups and to provide an additional and alternative perspective on aspects of their engagement with advocates across the NDIS pathway (see Appendix 6). This section explores these views with a focus on role definition and perceptions of advocacy. Key findings include:

- The role of Support Coordinator has been developing over time but is not yet fully defined by the NDIA. Their self-identified key role is to implement Plans, manage agreements with providers, and monitor personal developments across time.
- Support Coordinators do not feel they have had sufficient training in relation to any of their role, or in the NDIS system.
- Caseload management is a major issue for Support Coordinators and they often have complex cases or too many cases requiring attention which leads to service gaps. They try to fill these gaps by calling on others, including advocates. This can lead to requests that are not appropriate for advocacy.
- One Support Coordinator suggested they delivered something they described as 'little advocacy' in that they advocate for the client's rights and needs but cannot cross a line in advocating too strongly for a client's funding. This term 'little advocacy' resonated with other research participants, who agreed. However, they recognised there was a difference between this form of 'advocacy' and independent advocacy.
- Support Coordinators were supportive of advocates but related some experiences where the advocate seemed not to have known the NDIS rules sufficiently well. Additional educational resources in this area may be beneficial. Their biggest concern was that advocacy organisations were too busy to respond and they found themselves having to phone several agencies to find advocacy support.
- Support Coordinators were very positive about the contribution of self-advocacy in delivering peer support, information, and advice to their clients.
- LACs broadly defined their role as being to support a person to build a plan and have it signed off by the NDIS delegate. They also have a community capacity building role though most simply do not have time for it.
- Unlike Support Coordinators, LACs felt they had received excellent training and that this was ongoing.
- LACs saw themselves as advocates. They were 'on the side' of the person and in meetings simply brought information together to get the best plan. They saw themselves as objective and as managing competing interests in meetings. Because of this self-described objectivity and

neutrality, they were not happy when advocates (or others) were confrontational in meetings and did not realise they were all ‘on the same side’.

- Despite criticisms of advocates, LACs were able to provide a number of positive examples of where advocates had supported the person. However, there were some examples where LAC expectations of the advocates went beyond what would ordinarily be considered an advocacy role.

8.2 Support Coordination (roles, responsibilities, understanding relationships)

The role of Support Coordinator is relatively new within the NDIS system. Focus group participants reported that their role did not exist at the launch of the NDIS and has been gradually solidifying over time.

> *‘I feel like the role’s been developed while I’ve been working within it…’*
>
> *‘We’ve just finished the submission paper for support coordination, so we don’t actually have a framework…. we’ve pretty much designed the role which I feel is good because we’re actually helping shape it’.*

One Support Coordinator described their key role in the following way:

> *‘…We’ve helped our NDIS participants to implement their Plan. Basically, that means use the funding in their plan and linking with NDIS funders’ services and also mainstream support.’*

Little training has been undertaken with Support Coordinators to date:

> *‘The actual skill set is quite varied and there’s a lot of hats that we wear… to train up for a role that hasn’t actually been officially defined with a framework yet is really difficult.’*

Support Coordinators reported that they had just completed submissions to a consultation on their role being run by the NDIA and were hopeful some clarity would emerge out of this. Lack of role clarity can lead to issues at the boundary between their role and that of advocates.

It is important to note issues around caseloads and limitations to funding at this point. First, different Support Coordinators reported varied caseloads ranging from 10 complex cases up to 40 cases. They pointed out that variation in the quality of the plans they receive from LACs can have a significant impact upon their workloads:

> *‘I think the quality of the plans that come through is unfortunately too dependent on the planner that you get on the day and how much knowledge they have, how empathic they are, and how willing they are to try to work within the legislation to really genuinely help the person achieve and put things in place for their goals that they have.’*

Further, they described their work as “feast and famine”, with their workloads on specific cases varying considerably and often dependent on circumstances outside of their control.

> *‘If someone’s funded for say 53 hours… there might be six hours to start with to get everything implemented, nothing for a few weeks, and then all of a sudden a crisis happens…20 hours, and then obviously coming towards plan review there’s also a lot to build up towards that.’*

Caseload management by Support Coordinators is variable and dependent upon the complexity of cases, the quality of the Plan and allocated resources for their role, and critical client needs. Whilst they seek to manage caseloads with others, they might be unable to meet the needs of all clients at all times. This pressures them to seek solutions and input from others, including advocates.

Some teams have put in place management solutions in an attempt to address this issue. For example, having at least two people across each case or ensuring case notes are sufficient in quality to be picked up by others. This is important as there is a high turnover of Support Coordinator staff.

Support Coordinators often need support and supervision as they face significant challenges:

> *'We do have regular supervision, we also have regular debriefing too. When we are constantly dealing with our participants who are in crisis it can be quite confronting as well for us.'*

Key Findings 18

18.1 The roles of Support Coordinators have been solidifying over time. Little training has been undertaken given the lack of clarity over the role. Lack of clarity can lead to issues at the boundaries between their role and that of advocates, but consultation by the NDIA is hoped to deliver more role clarity in the near future.

18.2 Caseload management by Support Coordinators is variable and dependent upon complexity of cases, the quality of Plan and allocated resources for their role and critical client needs. Whilst they seek to manage caseloads with others, they might be unable to meet the needs of all clients at all times. This pressures them to seek solutions and input from others, including advocates.

8.2.1 Support Coordinators and advocacy

One focus group participant suggested that Support Coordinators had a "little advocacy" role but that this was clearly separated from the role of the independent advocates.

> *'… We all exist in that sort of grey area… we call "little advocacy", where we are in a sense advocating for the client's rights as a human being, their needs… so we do have that advocacy role.'*

They also observed that the need for advocacy is greatest for the most vulnerable members of the disability community, particularly those who cannot not speak for themselves.

> *'… Another really big impact and influence on whether a plan comes out well is the participant's capacity to be able to express what they need.'*

Support Coordinators were able to identify key advocacy roles and the focus of advocates:

> *'… The advocate needs to speak alongside the person with disability, so not just providing advice, actually be in the same room with them talking on their behalf against someone to solve a problem, or indeed standing in front of them and actually speaking on their behalf.'*

Support Coordinators related few issues with advocacy organisations and were particularly complimentary about the role of self-advocacy in building confidence to speak up, as previously reported in the section on self-advocacy. Most reservations about individual advocates related to the lack of knowledge of some individuals in relation to the NDIS:

> *'…Our local advocacy service here doesn't seem to have a good understanding of NDIS so therefore they're perhaps potentially giving people the wrong information and sort of setting up their expectations which is then going to fail.'*

Key Findings 19

19 Support Coordinators share a view with advocates about who requires advocacy most. They are highly complimentary of self-advocacy and only have minor criticisms of advocates when their knowledge of the NDIS may be lacking.

