Report on disability advocacy, representative and information organisations

NCOSS

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ncoss
NSW Council of Social Service

About NCOSS

The NSW Council of Social Service (NCOSS) works with and for people experiencing poverty and disadvantage to see positive change in our communities.

When rates of poverty and inequality are low, everyone in NSW benefits. With 80 years of knowledge and experience informing our vision, NCOSS is uniquely placed to bring together civil society to work with government and business to ensure communities in NSW are strong for everyone.

As the peak body for health and community services in NSW we support the sector to deliver innovative services that grow and evolve as needs and circumstances evolve.

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Executive summary

The issue of ongoing funding for disability advocacy and information organisations in NSW has been the subject of public, and more recently parliamentary, debate. Since the full-roll out of the National Disability Insurance Scheme (NDIS) in NSW the operating environment for these organisations has changed dramatically.

Between May and July 2019 NCOSS conducted a small research project that collected information from 34 disability advocacy and information organisations. The research focussed on the experiences of these organisations; the changes since the end of previous block funding for specialist disability services and the full roll out of the NDIS, and their plans for the future.

It is not possible to do justice to the complexity and sheer volume of information provided by organisations within the time frame for this report. Rather what this report provides is a snapshot of the information provided by senior leaders; on the supports they provide to people with disability in NSW, the challenges their organisations are facing and, inevitably, the insights provided about the NDIS in NSW.

The data collection for this research coincided with the passage of the *NSW Ageing and Disability Commissioner Act 2019.* The accompanying debate recognised the contribution made by advocacy and information organisations to upholding the rights of people with disabilities. As a result the Act includes a requirement for the Commissioner to report to Parliament on the funding arrangements for these organisations. While this report includes information related to funding, the funding arrangements were not the primary focus of the research. Rather, this report focuses on the key themes that emerged from the data analysis.

Organisations reported ongoing and increasing demand for disability advocacy supports in NSW. Supports are being sought by people with disability regardless of whether they are NDIS participants. In addition to the demand for advocacy supports for issues with mainstream service systems, particularly the education and health systems, many organisations are receiving requests from NDIS participants for assistance in solving problems with, and navigating, the NDIS.

Given that the NDIS does not fund advocacy and the absence of adequate alternative sources of funding for these services, many organisations are confronted with the question of how to continue to deliver advocacy and information supports. Despite the struggle, these organisations are continuing to provide supports and remain committed to advocacy.

There are practical barriers for many advocacy and information organisations in becoming NDIS providers. Providing direct support services to people with disability was often seen as a conflict of interest, incongruent with independent advocacy and at odds with the values of their organisations. This was particularly true for participants that explicitly mentioned a rights based approach to advocacy during the interviews. The tension, between independent advocacy and support provision placed parameters on the extent to which organisation could, and were prepared to, transition to the NDIS.

Many organisations that had transitioned to NDIS service provision reported that this had been challenging. Issues identified for these organisations included the NDIS pricing structure, moving from block-funding to fee-for-service business models, lack of stability and security in income and resulting impact on workforce recruitment and retention.

Unsurprisingly, given that organisations reported increased demand on their services, often people with disability and their families had noticed changes in advocacy and information organisations. Some organisations reported that people had commented on longer wait times and had noticed that the organisation was 'busier'.

Insecurity, related to the expiry of the NSW government funding in July 2020, was a key theme for almost all organisations. This insecurity was reported as a constant pressure that negatively impacted on organisational plans.

The changes in funding arrangements have resulted in some organisations planning for closure. Most reported that their boards of governance had engaged in planning processes that deliberated the changes in funding arrangements. Two organisations indicated that they were planning to cease operating.

There continues to be support for the intentions of the NDIS. All organisations identified participants that had benefited from the scheme. It was recognised that, as would be expected with any reform of this scale, that the NDIS is a work in progress. Hope was expressed that improvements would continue to be made to the NDIS to benefit both participants and all people with disability.

It was also clear that organisations will continue to 'advocate for advocacy', including through the *Stand by Me Campaign*, so that disability advocacy is valued and appropriately funded.

Background

Disability in NSW

There are over 400,000 people living with disability in NSW. Australians with disability have lower rates of labour force participation and employment, higher rates of unemployment and longer duration of unemployment.[1] In 2015, only 53.4 per cent of people with disability in Australia were participating in the labour force, compared with 83.2 per cent of people without disability.[2] This figure has changed very little over the past 20 years.

Barriers to employment mean people with disability may have to rely on income support payments, especially the Disability Support Pension and Newstart Allowance.

Almost a third of people with disability rent their homes, increasing their likelihood to experience housing stress. People with disability are four times more likely than people

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[1] People with disability were significantly more likely to still be looking for a job 13 weeks or longer after they first started (65.5 per cent) compared with those without disability (56.1 per cent), Australian Bureau of Statistics, *Disability and Labour Force Participation, 2012* (2015), and Australian Institute of Health and Welfare (AIHW), 2019. People with disability in Australia 2019: in brief. Cat. no. DIS 74. Canberra: AIHW

[2] Joenpera, J and Murdoch, F., 2017. Disability in Australia: changes over time in inclusion and participation in employment, AIHW ACT, p.2

without disability to rent from a state or territory housing authority[3] and 20 per cent of people with disability rent privately. More people with disability seek support from specialist homelessness services than people without disability.

People with disability are more likely than non-disabled Australians to experience violence, psychological distress and poor health. Only 32 per cent of people with disability have completed year twelve, compared with 62 per cent of those without.

People with disability face a range of environmental and societal barriers to inclusion and this results in a higher risk of disadvantage, poorer outcomes and a greater need for supports and services.

Disability service provision in NSW

The NDIS is the most significant reform to date for people with disability in Australia. The NDIS focus on choice and control for people with disability through individualised funding has changed the way that services are delivered in NS The approach taken by the NDIS stems from the UN Convention on the Rights of People with Disability (UNCRPD).

The 2011 inquiry by the Productivity Commission into *Disability Care and Support* was a key step in reform toward rights-based service provision. The Productivity Commission report that identified a number of problems with the ways supports were being delivered to people with disability. In the report of the inquiry the Productivity Commission recommended the establishment of a new national insurance scheme to replace the existing system.[4] This recommendation was accepted by Australian governments and in December 2012 the *Intergovernmental Agreement for the NDIS Launch* was signed.