8.2.2 Identifying the gaps between Support Coordinators and advocacy

Support Coordinators have often been unable to meet the needs of their clients due to persistently high caseloads and a lack of funding for support coordination in some NDIS plans. This sometimes results in them seeking solutions and input from disability advocates. The participants explained that when their caseloads were too high, or where their funding could not stretch, they would ask around to fill these gaps. Thus, the observation by advocates that Support Coordinators were trying to 'pass on work' might better be represented as a system with insufficient funding to cover the needs of some people with disability:

> *'The idea that people wouldn't need more assistance than minimum Support Coordinator hours to make life interesting and exciting and individualised and person centred is a huge miscalculation that has landed in the seat of individual advocacy.'*

The Support Coordinator participants were very aware of the issue of avoiding conflicts of interest, wherein they could be seen to be promoting service providers to whom they have an affiliation. As was pointed out earlier, advocates were also very careful to address issues where service providers were making choices for a person with a disability and, in some cases either not delivering or delivering low quality services for which they were funded:

> *'I think, you know, any system that has money attached to it, you're always going to get your unscrupulous folk there that want to take advantage and there may not be enough safeguards in place and that's down to advocacy or it's down to inherently how they've administered the programme.'*

As one Support Coordinator discussed:

> *'I mean what happens when an advocate's not available and there's a situation which really does necessitate them being present? The wheels can fall off. Providers will typically take that on but they're doing it in a way that's going to at the end of the day ultimately benefit the provider not the client, and that's definitely not across the board. There's good people in organisations who are going to do the right thing but you're*

> *always going to have, especially large organisations, that sort of undertone of what's best for the organisation having an advocate.'*

Key Findings 20

20 Clients' needs and choices may remain unmet where neither Support Coordinators nor advocates are able to commit resources to the problems in people's lives. These systems do not have sufficient funding to cover the needs of some people, who can then fall through the net.

8.2.3 Perception of advocacy issues and impacts

The following case studies exemplify the positive impacts of advocacy reported by Support Coordinators.

CASE STUDY 1

'When a participant had had a major change in their health and wellbeing, and they required a lot of extra hands-on support in the home, they were adamant that they did not want to end up residing in a group facility as no-one would generally want to, so they wanted to be able to stay at home. Funding in the plan was running out, wait times and delays as we know with unscheduled reviews with NDIA are quite extensive sometimes, so we engaged with an advocacy service beyond what as a Support Coordinator we felt like we could push for to actually get an outcome. And within a week the unscheduled review was accepted and then we took back on with actually mapping everything out and helping getting a new plan in place. But it was just that tiny little gap with what could actually be pushed, and at the time it was also with the whole change of NDIA stating that Support Coordinators couldn't be involved in that unscheduled review process full stop. So it was just that tiny little gap that we needed a bit of a push with and it facilitated a really good outcome.'

CASE STUDY 2

'…One with a young person who was hospitalised due to an injury and had a home that he was able to go back home to but his support needs had changed. Suddenly the hospital started talking about "well he needs to go to a nursing home because they're going to support him now", and it became a bit ridiculous. And I got an advocacy organisation in, a young people in nursing home organisation, and they were fabulous. They [advocacy organisation] got in there, they liaised, they got some really quick action and diverted him from being sent to a nursing home.'

Despite these positive experiences, Support Coordinators emphasised that the main problem they were having with advocacy was the waiting lists run by advocacy organisations. They expressed concern about the human cost of these lists, and the fact that demand for advocacy is outstripping the current capacity within the system. One participant observed:

> *'I think advocacy organisations are overwhelmed by calls to them and requests for assistance, and I think they're only getting involved when they genuinely have capacity to get involved.'*

One Support Coordinator reported having to contact around 10 different advocacy agencies to find advocacy support for a client who was being emotionally and financially abused.

Key Finding 21

Support Coordinators were experiencing long delays in accessing advocacy for clients, given many organisations had waiting lists or were too busy to respond. Support Coordinators were able to show the human costs of this, and data from this research confirmed that many people may be losing out on advocacy due to funding constraints.

8.3 The Local Area Coordinator (LAC) role

8.3.1 LAC Roles

The Local Area Coordinators (LACs) in Victoria are employed by an organisational partner and not directly by the NDIA. In exploring roles with LACs, we found two broad areas of operation but with some additional perspectives in terms of how that role might be delivered. The two stated areas related to development of the Plan, and community capacity building (CCB).

LACs work with NDIS participants to determine what supports should be included in their Plan, provide support along their NDIS journey, and review their progress. They play a significant role in planning, exploring eligibility, and making sure reports establish needs against expectations and choices, so that the correct services might be funded. Plans are submitted for review and approval to an NDIA Delegate.

LACs also make a valuable contribution to community capacity building (CCB), assisting NDIS participants to foster connections with their local communities:

> *'I think another really important part of our role is assisting participants to link into community and mainstream supports, which is often some of the biggest barriers that they're finding in their general life. So of course, funded supports and assisting them to develop their plan is super important, but that connection to community is a really, really important part of our role.'*

LACs see their key roles as supporting all aspects of NDIS Plan development and building community services through community capacity building.

LACs and community capacity building

There was frustration amongst LACs as to whether they had sufficient time to undertake the community capacity building role.

> *'Part of our role has been community capacity building, which for me, it's something I'd be very passionate about… But I feel that… we are very busy with individual participants,*

> *and so we do have very little time to do that more community side of things as much as we would like to.'*
>
> *'It's really hard to find the time to do that… so it's quite a big undertaking to be on top of that and to know what's happening on the ground in the community.'*

There does appear to be some crossover between the role of LACs and some aspects of the role this research found self-advocates to be playing, i.e. talking with people and linking them to community services, yet neither group seems to engage with the other. LACs do not have sufficient time to undertake community capacity building. Possible links with self-advocacy around working collaboratively on community capacity building would seem an opportunity that is still to be explored.

LAC's also observed that the NDIA seemed to undervalue this component of their work in favour of quantifiable outputs in the form of completed plans and reviews:

> *'When you look at all the literature on disability, one of the things that shines through is the social model of disability, which is really important… we're told that 20% of our role is this community capacity building, and that really feeds into the social model of disability. We have great ideas and great projects for that, but we just don't have time to follow because… the things that are measured most, it seems to me, is how many plans we've done and how much of that onboarding, and how much reviews… Community capacity building becomes an afterthought.'*

This may be because it is easier to count identifiable outputs in the NDIS pathway, i.e. to count transactional work and not relational work. It should be noted once again that there are no real metrics around community capacity building which builds social networks and community inclusion. As a result, despite these being central roles for the NDIS, they are not counted sufficiently at this point.

LAC training

Unlike the Support Coordinators, LACs rated their training highly and felt that they had been given ongoing training updates, sufficient to meet their roles and duties.

> *'Our organisation has an ongoing learning and development arm, so we're always training as well, which is fantastic.'*
>
> *'We do have continual learning, and I guess that's the nature of the beast with NDIS. It is constantly moving, it's constantly in motion.'*

LAC perceptions of their role

There was a very strongly held opinion across the focus group participants that they saw themselves as advocates. One person expressed the view that this was more likely in Victoria because the LAC roles do not sit with the NDIS – they are located in community service organisations. As a result:

> *'For Victoria the roles are partner LACs… So in that sense, I feel like LACs that work for partners probably take on a bit more of that advocacy, because we do form a middleman between the participant and the agency.'*

The LAC research participants felt dismissive of any view that they were not advocates:

> *‘When I think of our role, our advocacy role…we’ve had it drilled into us that we’re not advocates, but we do have a responsibility to make sure the participant gets all of the things that they want and has a fair experience, and… the description of what we’re doing describes advocacy in a way.’*
>
> And
>
> *‘…In the office, we’ve steered away from the word advocate but I feel strongly at the end of the day we do advocate on a personal level, because if we don’t, then often who will for that person? A lot of our role is, I feel, advocating for the individual.’*

LACs observed that they are ‘on the side of the person’. They translate what they know into language that allows the plan to be ‘recognised by delegates as NDIS fundable’ and they ‘make a case’ for the services required. These activities represent a form of advocacy. The LACs interviewed made no distinction between their advocacy and independent advocacy. Although specifically told that they are not advocates from the point of view of the NDIS, this group of LACs felt they played a strong advocacy role and that they were ‘on the client’s side’.