The Commonwealth *National Disability Insurance Scheme Act 2013* established the NDIS and the National Disability Insurance Agency (NDIA). NSW was the first jurisdiction to agree to the full scheme. The *National Disability Insurance Scheme (NSW Enabling) Act 2013* confirmed NSW Government withdrawal from frontline disability and home care services by full NDIS roll-out in 2018. The Act facilitated the transfer of specialist disability services, staff and assets to the non-NSW government (or private) sector. In July 2013 an NDIS launch site was established in the Hunter region. This was the beginning of the roll-out of the NDIS in NSW.

NDIS is funded by state, territory and the Commonwealth governments who all make contributions to the NDIS. IN 2012 the NSW government agreed to 'contribute its existing available funding for specialist and other disability services and supports' to the NDIS in 2018/19. [5] In July 2018 full roll-out of the NDIS in NSW was completed with all NSW Government funding for disability services and supports transferred to the NDIS.[6]

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[3] Australian Institute of Health and Welfare (AIHW), 2019. *People with disability in Australia 2019*: in brief. Cat. no. DIS 74. Canberra: AIHW.

[4] Productivity Commission 2011, *Disability Care and Support*, Report no. 54, Canberra.

[5] *Heads of Agreement between the Commonwealth and NSW Governments on the National Disability Insurance Scheme – agreed 6 December 2012*, https://www.ndis.gov.au/about-us/governance/intergovernmental-agreements

[6] Funding for the NDIS is held by the NDIA.

It should be noted that not all people with disability will become NDIS participants.[7] While there are approximately 4.3 million people with disability in Australia, it is expected that the full scheme will include 475,000 participants by 2020.[8] In NSW this number is expected to be between 140,000 – 150,000 participants.[9]

The full roll-out of the NDIS in NSW, in July 2018, ended block funding to advocacy and information non-government organisations. In response, the Disability Advocacy Alliance, a coalition of 22 disability advocacy, information and representation organisations in NSW, formed the *Stand By Me* campaign. The campaign is ongoing and aims to secure recurrent funding from the NSW Government for advocacy organisations in NSW.

The NSW Government has extended funding for a number of advocacy, information and representation organisations until June 2020 through the Transition Advocacy Funding Supplement (TAFS).

The importance of advocacy and information supports for people with disability is increasingly being acknowledged.

In 2018 the final report of the NSW Legislative Council Portfolio Committee no.2 – Health and Community Services' *Inquiry into the Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales* recognised the importance of supports outside of the NDIS to meet the needs of all people with disability in NSW. The report acknowledged the importance of advocacy organisations and included a recommendation for ongoing funding and support by the NSW Government.[10] The Inquiry findings are consistent with the Productivity Commission review of the National Disability Agreement that identified that improving the lives of people with disability will require responses that extend beyond the scope of the NDIS to other service systems.[11]

On 1 July 2019 the *NSW Ageing and Disability Commissioner Act 2019* (the Act) commenced. The passage of the Bill in the Upper House included vigorous debate on funding for advocacy and information organisations. As a result Section 26 of the Act requires the NSW Commissioner to consult with independent specialist advocacy, information and representative organisations for people with disability in NSW and provide a report on the funding arrangements to Parliament by 31 December 2019.[12]

What is disability advocacy?

The *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) purpose is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their

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[7] Scheme participants are people with a permanent and significant disability that receive individual NDIS packages.

[8] Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs, Study Report*, Canberra. pp. 3-4.

[9] *Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales,* Portfolio Committee No. 2 – Health and Community Services, Report 51, December 2018, p.12.

[10] op.cit. p. xii.

[11] Productivity Commission 2019, *Review of the National Disability Agreement, Study Report*, Canberra. p.2.

[12] *New South Wales Ageing and Disability Commissioner Act 2019*, Section 26.

inherent dignity'.[13] Australia ratified the CRPD in July 2008 and the accompanying Optional Protocol in 2009.

Disability advocacy is a term used to describe activities that support people with disability to understand and exercise their rights.[14] Activities may be undertaken by people with disability, those acting with them or on their behalf. Central to disability advocacy is recognition of the *inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons*. [15]

While there are different ways of describing advocacy, the Productivity Commission has identified four 'modes' of advocacy:

- Systemic advocacy — aimed at bringing about systematic improvement in policy and practice, and removing discriminatory barriers for people with disability.
- Individual advocacy — upholding the rights of individuals with disability by working on discrimination, abuse and neglect.
- Self-advocacy — supporting people with disability to advocate for themselves, or as a group.
- Legal advocacy — where a lawyer provides legal representation or gives legal advice to people with disability.[16]

There are a number of instruments that integrate the obligations under the CRPD into Australian legislation and policy. The *National Disability Agreement* (NDA) and the *National Disability Strategy* (NDS) operationalise the obligations under the CRPD to uphold the rights of people with disability and describe the roles and responsibilities of Commonwealth, state and territory governments for the inclusion of people with disability. The *Disability Discrimination Act 1992* (DDA) protects all people in Australia from discrimination based on disability and makes disability discrimination unlawful.

The NSW *Disability Inclusion Act 2014* acknowledges the rights of people with disability and the responsibilities of the state and the community to facilitate the exercise of those rights. Under the Act the NSW Government has a Disability Inclusion Plan and all NSW Government entities including local Government are required to develop a *Disability Inclusion Action Plan* that includes strategies to support people with disability to participate fully in the community and have access to the general supports and services they need.

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[13] UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106.

[14] Department of Social Services 2011, *National Disability Strategy 2010 – 2020, An initiative of the Council of Australian Governments*, Canberra. p. 17

[15] UN General Assembly, loc.cit.

[16] Productivity Commission 2019, *Review of the National Disability Agreement, Study Report*, Canberra. p. 91

About this research

In 2016 NCOSS was funded by the former NSW Department of Family and Community Services (FACS)[17] to undertake a project to build the capacity of 40 advocacy and information organisations in preparation for the NDIS. This project, which ran from July 2016 to June 2018, was known as Skilled to Thrive (StT).

StT was designed to ensure people with disability continue to have access to appropriate supports to exercise choice and control in their lives by building the capacity of 40 disability advocacy and information providers – largely small to medium organisations - to respond to the changing funding and service delivery landscape. It consisted of four main components: tailored group capacity building, individual organisational support, development of resources and targeted project management.

A key premise of the StT project was that organisations should aim for diversification or become an NDIS provider in order to adapt to the new operating environment. Many in the advocacy sector have expressed the view that this assumption is flawed, as the independence of advocacy – including its separation from direct service provision – is paramount. A number chose not to participate in the project as a result.

The project was completed in June 2018.

In May 2019 NCOSS commenced a small follow-up research project to gather information on the changes experienced by organisations since the roll-out of NDIS, which had marked the end of block funding, to explore how disability advocacy and information organisations are approaching the expiry of TAFS in 2020 and their plans for the future.

The focus of the research was on four main fields of inquiry:

1. Services currently provided
2. Changes to the organisation since the full implementation of NDIS in NSW
3. Feedback received by service users on organisational changes
4. Plans for the TAFS expiry in 2020

Organisations were identified from two sources; an NCOSS database of organisations that had participated in the StT project and a publically available list of organisations that had received the TAFS. Approaches were made to 42 disability information and advocacy organisations and 34 organisations agreed to participate in the research.[18]

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[17] In 2019 the Department of Family and Community Services was abolished and the Department of Family and Community Services and Justice was established under the *Administrative Arrangements (Administrative Changes—Public Service Agencies) Order 2019*. As FACS was responsible for disability funding in NSW prior to the NDIS, references to the former department in this report have been retained.

[18] Of the eight organisations that did not participate:
- One organisation had gone into administration.
- One organisation was uncontactable and no indicative information could be provided.
- One advised that they had not been in receipt of information and advocacy funding,
- Two no longer provided any disability services.
- Three organisations advised that due to staff turn-over they were unable to provide a person with the appropriate expertise to participate in the could participate, or that the appropriate staff member was uncontactable.

Methodology

Semi-structured interviews, including two group interviews, were conducted with 34 leaders of disability advocacy and information organisations. Chief Executive Officers of organisations and/or their nominated representatives participated in either face-to-face or telephone interviews with the research team[19] between May and July 2019.

The interview questions were designed around the four fields of inquiry. Each interview, undertaken by one or both members of the research team, was recorded and transcribed. Data collected was analysed thematically, coded separately by the researchers and then inter-rated. Initial coding of the data identified key themes and sub-themes which were then used as the basis for a more in-depth interrogation of the data. For example responses on impacts of change were initially coded as positive, negative or neutral and then themes identified through analysis. In this way, the analysis elicited both a quantitative overview of the major issues raised by the organisations, and a more in-depth qualitative analysis of the themes. An inductive approach allowed for new codes to be identified during data analysis.

A post interview survey was also provided to allow informants to interview participants to provide any additional information that they had overlooked or forgotten to mention during the interviews.

In addition, analysis of key documents and reference material was undertaken as part of this research. Material reviewed included organisational annual reports, government policy, information resources and *Stand by Me* campaign material.

As the interview participants were leaders and/or nominated representatives of their organisations, the terms “organisation/s” and “participant/s” will be used interchangeably with regard to information collected at interview in this report.

About the participating organisations

All of the organisations were either currently providing disability advocacy and/or information supports in NSW or had previously been funded to provide these supports by the NSW Government. The cohort included Disabled People’s Organisations[20], Family Organisations, Culturally and Linguistically Diverse (CALD) Organisations and specialist disability organisations. Some organisations had their origins in advocacy and activism for the rights of people with disability and included membership and governance structures comprised of people with disability and their families (where relevant). Others were service providers that also provided information and/or advocacy. The majority of the organisations have operated in NSW for over 20 years.

Almost all (33) of the 34 organisations were non-government organisations (NGOs). Most of these (31) were receiving TAFS funding. The three organisations not receiving TAFS funding had previously been funded by the NSW Government. One, a local council, had incorporated

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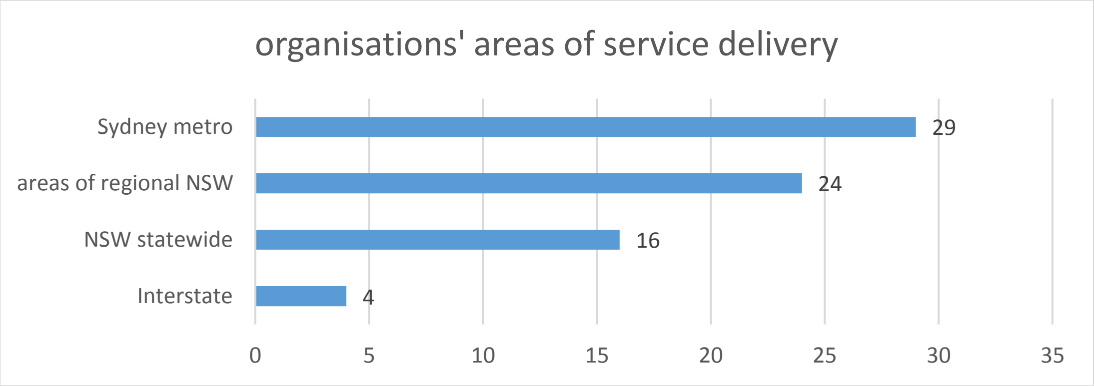
[19] The research team was comprised of two NCOSS staff, neither of whom had any role with the StT.

[20] The term Disabled People’s Organisations is used for non-government organisations that are governed, led and constituted by people with disability https://dpoa.org.au/about/terminology/#_ftn1.

disability work into council core business and funded a position. The other two were previously TAFS-funded NGOs that had received short term Information, Linkages and Capacity Building (ILC) grants.[21]

Most had an office located in metropolitan Sydney. Some organisations were delivering state-wide services; others operated in specific Local Government Areas, including areas of regional NSW. Four organisations were also operating in other jurisdictions as well as NSW. These organisations tended to be operating in geographical areas close to state borders.