A second interesting finding was that the LACs believe they are there to ‘balance competing interests’ by being ‘neutral’:

> *‘Sometimes I feel that I’m the only one in the room… whose role doesn’t depend on where the participant goes, so I feel like the only neutral person.’*

They collect information to translate for delegates and make the best case for each person in relation to their plan.

As a result of seeing themselves as being ‘on the side’ of the person and ‘neutral’, LACs related a number of stories about Support Coordinators, family members, specialists and advocates ‘putting their case too strongly’ and being combative.

> *‘We want to hear from the participant in their own words and encouraging that can be difficult when you’ve got a strong advocate, whether that’s a formal advocate or that’s a family member. That’s often quite a difficult road to navigate.’*

The LACs were particularly critical of clients, advocates or others who request excessive levels of support in the hope of extracting a better NDIS outcome. They did not feel that this tactic was useful in providing the best outcome for participants. They also expressed frustration at advocates or family members who adopt a confrontational approach and view the LAC as a barrier to getting the support that is needed.

> *‘I guess the first step for us is usually making it very clear that we’re on the same team, NDIS is on the same team, the planner’s on the same team, here are all the roles.’*

The LACs interviewed observed that their goal is the best outcome for the NDIS participant. This study cannot examine this claim, but it represents a key claim about the identity and actions of LACs.

The LACs also raised a number of issues with Support Coordinators. These included Support Coordinators over-advocating in meetings and speaking over the participant, and pushing to be included in meetings unnecessarily as a means of increasing billable hours.

> *'I actually had to have a word with a Support Coordinator a few weeks ago because they told their participant that they needed to be involved in the meeting because if they weren't there then they wouldn't get the supports that they needed… That's quite an unethical thing to tell your participants.'*

This narrative of balancing power comes from a position of power in the sense that the LAC knows the participants depend on them for decisions. It also speaks of the sense in which LACs consider their interpretations to be 'objective' and free from bias. Once again this study cannot comment upon nor explore these claims but it provides a clear indication of what the LACs are trying to achieve – an unbiased view in which they can 'make the case' for the NDIS applicant or person being reviewed so they can 'sell it to the Planner or delegate'.

Despite making these claims around 'advocating the case' and being 'objective', the LACs were very much aware of the barriers they encounter in their work, and the impact these barriers can have on NDIS participants:

> *'Sometimes it depends on the delegate that you get. There are… certain delegates don't agree with certain supports.'*

> *'…Sometimes we hear from delegates, "You need to justify this particular thing because it's what the agency is looking at right now.'*

They also discussed the impact of occasional misjudgements made during the application process, in particular the decision not to budget for a Support Coordinator where it is later revealed that one was needed.

> *'…The LAC has done a good job in building the plan…you have a conversation with them six months or 12 months down the track -…"What happened?" and they say, "Oh well, I didn't really know where to go from there.'*

Key Findings 22

22.1 LACs see their key roles as supporting all aspects of the NDIS planning process, to present Plans to delegates to authorise, and to buildi community capacity.

22.2 The capacity of LACs is primarily absorbed by organising plans and identifying services that respond to clients' needs and choice. LACs do not feel they have sufficient time to undertake community capacity building. Possible links with self-advocacy around working collaboratively on this would seem an opportunity structure that is still to be explored.

22.3 LACs see themselves as neutral, as collecting information to translate for delegates, and as balancing competing interests. They feel they are advocates making the best case for each person in relation to their plan.

8.3.2 LACs and advocacy

It has already been shown that LACs consider their role to be advocacy of a particular sort. Some interviewees spoke of the ‘shows of force’ or ‘grandstanding’ of some advocates:

> *‘…Part of the dilemma… is ensuring that the advocate is there to support the participant and not take over the meeting for the participant, which happens a number of times.’*

LACs would rather see what they consider as a ‘constructive’ form of advocacy.

CASE STUDY

‘I have a participant with MS… [Organisation] will provide an advocate to come to the meeting, and when they come to the meeting, they will have filled out a document that’s very similar to the information we need to submit. So they’ve basically done all of our work for us, so then when we sit down it’s just kind of a conversation that we’re having and filling in any blanks. For the most part, the advocate just kind of sits there quietly, or every now and then prompts, or might prompt something… any time they think there’s a spot where neither the participant or me has thought to explore further in a topic, because they know the participant better. So that’s the situation where I find that advocacy is really, really, really successful, because they’re still letting the participant speak as much as they like and say anything they need, and it’s just jumping in when they feel they need a bit of support.’

It can be seen here that the LAC was assuming the role of the advocate to be ‘filling in documentation’, ‘attending the meeting’, and to ‘prompt or clarify’, yet these are responsibilities that should be undertaken by the LAC. It is interesting to note that independent advocates do not necessarily have similar ideas about the ethos of their advocacy role.

As with the case study presented above, LACs did provide some positive examples of their engagements with advocates. However, like the Support Coordinators, there are things that sit outside their role which prompt them to ask others to act, creating role boundary issues. There were several examples including referring participants to advocacy services if they did not have funding allocated for a Support Coordinator but needed more help to navigate the system, or referring people to advocates who did not meet NDIS requirements but needed assistance in connecting with services in their local community.

CASE STUDY

‘So she’d engaged an advocate to help her to collect all the information and all the reports from allied health professionals and things like that… but then when it came time to engaging with me and doing the meeting, the advocate was really unresponsive… the only responses I ever heard from her was, “I’m too busy to take this on at the moment.” …Maybe that particular organisation is really understaffed and maybe there isn’t bigger need for advocacy in that particular area.’

As in some of the stories from Support Coordinators presented earlier, the advocate seems to be too busy to be able to follow up. This once again highlights the pressures advocates are working under.

A common message confirmed by both the secondary data analysis and the interview data with advocates is that there are insufficient resources to meet demand.

The case study above also indicates that the LAC saw it as the advocate's duty to collect data from others for the purposes of review which the advocate had done. There was also an expectation that the advocate should attend the review meeting. In other words, even if this documentation were sufficient, or the person could make their own case at review, advocacy was seen as having a role.

Like all other participants in this study, the LAC participants had nothing but good will and a belief that their role was to do their best to improve the lives of the people with disability with whom they worked. They emphasised the importance of others understanding their role and having a greater mutual exchange with advocacy to understand their work also.

> *'I would love for NDIS to actually reach out to advocacy groups to work with them… I feel like we really need to be engaging these groups more one-to-one and answering their questions and trying to counteract the misconceptions that are coming up, so that… we can work together better.'*
>
> And,
>
> *'Sometimes we have great experiences with advocates and sometimes it's less great, but I think that there could be a bit more work done to really engage those groups so that it is more a whole bunch of different people coming together to support the participant on their journey, rather than people coming in with their conceptions thinking that they have to fight us for support.'*
>
> And,
>
> *'I think just a little more understanding about our role and what our role is. Advocacy is super important, and we often connect people to advocates, so just that understanding that we're on the same team. We want a great outcome for the participant. We want them to get what they're entitled to, and we actually can work together.'*

There is an implicit suggestion that some advocates do not feel part of a team and are therefore acting in opposition to LACs as if they are an enemy.

At the end of the day, though, the LACs seem apt to make the same 'category mistake' as Support Coordinators. Simply because advocates do certain tasks for some NDIS participants, does not mean they do these tasks for everyone. The importance of having a defined role is as important for advocates as it is for NDIS workers.

Key Findings 23

23.1 The lack of capacity of individual advocates to meet demand and support clients who need assistance to navigate the NDIS has now been clearly demonstrated in the rising caseloads, yet mediocre funding rises. This has now been evidenced in the secondary data, and in interviews with advocacy leaders, Support Coordinators and, in this case, from LACs. Such a consistent story is strong evidence that this is the case.

23.2 There is not a clear understanding amongst LACs about the roles of individual advocates. There is a potential that expectations amongst LACs advocates may in some cases be unrealistic and that knowing the independent advocates' role will help them to ask for advocacy support in a more appropriate manner.

9. Conclusion

9.1 Limitations

All research is limited by its methods and by the data that can be accessed. There have been some limitations as a result of not having funding data from Victoria relating to advocacy. The QDC data was limited by not having a means of reflecting the outcomes of self-advocacy using indicators, systems advocacy and the work of advocacy resource centres. Recommendation 12 puts forward solutions to address this. The data received from DSS DEX was useful, though we did not get data relating to reviews and appeals. It should be observed that the data collection methods between DSS and DHHS differed slightly and this needs attention.

A second limitation of research is that often the critical issues of the timing can affect the range of issues raised by research participants. One key limitation experienced in this research was that participants did not talk very much about systemic advocacy. The few comments made about this show that it too is becoming a casualty of the demand for individual advocacy. But the focus on systemic advocacy was not sufficiently addressed in the narratives that were collected to be able to form a rounded view of that part of the advocacy sector.

Despite these constraints, this report presents a compelling picture about the impact of the NDIS on disability advocacy and self-advocacy.

9.2 Further Research

Additionally, we note that this report has identified areas for potential additional research, as follows:

- The impacts of the NDIS on people with disability in Victoria
- The DEX database in relation to hypothesized increase in the range of disability groups receiving advocacy over the NDIS period
- Waiting lists to examine who is losing out and what the impacts are
- How best to scale supported decision-making, drawing on previous evaluations of supported decision-making projects
- The spread of different forms of advocacy and their availability and accessibility in urban, regional and remote areas across Victoria
- The development of indicators through which outputs and impacts for self-advocacy can be measured
- The number of people who fall through the support coordination and advocacy gap, and the impact this has on their lives.

9.3 Concluding remarks

The NDIS has been disruptive for people with disability and to all of the services, supports and advocacy agencies that seek to improve their lives. The demands placed on Victorian disability advocacy organisations have increased significantly since its introduction, as they have been needed to support people to access and navigate what is a complex and bureaucratic system.

Advocacy organisations have undertaken this work without any formal NDIS training, nor resources to support their learning. Advocates are often required to step outside the boundaries of their funded role in supporting people to receive an optimal outcome from the system.

The NDIS period has seen changes to the funding environment for advocacy organisations, with increases in funding flowing from a number of sources. Yet, for the most part, these increases have been time limited, tightly prescribed, and have mostly been received by larger organisations. Small and medium sized organisations have seen only modest funding increases in this period.

The introduction of ILC funding has been a significant development, and has provided a number of advocacy organisations with large, temporary capacity boosts. However, many smaller organisations have struggled in the competitive application process relative to larger organisations, and have also found it difficult to sustain an expanded capacity once the time limited funding has expired. This has been particularly difficult for self-advocacy groups, some of whom rely on continued receipt of ILC funds to maintain operation.

Despite many organisations proactively implementing strategies to adapt to increases in demand, the advocacy sector on the whole is hamstrung as it is not sustainably resourced to meet growing demand and to deliver quality services to all people who require advocacy.

Implementing recommendations in this report will help to alleviate the burden on advocacy organisations by making the NDIS system easier to navigate and reducing the number of people who need advocacy to achieve an optimal outcome through the system. Acknowledging that advocates will continue to play on ongoing role in supporting people to access and navigate the NDIS, advocacy organisations should be provided the financial and training resources to adequately meet demand.

The work of disability advocacy organisations is vital to ensuring that the rights of people with a disability, their families and carers, are protected and promoted. It is therefore crucial that disability advocacy organisations have the resources to provide advocacy services to all who need them and have the capacity to undertake systemic work that can produce long-term positive changes.

It is also crucial that self advocacy groups are well resourced to continue their role as a major source of information and advice, and can continue to build and maintain significant networks which build confidence and support people to learn self advocacy skills. In undertaking this work, disability advocacy organisations and self-advocacy groups are contributing to meeting the ultimate aims of the NDIS in delivering inclusion for all people with a disability.

Appendix 1

Data was collected by the research team from the following web sites:

http://www.amida.org.au/
http://www.adec.org.au/
https://www.voicestogether.com.au/self-advocates/find-group/vic/all-abilities-advocacy/
https://www.facebook.com/allaboard4access/
https://www.amaze.org.au/
https://aspergersvic.org.au/
https://www.acd.org.au/
https://www.aed.org.au/
http://www.adde.org.au/
https://www.bdrc.org.au/home-67146
https://www.voicestogether.com.au/self-advocates/find-group/vic/bendigo-have-a-say/
https://www.bca.org.au/
https://www.braininjurymatters.org/
https://www.cyda.org.au/
http://www.chronicillness.org.au/
https://www.citizenadvocacysunbury.com.au/
https://www.coras.com.au/index.php
https://www.coshg.org.au/
https://www.communityabundance.org.au/
https://cfcc.org.au/
https://www.daru.org.au/find-an-advocate
https://www.deafvictoria.org.au/
https://deafblindvictoria.com/
http://www.disabilityadvocacyvic.org.au/
https://www.mrcnorthwest.org.au/disability_services
http://ddlsaustralia.org/
https://dja.org.au/
http://drc.org.au/
https://www.downsyndrome.org.au/vic/
https://providers.dhhs.vic.gov.au/disability-advocacy-and-self-help
https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability/individual-capacity-building
https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap
https://www.gdai.com.au/
http://grampiansadvocacy.org.au/
https://www.imha.vic.gov.au/
http://leadershipplus.com/
https://meda.org.au/
https://mhlc.org.au/
https://www.mrcnorthwest.org.au/
https://www.ndis.gov.au/

http://www.saru.net.au/Groups/NDIS-Working-Group
https://www.voicestogether.com.au/self-advocates/find-group/vic/new-horizons/
https://newwavegippsland.com/
http://www.citizenadvocacy.com.au/
https://www.voicestogether.com.au/self-advocates/find-group/vic/positive-powerful-parents-victoria/
https://www.postpoliovictoria.org.au/
https://providers.dhhs.vic.gov.au/disability-advocacy-organisations
https://www.pwsavic.org.au/
https://rainbowrights.com.au/
https://rdas.org.au/
http://reinforce.org.au/
https://riac.org.au/
http://saru.xtremeproductivity.net/Groups/Shout-Out-Shepparton
http://www.daru.org.au/organisation/sister-rocks
https://southernda.org.au/
http://www.southwestadvocacy.org.au/swaa/
https://www.voicestogether.com.au/self-advocates/find-group/vic/speak-up-alexandra/
https://starvictoria.org.au/
https://swanaus.org.au/
http://www.unitedbrains.org.au/
https://www.valid.org.au/
http://www.villamanta.org.au/
https://www.vmiac.org.au/
https://www.voicestogether.com.au/self-advocates/find-group/vic/power-of-self-advocacy-group/
https://www.wdv.org.au/
https://www.yacvic.org.au/ydas
https://www.ypinh.org.au/
http://www.amida.org.au/
http://www.adec.org.au/
https://www.voicestogether.com.au/self-advocates/find-group/vic/all-abilities-advocacy/
https://www.facebook.com/allaboard4access/
https://www.amaze.org.au/
https://aspergersvic.org.au/
https://www.acd.org.au/
https://www.aed.org.au/
http://www.adde.org.au/
https://www.bdrc.org.au/home-67146
https://www.voicestogether.com.au/self-advocates/find-group/vic/bendigo-have-a-say/
https://www.bca.org.au/
https://www.braininjurymatters.org/
https://www.cyda.org.au/
http://www.chronicillness.org.au/
https://www.citizenadvocacysunbury.com.au/
https://www.coras.com.au/index.php
https://www.coshg.org.au/
https://www.communityabundance.org.au/
https://cfcc.org.au/
https://www.daru.org.au/find-an-advocate