If using the classifications developed by the Australian Charities and Not-for-profits Commission (ACNC) just over half of the organisations would be classified as large (18) with the rest of the cohort comprised medium (6) and small organisations (7).[22] However many organisations with a budget of $1million described their operations as being 'like a small business'. [23]

Mergers

Two organisations had successfully undertaken a merger since the commencement of the NDIS roll-out in NSW. One small advocacy organisation had merged with a larger disability service provider and reported that it had retained the 'independence' and integrity of the advocacy service. The other had merged with its national 'umbrella' organisation though had retained its NSW specific offerings.

A further four organisations had actively considered mergers, but for various reasons had not proceeded or had put the decision off until they had more clarity about future funding arrangements.

Additional services provided related to NDIS

Fourteen organisations had become NDIS service providers. While most of these organisations were providing support coordination and /or plan management five organisations were providing direct supports.

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[21] Further information on ILC grants is provided at p.9.

[22] The Australian Charities and Not-for-profits Commission (ACNC) classifies charities by revenue. Large organisations are those with revenue over $1million, medium between $250 000 and $1 million and small under $250,000.

[23] The Australian Bureau of Statistics (ABS) defines a small business as a business employing less than 20 people. https://www.abs.gov.au/ausstats/abs@.nsf/mf/1321.0

Eight organisations were providing NDIS Appeals support and services under the National Disability Advocacy Program.

A total of seventeen participating organisations had been granted Information Linkages and Capacity-Building (ILC) grants, including ten (of the aforementioned fourteen organisations) that had become NDIS service providers. Two of the organisations receiving ILC grants received no TAFS funding.

Summary of supports and programs provided under the NDIS

In order to understand the insights provided by organisations in the following sections of this report it is helpful to understand the supports provided by the NDIS. The following provides a brief summary of NDIS supports and related programs.

Participants in the NDIS are those assessed to have a permanent and significant disability. A significant disability is defined as one that is likely to be lifelong and with a substantial impact on one's ability to complete everyday activities.[24] Eligibility for NDIS is determined by the NDIA. Once a decision is made that a person is a participant of the NDIS an individualised NDIS plan is developed with the participant and an individualised support package (funding) is approved by the NDIA. Plan management and payments can be managed by participants directly, by the NDIA or by third parties. It is the participant's choice who provides supports and manages payments. Supports identified in NDIS Plans are provided by organisations known as NDIS providers.

NDIS providers offer a range of supports to NDIS participants, according to the parameters set out in participants' plans. NDIS supports are sorted into three main categories:

- Core supports for assistance with daily living, community participation, transport supports and for purchasing consumables.
- Capital supports, which consist of payments for things like assistive technology and home modifications.
- Capacity building supports are intended to build participant independence and skills and are to be used to achieve goals identified in a participant's plan. This category includes support coordination and plan management.[25]

Each support category has many specific support types or 'line items' that are recognised in the NDIS payment system. For the purpose of this report, the term 'direct support' has been employed to describe all of the support categories with the exception of support coordination and plan management. Further information on supports provided under NDIS are included at attachment A.

There are also related programs that accompany the NDIS.

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[24] Australian Government *National Disability insurance Scheme Act 2013* Section 24 Disability requirements

[25] National Disability Insurance Agency July 2019, *NDIS Price Guide*

Information Linkages and Capacity-Building (ILC)

The NDIS also provides supports intended for all people with disability, including those who are not NDIS participants, through the NDIS Information Linkages and Capacity-Building (ILC) program. It is designed to provide information, linkages and referrals to people with disability, their families and carers, with community and mainstream supports. The focus of ILC is on individual development and community inclusion and ILC services provide information about, and referrals to, community and mainstream services (including health, education, employment, transport, justice and housing).[26] Peak body activities, such as policy advice, advocacy and operational costs and the provision of individual or systemic advocacy are excluded from the ILC.[27]

National Disability Advocacy Program (NDAP) and NDIS Appeals Support

Some advocacy services for people with disability are funded by the Commonwealth Department of Social Security (DSS) under the National Disability Advocacy Program (NDAP). NDAP funded services can deliver individual advocacy and legal advocacy and are not restricted to NDIS participants. DSS also provides funding to services to support people with disability seeking external review of decisions made by the NDIA through the Administrative Appeals Tribunal – this is referred to in this report as NDIS Appeals Support.

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[26] Productivity Commission 2017, p.3

[27] NDIS, *Community Inclusion and Capacity Development (CICD) Program Guidelines, Implementing Information, Linkages and Capacity Building (ILC), 2016-17 to 2019-20*

Research findings

Services provided under TAFS

The first interview question asked organisations to describe the services that they have been providing using the TAFS. Answers to this question provided an overview of the nature of the day to day work of TAFS funded organisations.

Participants described a range of activities undertaken with and for people with disability, their families and carers. They reported consistently that the advocacy support they provide is determined case by case, based on people's unique needs. However, common their clients was the need for support to interact with the NDIS and with mainstream service systems.

Key findings

- Advocacy and information supports are being provided to both NDIS and non-NDIS participants.
- There is a strong focus on advocating for equitable access to services and the community.
- In particular, organisations work with NSW mainstream systems including education, health, justice, transport and housing; NSW Government-run agencies.
- Organisations are experiencing an increasing focus on NDIS and issues related with access to the NDIS. As such, organisations have a whole new service system to navigate with the people they support.

Types of services provided

At the time of the TAFS program establishment FACS described TAFS as for 'individual advocacy, information and representative services for people with disability in need of specialist disability supports.'[28] These supports were categorised as information/referral, individual advocacy and systemic advocacy.

During the interviews participants described complex work, in which providing supports across these categories are interrelated tasks. A picture emerged of organisations that all provide a combination of information and referral, along with individual and systemic advocacy in response to the needs of the people they support. Across the information, referral and advocacy 'categories', the most commonly cited use of TAFS was personalised support based on individual issues requiring advocacy.

This section reports on the ways participants described these 'categories' of support.

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[28] NSW Government, 2017, *Advocacy for people with disability in NSW. Fact Sheet.* Available at https://ndis.nsw.gov.au/wp-content/uploads/2017/10/Fact_Sheet_Advocacy_For_People_With_Disability_FINAL.pdf

Information and referral

Most organisations reported providing information and referral services and supports. All of these organisations deliver these supports to NDIS and non-NDIS participants, regardless of whether the organisation was itself an NDIS provider.

Organisations providing information and referral supports undertook a range of activities including:

- workshops and training
- social information sharing opportunities
- responding to and following up phone enquiries
- supporting individuals to make informed choices
- information as a form of advocacy
- emotional support
- online material
- print materials and newsletters
- disability specific or general information provision

Organisations implicitly described a basic hierarchy of support, from personalised to general. Information was most often provided directly to individuals as a form of support, either in person, over the phone, or through support groups. Many had an enquiry line through which they answered questions, made referrals and followed up. More personalised engagement happened through bringing people together for workshops, forums, group get-togethers and information sessions. Some organisations also provided cohort-wide or population/disability specific information online or in physical resources.

> “We have an extensive information portfolio of booklets that we’ve written, information sheets about [disability]… that’s our main one, in addition to that we have publications, we have [disability] News, which is a journal type publication which goes out twice a year and we have what we call our [newsletter] publication that goes out four times a year.”

> “We are a very, very specialised organisation. So there is a lot of knowledge that we have.”

> “The other thing that we have done, we’ve had running for a year now is an NDIS coffee club for carers and participants, but it seems to be more the carers who come than the participants. It is a peer support group really that responds to what the attendees tell us they want to know. So it is a way of exchanging information, they actually exchange actively between them and gripe together about their problems. But they, that information is useful [also] for if someone has found a good service to talk about that.”

> “…if some families are managing really well, we can just provide them with information, and they are able to do the follow up themselves. But for those families who are really vulnerable and at risk, we can do that leg work for them.”

Individual Advocacy

Two thirds of organisations were providing individual advocacy, many in addition to information and referral. All of these organisations provide supports to NDIS and non-NDIS participants, with the exception of two, whose cohorts are entirely NDIS participants due to the nature of their disability.

In seeking to identify what providing individual advocacy means on a practical level, organisations consistently described advocacy as a verb – a purposeful activity, something that people ‘do’ for and with other people. The work of advocacy included:

- supporting/assisting a person with disability to access the community and services to which they are entitled
- supporting /assisting the family and carers of a person with disability
- interacting and negotiating with other service sectors including the NDIA
- addressing and resolving a specific crisis
- upholding a service user’s rights and holding others to account
- growing support user’s skills in self-advocacy

> “Advocacy… that could be basically around families and anything that families needed in that information that we supplied. It’s hard to, on the spot, to sort of go, what we actually did. Whatever situation… we have to go in in an advocacy role going, hey, you know, and doing battle with them on behalf of the person.”

TAFS funded systemic advocacy

The majority of organisations were undertaking systemic advocacy. All systemic advocacy providers were operating beyond the NDIS with the aim of improving mainstream systems for people with disability. During interviews a range of activities were described. The most frequently cited were:

- articulating and communicating systemic issues and problems to state and Commonwealth Governments and Government departments
- informing policy development through submissions and representation to and at the request of state and federal Government and Government departments
- participation on advisory groups and panels
- providing information and advice to parliamentarians, public servants and departmental staff
- facilitating the meaningful inclusion of people with disability in systemic advocacy

All of the organisations providing systemic advocacy were also either an information/referral provider, a provider of individual advocacy or both in some capacity. Several reported on the need for organisations providing systemic advocacy to be connected with individual advocacy issues. A couple of organisations informed their systemic advocacy by purposefully collecting data on their individual advocacy. They reported the importance of clear evidence of the impacts of system pressure points to prosecute their cases for systemic changes.

"It's advocating for changes in service systems, policies, laws, other aspects of the systems that effect people. So, as to make them work better for people with intellectual disability."

"…you get a whole plethora of examples of things that are going wrong and you can actually then see clusters forming together in relation to pinpointing particular issues that are happening, which very much then feeds our systems advocacy work."

Systemic advocacy often arose out of repeated complaints or issues with a service experience. For example many reported that issues with schools were an ongoing concern for people with disability, their families and carers. Repeated requests and activities to assist with these school-related issues informed systemic advocacy. Access to health services also resulted in systemic approaches from more than one organisation. Through the interviews it became evident that systemic advocacy was viewed as an efficient way in which organisations were working to reduce future demand and improve life for people with disability. Organisations sought to address ongoing problems at the 'source' by drawing the attention of responsible actors to these issues within their systems.

"…you can count a thousand individuals that you helped with advocacy services, and that is great that we helped a thousand people. But did you also help a thousand people with problems that systemic advocacy would take and deal with and help you change the system so you don't have a thousand people coming to you?"

Themes

Individual advocacy is responsive

Advocacy is demand driven. The services described in the interviews were responsive rather than planned in advance. This is a key difference from support services that work within the confines of NDIS individual plans.

The NDIS provides individual plans that are orientated around a person's goals. NDIS plans remain in place, mostly unchanged for at least a year. In contrast advocacy and information organisations provide services for people when something changes suddenly or when something goes wrong. These organisations provide support as a crisis unfolds and when support needs suddenly change. Advocacy and information organisations are experienced in responding quickly to complex, changing circumstances.

The advocacy that was described cannot be prescribed in advance.

"Basically wherever she's at, we meet her wherever she's at."

Advocacy and information organisations described their work as filling the gaps in other formal or government service systems and the community.

Services were delivered in an absence of lengthy eligibility and intake procedures and with flexibility resulting in a capacity to respond to the needs identified by people when they presented to services (walk ins).

> "…we had a guy come in Easter Thursday… of course… a young man mid 20s just out of gaol… was in gaol because he had PTSD, had come out of the armed forces. Was not ok and knew he wasn't ok and needed to see a doctor but none of the doctors would actually see him… this is advocacy, sorry, none of the doctors would let him in because he'd go to the reception and tell them his story and then they'd say 'no we have no appointments'. And we rang around and got him an appointment, we got him into a doctor that afternoon and he came back and said to us, you know 'I can get through the weekend, I now have a psychologist appointment organised, I have this in place for the next week…' That stuff. And we get that all the time."

In describing this responsive advocacy, organisations identified established relationships with people and communities as key to the effectiveness of individual advocacy.

> "There's a lot of people who just because they know us, they just ring when things are bad. They don't really know what they want, but they ring because it's just a place they know and again, I sort of think that these are often people who don't have anybody else to call. I think that's the same with a lot of advocacy organisations."