https://www.deafvictoria.org.au/
https://deafblindvictoria.com/
http://www.disabilityadvocacy.vic.org.au/
https://www.mrcnorthwest.org.au/disability_services
http://ddlsaustralia.org/
https://dja.org.au/
http://drc.org.au/
https://www.downsyndrome.org.au/vic/
https://www.gdai.com.au/
http://grampiansadvocacy.org.au/
https://www.imha.vic.gov.au/
http://leadershipplus.com/
https://meda.org.au/
https://mhlc.org.au/
https://www.mrcnorthwest.org.au/
http://www.saru.net.au/Groups/NDIS-Working-Group
https://www.voicestogether.com.au/self-advocates/find-group/vic/new-horizons/
https://www.ndis.gov.au/
https://newwavegippsland.com/
http://www.citizenadvocacy.com.au/
https://www.voicestogether.com.au/self-advocates/find-group/vic/positive-powerful-parents-victoria/
https://www.postpoliovictoria.org.au/
https://providers.dhhs.vic.gov.au/disability-advocacy-organisations
https://www.pwsavic.org.au/
https://rainbowrights.com.au/
https://rdas.org.au/
http://reinforce.org.au/
https://riac.org.au/
http://www.saru.net.au/
http://saru.xtremeproductivity.net/Groups/Shout-Out-Shepparton
http://www.daru.org.au/organisation/sister-rocks
https://southernda.org.au/
http://www.southwestadvocacy.org.au/swaa/
https://www.voicestogether.com.au/self-advocates/find-group/vic/speak-up-alexandra/
https://starvictoria.org.au/
https://swanaus.org.au/
http://www.unitedbrains.org.au/
https://www.valid.org.au/
https://www.vic.gov.au/disability-information-linkages-and-capacity-building
http://www.villamanta.org.au/
https://www.vmiac.org.au/
https://www.voicestogether.com.au/self-advocates/find-group/vic/power-of-self-advocacy-group/
https://www.wdv.org.au/
https://www.yacvic.org.au/ydas
https://www.ypinh.org.au/

Appendix 2a

Interviews with advocacy leaders: Semi-structured interview schedule:

If data is collected from websites or databases, then use the questions below as confirming this data (that will mean individualising each schedule) and update on the basis of their responses.

Section 1 – Background

1. In what disability advocacy organisation do you work?
2. How many people work in your organisation?
3. How many volunteers work in your organisation?
4. Does your organisation focus on all people with disability or has it a focus on particular groups?
5. What is the major advocacy focus of your organisation? (prompt: individual, legal, self, systemic advocacy)
6. Can you describe how this work takes place?
    a. Do you have an estimate of your overall funding for this year?
    b. How does this funding compare to five years ago?
    c. Do you expect similar funding next year?
    d. What have been your major worries about funding in the last five years?
    e. Are you funded:

	If yes …	
a. National Disability Advocacy Program		Describe this work?
b. Through the Victorian Disability Advocacy Program		Describe this work?
c. Through the ILC at any time		Describe this work?
d. From other sources (please specify)		Describe this work?

Section 2 – The NDIS and its impact

For each type of problem try to get a *case study* and explore *SOLUTIONS*

7. Can you describe the changes that have been taking place in your organisation since the implementation of the NDIS?
    a. What has been the impact on your organisation (in terms of the work you do, funding, prioritising cases)?
        i. the complexity of cases;
        ii. pressures from NDIS referrals;
        iii. Has it changed the frequency, duration or intensity of cases and in what way?
        iv. Issues relating to ILC funding such as boom-and-bust
    b. Has it changed your role and focus? (Explore changes to systems advocacy and roles individual advocates play)
    c. Has this work been increasing over the years of NDIS implementation or have things improved?
    d. Does the NDIS work have an impact on what you are funded by other agencies to do? In what ways?
        i. Do you think the administrative burden of responding to funding agencies has changed over the years? What amount of time is this taking up?
    e. If relevant (i.e. the organisation is jointly funded), has this impacted on the advocacy work funded by the Office for Disability in Victoria? Describe in more detail.

Prompt in relation to:

- Are there any other factors which have increased or reduced your workload since the implementation of the NDIS? - March 2020 changes to Victorian guardianship laws?

- Are there any problems specific to the geographical area you are serving?
  Prompt (If organisation is serving a specific geographical area) - Are you advocating for people outside your stated region of focus?

8. a. Have you helped people with disability complete complex NDIS forms or negotiate the NDIS system?

   If yes,

   b. Has this involved:
      - Assisting in the pre-planning phase and applying for the scheme
      - Experience in the planning meeting with the LAC.
      - Assisting the person to choose services.
      - Challenging planning decisions
      - Assistance with applying for DSP, addressing housing, or any other issues?

c. Have there been any gaps in support in this process, or times when you believe that the advocate has taken on the role of an LAC or support coordinator? Have there been timing pressures in getting any of the above jobs done successfully and on time?

- Have there been some people who have lost out because of the circumstances you have described? (prompt people with complex needs, people with disabilities, people who cannot speak from themselves; people from CALD, ATSI or LGBTIQ communities)
- Do you tend to be providing more support to people at certain phases?
- What have you found to be effective or successful in helping people negotiate the NDIS system?

9. If you had all the funding you need, what changes would you make to ensure the Victorian disability advocacy sector was successful in the future?

Section 3 – ILC funding and its effect

10. Have you had ILC funding or applied for ILC funding, including both state-based and NDIS administered ILC funding?
    a. For those who have been unsuccessful:
        i. Did you understand the ILC tender document, who was eligible, and what they wanted?
        ii. Did you receive feedback on why you were not successful in your bid? If so, what were the reasons given? If not, why do you think you were unsuccessful?
        iii. How much time did this take your organisation?
        iv. Would you make another application?
        v. Did this have an impact on the advocacy work you were already doing and on your organisational viability?
    b. For those who have been successful:
        i. Confirm funding.
        ii. How has the funding affected your staffing levels?
        iii. How have you managed issues around changing funding levels?
        iv. Has the ILC funding impacted your independence and autonomy in any way?
        v. Describe your experience of the ILC process and meeting project requirements.
        vi. Did you work with other partners? How did this work?
        vii. (If ILC project is completed) - Have you been able to put things in place that have carried on after the funding period? What effect on staffing? What effect on your ongoing funding? Has the project resulted in a sustainable program or advocacy group?
        viii. Did the ILC project have an impact on the advocacy work you were already doing?
        ix. ‘How would you improve the ILC and the processes it uses to make it better for the advocacy sector?’

Section 4 – State based project funding (TSP and advocacy futures)

11. Do you receive project funding from the Victorian government? If yes:
    a. What is the focus of the advocacy that your organisation is funded to undertake? Has this changed since the introduction of the NDIS? In what way?
    b. Approximately how much of your organisation's time is taken up with this work?
    c. If you receive funding from other sources, what distinguishes what you are funded to do through this funding and other funding you may receive at Federal level?
    d. How do you manage the boundary between the two activities?