> "…in times where things maybe don't go quite right, that we can be there to support them through that and hopefully see that those things change."

> "It's about having an understanding of what fits. It's understanding their goals and looking at them. For the NDIA to say, we're providing this support so that you can meet that goal then that's what we're working on. It's only when I guess somebody has something happen that is outside of those goals is when we provide advocacy on top of support coordination."

> "Particularly in rural and remote regions, where for some people it's just a phone call to you know, help them move in another direction. To sort out things that are happening in their life."

Advocacy, information and not pigeonholing

The services being delivered were described during the interviews as individual advocacy, systemic advocacy, information and referral. Organisations often didn't separate these service 'categories' to describe what they do. Rather, they used them to explain the trajectory of their supports in response to the presenting needs of people with disability.

The meanings attached to advocacy and information varied between organisations. For some, providing information and support was a form of advocacy and could lead to, or facilitate, self-advocacy.

> "So it would be about actually talking to families and providing them with information and resources… around how to actually navigate that, how to prepare for a meeting, how to

> respond to an email, what's the next … help them think through, what's that next step in this barrier that they're facing to actually get to the end goal, what is the end goal? …it's about trying to work with families and provide them with what they need so that they can actually advocate with or on behalf of their family member with disabilities, around the barriers that they experience in society."

> "We are an 'information advocacy' service – the idea was that the advocacy happens through the provision of independent information, connection and referral… the primary basis of that money originally is that the advocacy falls through the ability of people to articulate and advocate for themselves. So its capacity building."

In these cases 'information as advocacy' was a way of providing people with disability, and their families and carers, with the opportunity and agency to seek appropriate services, make informed decisions, learn skills to self-advocate and extend their community access.

Other organisations described providing all types of advocacy and information supports throughout their interactions; one leading to the other, one feeding the other, or one as dependent upon the other; part of the 'wraparound' nature of the way their services work with people.

> "…over the phone we basically historically have always said we'll deal with … we'll try and deal with the issue in the first instance, make a few phone calls, see if we can resolve the issue over the phone. If it actually needs an advocate to go out and meet with someone face to face that's when we would send it to advocacy."

Revealed in these quotes individuals and families are managing unique, complex and changing problems. Their supports must respond to these unique needs.

Problems with mainstream services

Many organisations described interacting and negotiating with mainstream service systems as core work; undertaken in the interest of people with disability and their family. Several reported that this had not changed as a result of the NDIS, remaining a primary concern.

> "…while most of the focus over the last five years or so have been around the NDIS we know that the issues that people are dealing with aren't just NDIS even though that's the big thing. But for us it's the non-participants, people that don't have a package, a funded package and are trying to deal with mainstream services… so that's an issue for us."

The most frequently cited mainstream service sectors that were the subject of advocacy efforts were:

- housing
- health
- education and schools
- justice
- transport

Work with families was also specifically mentioned by several organisations. Organisations described that support needs for families and informal carers are often not considered with depth as part of individual NDIS participant plans. As a result, many participants indicated that their organisations have found a role in addressing the particular needs of the families they support at a local or disability-specific level. For example, support and information groups for carers and self-advocacy skill building.

> "A lot of it's around, we have run 'care for the carers' programs and newly diagnosed. There's a lot to do with the families, education of the families and helping them find resources."

> "Yes and it's about empowering our families to know, first of all to know, to understand it and to know what they can ask for and what they can't ask for. What is reasonable and necessary within, you know, and yeah, so a lot of that is empowering people. Knowledge is power."

Organisations reported that mainstream services were not always inclusive of people with disability. Many explained that advocates work with people with disability, their families and carers to identify and work through particular barriers as they are presented by mainstream services. They also explained that advocates build relationships with a range of people in key roles in those systems in order to resolve barriers for the people they support. Knowledge and relationships were used to hold those systems to account for their obligations to people with disability.

> "Well, you know, it's to do with a problem that you're having with housing that's quickly going to lead you to eviction… It's mainly with State Government instrumentalities rather than the Commonwealth, of course, that's growing with the NDIS."

> "It depends. I mean, they may have issues to do with housing, as an example. So housing, appropriate housing for people with disability, is pretty few and far between as is, as it is."

> "So we still hear that in relation to access to health services, that mainstream health services still struggle to support all people with disability."

> "It would have been issues possibly with health as far as complaints about the health system."

> "…we don't mind that they ring us when they don't really know what they want, but just so we can tease it out with them to see what might be able to help. And quite often they are needing legal help. They might not know they've got a legal problem but often there is."

> "We also negotiate with schools through school linking when there's been a breakdown between the communication between parent and the education department."

> "Individual advocacy and information has been for school aged children dealing with bullying at school. So I have gone with parents to meetings with school principals, and

ensured that the school has put measures in place to get on top of that, and that kind of thing."

"You'll get the concerned schools that really want to make it work. I love those ones because they really want to make it work. When they contact us and ask us would we come and do some training. And so we hold their hand and that can take several phone calls, providing resources for them, going into the school and observing, like observing the child to see just what the barriers are and then taking it from there."

"Our Aboriginal communities, we would say there has always been a lack of linking with the service sector for many, many historical reasons."

Working with these sectors was reported as 'business as usual'.

"10 per cent of people are on the NDIS, 90 per cent of people with disability aren't and you've still got a lot of advocacy issues you've got to help those people with."

Problems with the NDIS

Most advocacy organisations reported that in addition to their mainstream advocacy, a significant part of their work has become supporting people to access and navigate the NDIS. The NDIS was the sector most frequently identified in which advocacy with people with disability, their families and carers is now taking place.

"…the big issue for advocacy services is getting people through the NDIS issue, you know, it's not easy for some people and their families. So, advocacy can really help them get what they're entitled to."

Organisations talked about this as having become an additional 'sector' for their work. Examples included:

- promoting the NDIS and supporting communities to understand it
- working through cultural and other barriers that prevent people from seeing the value in the NDIS, for example fear of change
- working with individuals in the pre-planning phase to understand and commence the NDIS intake process
- supporting participants to access and set up new services
- helping NDIS participants who have issues with their plans to negotiate with their provider and/or the NDIA

This is significant because the NDIS is the only service system that is disability specific rather than mainstream. Further, the NDIS is relevant to just 10 per cent of the population of people with disability[29] yet has become the largest area of work for advocacy and information organisations.