Section 5 – NDAP funding

12. Do you receive funding from the NDAP? If yes:
    a. What is the focus of the advocacy that your organisation is funded to undertake? Approximately how much of your organisation's time is taken up with this work?
    b. If you receive funding from other sources, what distinguishes what you are funded to do through this funding and other funding you may receive?
    c. How do you manage the boundary between the two activities? Has it become more difficult during the NDIS period? Why?

Appendix 2b

Post-interview questionnaire for advocacy leaders

	Gone up a lot	Gone up a little	About the same	Gone down a bit	Gone down a lot	Comments
Since last year my organisations **CORE** funding has						
Since last year our organisation's **overall** funding has …						
Between now and five years ago our organisation's **CORE** funding has …						
Between now and five years ago our organisation's **overall** funding has…						
The number of paid staff over the last five years has…						
The number of paid staff hours over the past five years has...						
The demand for advocacy in the past five years has...						
The complexity of cases we are supporting over the last five years has..						
My confidence in future funding for our organisation has....						

Appendix 2c

Focus Group questions for self-advocates:

This exercise will be managed through Microsoft Teams where a whiteboard can be set up on screen and people can add changes.

Introduction

Use large whiteboard for each exercise.

Exercise 1: What is your role as self-advocates?

What does a self-advocate do?

What does your self-advocacy group do?

Why is this important?

Why is self-advocacy important because of the NDIS?

Exercise 2: I now want to look a bit more closely at what has happened since the NDIS started (This may be about you or about other people – please do not use real names or services names)

Have there been changes for you as a self-advocate since the NDIS started? Draw changes on the whiteboard.

Has your team size changed and if so has it increased or decreased?

…and what changes have taken place in your advocacy group?

Have you been in contact with more people with disability as a result of the NDIS?

Have you applied for ILC funding? What was the process like? How did receiving/not receiving it impact your organisation?

Exercise 3:

You have had a lot of contact with people with disability – what are the problems for them since the NDIS came in? Do they need more advocacy?

Exercise 4:

Have some people lost out under the NDIS – who? (prompt on people with different types of disability, people who cannot speak for themselves, people from CALD, ATSI and LGBTIQ as well as people in rural areas)

Exercise 5

If you had all the money in the world, how would you improve self-advocacy in the future? Why?

Appendix 2d

Focus Group questions to Support Coordinators

Support Coordinator focus group

1. First, I want to get a sense of the role you play and what activities this involves for each person for whom support coordination is funded in their NDIS plan.
2. Do you think your training has adequately prepared you to perform your role? to understand and support people with various disabilities?
3. Can you tell me a little bit more about how many cases you work with at any one time? How manageable do you think your workload is? What proportion of these cases would require the support of advocates?
4. In linking people with appropriate services do you have a clear idea about what services fit with the needs laid out in plans? How do you check this choice with the person?
5. What do you think the roles of individual/professional/legal or self-advocates are?
6. Have you ever relied on the work of individual/professional/legal and self-advocates in the roles you play as a support coordinator? Can you give examples.
7. Why have you relied on their work?
    - Do you find it hard to deliver services with the funding provided?
    - If the funding is inadequate, who would you go to for assistance?
    - Ask about conflicts of interest, independence, and about whether they refer on to advocates and if so how.
8. Are there limits to the role of advocates? What are these?
9. On the whole, have advocates been helpful and supportive? In what ways could their service be improved?

Ask for a case study for each example of where an advocate has been involved in any case.

Appendix 2e

Focus Group questions to Local Area Coordinators

Support Coordinator focus group

1. First, I want to get a sense of the role you play and what activities this involves for each person for whom support coordination is funded in their NDIS plan.
2. Do you think your training has adequately prepared you to perform your role? To understand and support people with various disabilities?
3. Can you tell me a little bit more about how many cases you work with at any one time? How manageable do you think your workload is? What proportion of these cases would require the support of advocates?
4. In linking people with appropriate services, do you have a clear idea about what services fit with the needs laid out in plans? How do you check this choice with the person?
5. What do you think the roles of individual/professional/legal or self-advocates are?
6. Have you ever relied on the work of individual/professional/legal or self-advocates in the roles you play as a support coordinator? Can you give examples.
7. Why have you relied on their work?
    - Do you find it hard to deliver services with the funding provided?
    - If the funding is inadequate, who would you go to for assistance?
    - Ask about conflicts of interest, independence, and about whether they refer on to advocates, and if so, how?
8. Are there limits to the role of advocates? What are these?
9. On the whole, have advocates been helpful and supportive? In what ways could their service be improved?

Ask for a case study for each example of where an advocate has been involved in any case.

Appendix 2f

Members of the Action Research Group

1. Deaf Victoria – Maxine Buxton
2. Villamanta Legal Service – Deidre Griffith
3. Southwest Disability Advocacy – Adele Maxwell
4. Gippsland Disability Advocacy – Adrian Terranova
5. Action for Disability in Ethnic Communities – Sarina Sanna
6. Rights Information and Advocacy Centre – Nicole James
7. Leadership Plus - Geoff Southwell
8. Deaf Victoria – Catherine Dunn
9. Rainbow Rights – Cameron Bloomfield
10. Brain Injury Matters – Nia Giddings
11. DARU – Melissa Hale
12. SARU – Sue Smith

Appendix 3

Categories of ILC funding (NDIS and Victorian Government administered) related to organisations receiving this funding

ILC Funding (NDIS and Victorian Government administered)

To create new and/or support existing self-advocacy groups	Action for More Independence and Dignity in Accommodation, Southwest Advocacy Association, Victorian Advocacy League for Individuals with Disability
To create new programs to support people with disability to build self-advocacy skills	Action on Disability within Ethnic Communities, Association for Children with a Disability, Brain Injury Matters, Children and Youing People with Disability Australia, Community Abundance, Deaf Victoria, Down Syndrome Victoria, Grampians Disability Advocacy Association, Independent Mental Health Advocacy, Reinforce
To develop programs to teach people with disability other relevant skills (e.g., leadership, employment, NDIS readiness)	Blind Citizens Australia, Children and Young People with Disability Australia, Disability Resources Centre, Down Syndrome Victoria, Grampians Disability Advocacy Association, Regional Disability Advocacy Service, Rights Information and Advocacy Centre, STAR Victoria, Victorian Mental Illness Awareness Council, Women with Disabilities Victoria
To create new and/or support existing peer support groups	AMAZE, Association for Children with a Disability, Blind Citizens Australia, Community Abundance, Disability Resources Centre, Grampians Disability Advocacy Association, Victorian Mental Illness Awareness Council, Women with Disabilities Victoria
The creation of new, multi-format information and referral portals	AMAZE, Children and Young People with Disability Australia
Expansion of current programs being run by the organisation	Disability Justice Australia (to expand their volunteer progarm), Prader-Willi Syndrome Association of Victoria (to expand their annual camping event)
Resource development for people with disability and their families	Prader-Willi Syndrome Association of Victoria (plain language guides and toolkist), Victorian Advocacy League for Individuals with Disability (planning resources)
Systemic advocacy endeavours to create opportunities for people with disability	Aspergers Victoria (employment opportunities), Youth People in Nursing Homes National Alliance (accomodation opportunities)

Appendix 4

Percentage of advocacy cases by disability type across each quarter (Data from Victoria OfD's QDC)