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[29] Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs, Study Report*, Canberra. pp.3-4

"Before, a couple of years ago, our number one issue is always accommodation and then we have issues about immigration, access to services. These are the big main issues that we had before. But now it's overrun by NDIS and as I said, most of the people that we see from culturally and linguistically diverse background don't have access to NDIS and therefore advocacy is very important for them. Because if there is no advocacy, they really wouldn't know where to go…"

"But the advocacy services have been well, largely one to one supporting people with NDIS issues or lack of information, um, also going to planning meetings or, what I've done a lot recently is helped people with pre-planning where they have more complex plans, where support coordinators have so much time allocated but it's not enough. When you've got a very complex case."

"I think the top two or three questions would always be around navigating the NDIS, whether it's pre assessment or planning and then afterwards 'what do I do now? Who do I connect with? Who do I have the conversation with? I don't understand any of this, I don't know what to do.' Lots of stuff around that… The biggest one is people not feeling that their packages are adequate. So they don't know where to go to for review purposes… It's largely been people not understanding that they have a package, or tied to that, "How do I get to be part of the system, what do I need?"

That advocacy and information organisations are spending such a proportion of their resources on supporting people to access and navigate the NDIS in addition to their 'business as usual' advocacy in mainstream sectors has implications for the way we understand the purpose and value of advocacy and information organisations. The NDIS has not reduced the role of these organisations, rather it has significantly increased it.

Changes to organisations since full roll-out of NDIS in NSW

The interviews included a question on the most significant change for organisations since the full roll out of the NDIS. There were no responses that identified the change as 'positive' despite all participants expressing strong support for the 'intention' of the NDIS.

While this question sought to capture information on the changes to organisations, interview discussions often gravitated towards changes for people with disability that were either reported to or observed by organisations. This is not surprising given that the NDIS is now the dominant system through which disability supports are delivered. However it became clear during the interviews that the NDIS is not the only lens through which these organisations understand and experience their role with people with disability. This was highlighted by the frequent references to the 90 per cent of people with disability who are not accessing supports through NDIS.

Key findings

- Most participants reported that the NDIS had impacted negatively on their organisations.
- Organisations are operating in uncertain environments both in terms of policy and funding.
- Organisations reported an increase in demand for services.
- There are ongoing challenges for many organisations with the transition to NDIS including moving from block funding to becoming 'a business'.
- Workforce challenges include retaining skilled staff and instability in employment arrangements.
- There are barriers for some organisations in adopting NDIS business models and some of these are ethical.
- There is widespread agreement and concern among organisations that the NDIS does not fund individual advocacy.
- Despite concern NDIS is strongly supported.

Themes

The full roll-out of the NDIS has transformed the service landscape for people with disability in NSW. Clearly, from the interview data this is also the case for organisations providing advocacy, representation and information services. A number of themes emerged in response to this question with participants reporting on both the impact of the changes to their organisations and to people with disability.

Unsurprisingly, funding; the lack thereof and challenges in securing funding for the future - including TAFS, emerged as a core theme in responses to this question. Discussions about funding, either reductions in funding or changed funding sources, were often accompanied by descriptions of additional pressures on organisations. Funding uncertainty was often highlighted with many describing challenges for organisations arising from short-term funding arrangements (ILC grants). Most interviews included at least some discussion of the inadequacy of NDIS pricing. Many people spoke about the way in which changes to funding had impacted on the organisational structure and work force.

Although this question focussed on changes to organisations it was common for participants to talk about the impact of the NDIS on people with disability in NSW. While support for the NDIS was expressed by all, this support was qualified with many reporting on challenges faced by NDIS participants.

The impacts of the system changes were felt heavily. Many of the organisations that participated in the research were long standing (about a third of the participants interviewed made direct reference to the age of the organisation) and many had been established by people with disability and their families. These organisations have significant history in the provision of advocacy services. All participants expressed concern about withdrawal of support for advocacy and information services by the NSW Government and the impact this would have on people with disability and their families.

> "There is just too much uncertainty at the moment."

Independent advocacy organisations transitioning to the NDIS service system – the 'line'

The *National Disability Insurance Scheme Act 2013* includes a definition of independent advocacy that clearly requires an advocate to be 'independent of the Agency, the Commission and any NDIS providers providing supports or services to the person with disability'. [30] Organisations were highly cognisant of this and of the limitations this places on 'signing up' to provide NDIS services.

> "We have tried and we are starting to do, support coordination. The issue there is that we do not want to be doing many NDIS services of course because that is going to be a conflict. We are an advocacy organisation mainly. That's how we see ourselves. So if we go into service provision then that will sort of become blurry for us."

As interviews progressed it seemed that there was a 'line' drawn by many organisations regarding NDIS service provision. Often organisations that had transitioned to become NDIS providers had done so with much consideration and deliberation. Many organisations spoke of having considered the extent to which providing direct supports would be in conflict with the requirements of the NDIS Act regarding advocacy.

> "You really do need to keep that advocacy role quite clearly separate from a service provider role because otherwise I'm sorry there is a conflict of interest there and why that's not seen is lost on me."

For the majority of organisations the 'line' was drawn at support coordination and plan management. Providing direct support services to people with disability was often seen as a conflict of interest, incongruent with independent advocacy and at odds with the values of their organisations. This was particularly true for participants that explicitly mentioned a rights based approach to advocacy during the interviews. Many of these were from Disabled

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[30] *National Disability Insurance Scheme Act 2013*, Part.2, section 4.

Persons Organisations and/ or organisations with boards comprised of people with disability and their families.

It should be noted however that there was one outlier. One organisation considered that advocacy could and did inform all aspects of their NDIS service delivery and, as such, being a NDIS provider was considered congruent with the values and ethos of their organisation. While distinguishing between specific individual advocacy activities and NDIS service delivery this organisation appeared to be embedding advocacy as a framework to guide service delivery.

> "Our whole philosophy is based on advocacy so everybody that comes here if there is any need for them to have somebody advocate on their behalf for something, then it will happen regardless of what program they're in. So a lot of the advocacy work comes around some of that stuff."