Percentage of advocacy cases by disability type across each quarter																
	Q1 2016/17	Q2 2016/17	Q3 2016/17	Q4 2016/17	Q1 17/18	Q2 17/18	Q3 17/18	Q4 17/18	Q1 18/19	Q2 18/19	Q3 18/19	Q4 18/19	Q1 19/20 ***	Q2 19/20	Q3 19/20	Q4 19/20
Acquired brain injury	4.9	5.1	5.3	5.4	12.2	8.8	13.4	8.7	3.3	5.7	4.7	3.2	3.9	2.9	3	3.2
Autism Spectrum Disorder	16.8	17.9	13.5	8.1	15.6	19.5	10.5	8.4	22.1	24.4	23.1	26.7	28	27.4	31.9	43.9
Deaf Blind	.4	.7	.3	.5	.4	.2	.2	.1	.2	0	.2	.4	0	.4	1.2	.5
Deaf/ Hearing impairment	1	2.6	4	3.1	1	1.4	1.9	2.8	2.4	3.3	2.9	2.1	2.4	1.6	2.4	.3
Intellectual Disability	28.8	29.7	31.7	24.8	26.2	19.4	25.7	21.9	25.8	20.1	17.8	23.9	24.9	28.9	13.1	13.5
Neurological disability	5.8	7.5	5.3	7.3	5.8	6.9	6.3	6.6	5.5	6.4	5.9	3.8	4.1	4.1	2.7	4.3
Physical Disability	16.9	15.6	12.4	16.8	16.5	13.6	16.9	15.8	13.6	14.6	17.1	11.8	12.2	9.1	11.9	12.4
Psychosocial disability	10.9	7.5	11.4	16.5	11.5	11.2	12.4	11.9	11.4	14.5	14.2	10	7.3	9.1	11.9	7
Speech impairment	5.4	5.3	5.2	3.2	4.2	3.3	5.5	5.3	5.2	7.8	2.5	2.9	.6	.4	.6	1.9
Vision impairment	3.7	1.9	3.6	4.9	1.2	3.9	1.4	3.1	2.8	3.5	3.6	2.9	5.5	3.3	2.1	.8
Undisclosed	1.1	2.5	1.1	1.5	.8	.8	2	1.5	1.7	.8	2.5	4.2	.5	.6	0	2.2
Unknown	4.2	2.5	6.1	6.9	4.5	13.6	3.9	1.5	5.3	6	5.6	7.9	10.8	12.2	16.1	10

Appendix 5

Number of clients seen relating to type of issue addressed by advocates over each quarter (Data from Office for Disability's Quarterly Data Collection)

Showing the proportion of NDIS cases rising sharply over the years as a proportion of overall cases for each area of need being addressed:

Number of clients seen with issues addressed by advocates over each quarter																
	Q1 2016/17	Q2 2016/17	Q3 2016/17	Q4 2016/17	Q1 17/18	Q2 17/18	Q3 17/18	Q4 17/18	Q1 18/19	Q2 18/19	Q3 18/19	Q4 18/19	Q1 19/20	Q2 19/20	Q3 19/20	Q4 19/20
Abuse neglect	60	40	21	36	37	60	29	25	10	31	29	21	9	16	10	2
FV									13	3	7	7	1	7	9	3
Building	7	8	11	14	8	41	7	6	8	21	18	9	10	7	3	6
Justice	109	80	76	80	85	105	69	64	41	51	42	33	15	17	22	6
NDIS	54	81	66	79	154	155	180	208	191	148	203	211	160	149	99	130
Educ	91	91	104	60	104	114	89	133	116	86	113	103	90	86	70	134
Employ	30	25	23	36	32	21	14	25	12	22	36	9	5	3	6	6
Centrelink										37	37	34	32	36	19	20
Financial	9	7		7	17	7	6	11	39	34	35	22	16	11	16	15
Housing	95	82	72	77	70	72	56	81	59	35	39	43	24	24	17	7
Health	25	58	70	82	61	96	59	52	43	47	64	35	29	22	11	12
Non-NDIS service	175	147	135	178	158	163	133	101	62	33	50	29	12	26	19	13
Leisure	22	14	8	36	21	11	12	15	9	25	25	10	7	3	3	4
Transport	22	25	39	19	25	11	8	15	4	21	21	5	2	7	3	1
Family	41	32	32	20	26	29	28	24	22	22	32	11	13	7	16	8
Other	29	90	85	38	43	109	34	58	46	43	40	27	28	20	32	21
All	760	773	742	755	841	994	724	818	675	659	791	609	453	441	355	388
% NDIS cases	7.1	10.5	8.8	10.5	18.3	15.6	24.9	25.4	28.3	22.8	25.7	34.6	35.3	33.8	27.9	33.5

Appendix 6

Examples of issues at NDIS Pathway Stages with quotations

NDIS stage	Area	Example Quote(s)
Pre-planning:	Proving eligibility	'…and I could read a letter from a doctor, occupational therapist or a medical practitioner, and we see it one way but the … local area coordinators … who basically adjudicate eligibility may see it…in another way…' 'it's hard to get reports, specialist reports, in a country area …you used to be able to just take your access request form to your GP and they fill it out…So then how did they get the specialist, and how do they pay for the specialist, and how did they find the specialist? And, you know, helping people work through all of those issues can be time consuming'.
	Filling NDIS forms	'… your LAC will help you fill out the form, your LAC will help you find the evidence. your LAC will link you into other community organisations. Now, none of that ever happened'.
	LAC referring on to advocacy to cover LAC roles	'And the LACs, honestly, we people would come here and say I want to apply for the NDIS we'd send them around to the LAC … And they turn up back here and say all the LAC told me to come to you…is it appropriate to be doing someone else's job for them? No'.
	Managing boundaries	'We, generally speaking, don't do NDIS applications for people, because if I were to say, "Yes, I'll do that," I'd have to do it for everyone… So we will provide some general guidance'. 'when people are first applying for NDIS that we help them with that initial identifying what they want in their plan. So that the idea being that if they can get what they want from the start then we don't have this problem down the track. But people who are - yeah maybe if they've applied and they've been knocked back, we'll send them to one of the NDAP funded'.
	Support to other professionals	'but I have certainly said to the GP, "Hey look, I can provide a support letter for you then to modify as you see fit," and they'll jump at it, "Yes please, yes please." …they're often really happy to do that, because they have this idea that there are magic words, there are buzz words to use with NDIS'.
	Systemic issues	'one of the TSP projects that we're funded for is an NDIS guide for professionals…making sure that professionals are understanding what's happening. It means that there's less risk of it'll rejected for their access requests and hopefully means that there's less need for advocacy throughout the sector'.

NDIS stage	Area	Example Quote(s)
	Getting it right from the start	'Whereas if we were funded properly, to attend the initial planning meeting with everyone who asks us again, it's a lot of those other issues could be avoided. And in … the long run, you'd be saving, besides the taxpayer money, you'd be saving everybody stress. And everything else, having saved the city saving your advocates time, if they were attending it, resolving things'.
The Planning Meeting and NDIS Plan	Boundaries for advocates	'if there's a request for advocacy to go to a planning meeting where that's the only involvement we've had with the person, we won't do that, and we've had lots of those requests…I don't have the capacity to go to every single planning meeting for every single person in our catchment. I will again provide some guidance over the phone when people ring and ask'.
	Understanding disability	'One of the questions that they got asked was, is this lifelong disability? You know, it needs to be a lifelong disability. Well, come on with cerebral palsy!' 'Again, I think it was a lot of naivety from the local area coordinators… come from a different sector…Don't understand what disability is.' 'So I just think they're not trained well, and they're not supported well within their organization'. 'You know and then my NDIS funding was cut even more. You know just because what, I can drive, I can get around independently. There are other barriers I have like you know reading, writing, you know sending emails'.
	Dealing with complexity	'there is an underestimation of the complexity of the issues that face people with intellectual disability and I think a lot of people have probably ended up with an LAC who probably needed a planner and may have needed a complex planner'.
	Supporting LAC understanding for the Plan	'Yeah, we've had to provide a lot of information and put into the layman's terms for the LACs and making sure that the listening to the person …I mean trying to get the story across'. 'But unfortunately at times the support coordinator, at times the OAC as well, will make some assumptions as to what the requirements of that…person - what their requirements are'.
Post LAC planning meeting	No action to implement plan and no appointment of support coordinator	'So we are being inundated with a lot of that sort of work...people whose plans are sitting dormant because no one's actually supporting them to engage with any services'. '…you get a family in with a mother with three children all on scheme and never got support coordination. Now she didn't know where to go... hadn't heard from an LAC…So you know, it's and then you go, they go back, you go back to the plan, review with his family. And first of all, I haven't spent your funding. So you know, it's a vicious circle'.

NDIS stage	Area	Example Quote(s)
	Extending roles – Plan Nominee	'…he NDIA doesn't have a process of consent if a person doesn't have a substitute through a plan nominee. They have no other process and there are people who have no one to nominate and we support hundreds of them'.
Support coordination	Inappropriate referrals to advocates and 'off-loading' work	"This person needs an Advocate." And so our Advocate's are saying "No, no that's your role. This is what you can do." And so we do have this sense of maybe the Support Coordinator's…wanting to offload it'. 'we get a lot of referrals from support coordinators, because they saying, Hey, I can't do this… they receive a percentage of the total plan to be able to carry out their work…and they're going to benefit by additional resources'.
	Support coordinator lack of knowledge	'spending you know 20 minutes, half an hour with a Support Coordinator, teaching them what to do. And that's not our role but in terms of it might be quicker to help the person by doing that'.
	Clarity of roles	'…one request was for a young lady with autism who hates where she's living, and the support coordinator wants to support her to move out but feels that the young lady can't choose her own services and wants an advocate to assist with that. Well, that's actually a support coordinator's role to assist her to choose services. Now, perhaps that person needs a plan nominee, and if I had unlimited capacity, yeah'. 'The referral for advocacy was in part to get me as an advocate to explain their service agreement to the client, and I'm saying, "Well no, that's your document. You need to explain it to them".
	Limited support coordinator hours	'linking people in with service providers or attending planning meetings or talking to the end is for the client. And we're like, well, that's your job, really…they only get limited support coordination hours in the plan anyway…' 'The idea that people wouldn't need more assistance than minimum support coordinator hours to make life interesting and exciting and individualised and person centred is a huge miscalculation that has landed in the seat of individual advocacy. So when support coordinators give up on a person, they call us and say we've run out of money, your turn'
	Dealing with issues after the fact	'…still have a lot of people whose plans are sitting dormant because no one's actually supporting them to engage with any services…You know, a lot of people don't know how to do that'.

NDIS stage	Area	Example Quote(s)
Review and Appeals	Chasing up information	'…you can request a review, but there's no point just submitting the same stuff…Well, you've been knocked back because you didn't have this report. Well, we know that that's was the whole problem'.
	Appeals are time-consuming	'…because the NDIS appeals, it gets quite legalistic at a certain point that's definitely the most consuming'.
	NDIS expectations	'the NDIA refusing to do plan reviews without the person's consent or refusing to do plan review meetings without an independent representative. But of course we don't have the resources to go to every NDIS planner review meeting of everyone who has no next of kin in the state. Not even close'. 'NDIS appeals funding came through. And some of the areas didn't match up with our advocacy areas because they had some other thing on their mind. I'm not exactly sure what'.
Service provision	Maintaining quality services	'a lot of problems with the ways in which services are provided that mean that problems get created that advocates then need to solve. And a lot of it is about standards of practice'.

Appendix 7

Responses in self-advocate focus groups

Question	Responses
What does a self-advocate do?	• Talk to other people and make sure that they are happy • Give people information about where they can go for help • Talking to people in CRUs and day centres • Self advocacy is action for change, engaging with government and organisations for change • Developing relationships, talking at forums, steering projects • Breaking down barriers, sitting on committees • Changing peoples attitudes about disability • Capacity building projects through ILC • Building confidence • Social media, building connections with other self advocacy groups • Making resources (eg. How to do Zoom meetings) • Problem solving • Believe in their rights • speak up and lobby for their rights • Help and support people with a disability to get the same human rights as others in the community • Network and communicate with others with the same disabilities and experiences • Build and update resources to assist others • Make materials like postcards • Apply for grants • Educating the general community and working with government to improve understanding
Have there been changes for you since the NDIS started?	• ILC grants – more money, more people, training • NDIS plan - access to resources that you need (COVID has made this more difficult) • ILC grant – connecting through technology, expanding groups/networks • NDIS plan – support worker • Lots of work to do ILC applications • People with disability need help to do NDIS applications, get help from SARU • NDIS applications need to be more accessible – should be in plain English. • Less time for protesting, other activities

Question	Responses
	• Not working, plan needed a review – with help from an advocate • Cant spend money from plans during COVID • A lot of changes – access to items and services that can help in everyday life
You have a lot of contact with people with disability – what are the problems for them since the NDIS came in?	• There is a cut off age for accessing NDIS • Issues around public transport funding, some people have lost their funding • Hard to understand how much money you have left, and invoices • Hard for CALD people to understand the NDIS system and forms – if you don't explain it then they miss out • NDIS workers don't give people enough assistance • A lot of issues – decision making done for you, NDIS not listening to you • Transport funding removed – security and safety not considered • People with physical disabilities can better access things they need • Support worker not listening – training not good enough • Planners need more training • Wouldn't cover needed assistive technologies • NDIS workers (and society) don't understand peoples individual needs • People haven't been able to get NDIS without support • People that don't have physical disabilities may find it harder to get NDIS support – workers may judge on appearance • NDIS doesn't believe that support groups are needed • Peer support groups are essential • Not enough information forthcoming to make people aware of what supports they can access
Have some people lost out under the NDIS? Who?	• Yes, people without English skills and with different values – in some communities there is shame around getting help • Some groups put in the "too hard basket" – not given choice and control • People with intellectual disability, because its not visible • People with severe disability, like those that need wheelchairs • Without self advocacy, the NDIS doesn't work – it helps people make their own choices • Self advocates connect people with other self advocacy groups that can help them with the NDIS • Indigenous people aren't getting help or access – language issues • NDIS not communicating in other languages • NDIS has a language of its own • NDIS needs to put their language into easy English • Agreement that the NDIS is racist • People in rural areas lose out

Question	Responses
What needs to happen to make self advocacy stronger in the future?	• Funding • Lots more going out to the country – helping more people • More protests • Separate protesting from project work • More office space • Funding to produce more resources and advertising in the media • Technology to improve connections • More persons with a disability are put on committees and included in decision making – quotas • More employment opportunities • Better connecting with people in rural areas • A strong base like SARU • Self advocacy as common knowledge • Get people to want to listen • More awareness around different types of disability and how they may affect a person • More training for NDIS workers like planners • Self advocates need a plan • Guaranteed peer support funding – ILC doesn’t fund this • Agreement that self advocacy needs ongoing, consistent funding • Government needs to be less dismissive and listen to self advocates • Self advocates need to band together

FSSI FUTURE SOCIAL SERVICE INSTITUTE

VCOSS Victorian Council of Social Service

RMIT UNIVERSITY