Funding

Given the scale of the NDIS reform, funding was an *a priori* theme that was confirmed by the interviews. Almost all participants expressed concern, and often frustration about the end of NSW funding for advocacy services, particularly as there was no readily identifiable alternative source of funding for individual advocacy.

> "We get a small percentage of our funding from the Federal Government for systemic advocacy. The State Government money, its individual advocacy."

> "When they agreed to this [the NDIS] they knew that it wasn't going to fund individual advocacy, and at the same time, we're aware that individual advocacy was important to enable people to access mainstream services…there is no capacity within NDIS to fund advocacy at all."

> "…there's no way we can generate and get people to pay for advocacy. It's not in the NDIS. They would have to pay for it out of their pension or something which we find is not the case. We wouldn't do that."

Only four organisations were solely reliant on TAFS funding. Most organisations had managed to secure funding through ILC grants, or from the NDAP or NDIS Appeals program though DSS to provide other services. Despite this funding was an ongoing source of stress.

> "Prior to the NDIS and prior to all that, we had a number of fixed term contracts and we knew that they were going to roll over year in and year out. Since the NDIS, we now got two ILC grants…um we got some small project grants – but they are year on, year by year, they don't, there is no continuation of funding. Now NSW was ongoing funding up until 2018 and now …this is two year…so it is very hard to plan, forward plan, when you only got short term funding."

In particular, people spoke about the impact of short-term funding and lack of certainty about ongoing funding as having significant impacts on planning and staff retention.

> "In terms of the community development officer that I spoke about before, we don't have that position anymore. It was just something we couldn't sustain. And that team that I mentioned where clinicians were available just to go out and offer support to whoever needed it, that team has dissolved."

> "…so I have lost staff too, you know. Partly I think because there had been a little bit of this you know constant 'we don't know'."

Interestingly even organisations that had transitioned to provide NDIS services or who were funded for services from the Commonwealth (either ILC grants or NDAP, NDIS appeals) reported that change had negative impacts on organisations.

> "We don't function in the same way that we did…it's very much driven by what people have in their plans and what they need to engage with. So whereas before we had the service and we offered it, now it's more we have the service but people need to come to us if they require it, and if they've got funding in their plans for it."

Changes to the funding arrangements had impacted on changes to the services and service delivery.

> "So there's lots of things that you are just not able to do anymore because other departments have pulled out, and your NDIS is very specific what you can manage with that money."

There were consistent reports that the pricing structure of the NDIS was inadequate and does not allow for organisations to deliver the services in the way they once had.

Increased demand for services

> "…the most significant change, is I think the fact that it has added work."

Adding to the funding pressures being experienced by organisations was an increase in demand for advocacy services. Much of this increased demand was attributed to the NDIS.

> "…but once the NDIS was rolled out, well, that became the main source of our work. It's increased our (advocacy) workload nearly double, and the majority of referrals now are people trying to access the NDIS who don't have specific disability, but they have a lot of health issues that are lifelong and they feel that they should get into the NDIS so, of course, we deal with that."

Many participants spoke about struggling to meet an increasing demand for advocacy and information services related to the NDIS while continuing to deliver advocacy supports to people with disability experiencing difficulties with state service systems (such as education, housing, justice, health, transport). Advocating for people experiencing difficulty with the NDIS was a significant change for many of the organisations from what was often described as having previously been their 'core work' with the 'mainstream' system.

> "…we are seeing, we still got our normal clientele, although issues that were around before NDIS um school education, elderly health issues – they haven't gone away – so the NDIS issues are on top of what people…the issues we had."

During interviews a number of concerns were raised accompanied by examples of the need for both individual and systemic advocacy for NDIS participants as well as other people with disability in NSW. This was often attributed to the newness of the NDIS and the complexity of the new bureaucracy that many people with disability are attempting to navigate.

> "We've noticed a noticeable increase in the number of people we're trying to assist, mainly with NDIS-related issues. Whereas at first it used to be 10 per cent of our work, now they're getting close to 40-50 per cent of our work related and I expect that will go up in time as well."

> "…we're also expected to cope with the …Well 90 per cent of the disability population doesn't get the NDIS and they often have issues as well."

> "So even for that 10 per cent of the people that are accessing NDIS, who are still having challenges accessing mainstream services, there is no capacity within NDIS to fund advocacy at all."

The previous quote highlights the statement frequently repeated during interviews that only 10 per cent of people with disabilities in NSW are eligible for the NDIS. This was most often expressed as a deliberate, as opposed to an unintended, outcome and a truth known by those responsible for the NSW NDIS agreement.

> "But only 10 per cent of people will be able to access the NDIS. It was always going to be that way. NSW has an obligation to then 90 per cent of people with disability who are never going to be part of the NDIS, were never going to be part of the NDIS, but still have a right to access health, education, public transport, vote, you know, you name it, housing."

Regardless of the NDIS, many expressed strong views that the NSW government continues to have responsibility for safeguarding the rights of people with disability in NSW, explicitly referencing the *Disability Inclusion Act* and the *International Convention on the Rights of Persons with Disabilities*. Providing ongoing access to advocacy services for all people with disability in NSW was viewed as an important mechanism for fulfilling these responsibilities.

> "…we won't ever give up advocating…that's the core business we do, it was why this organisation was set up…"

In many of the interviews advocacy was expressed as a value - essential for the protection and promotion of the rights of people with disability, understood as central to the lives of people with disability and fundamental to the purpose of their organisations. It was made clear in interviews that while the service system may have changed, advocacy and information organisations remain focussed on an understanding of rights of all people with disability that extends beyond services provided under the NDIS.

The 'business'

The NDIS adopts a fee-for-service market-based approach to disability supports. As such providing supports is no longer restricted to NGOs or not-for profits. The NDIS has facilitated opportunities for new entrants into disability service provision, including for-profit providers, and created a new 'market' for disability services and supports. The information shared during the interviews supports a view that this has completely changed the operating environment for disability NGOs.

For organisations that had 'signed up' to provide NDIS services experiences were mixed. Many spoke of financial challenges and the challenges of becoming a 'business'.

"Because the NDIS pricing doesn't match the cost. It certainly doesn't… there's also not the development costs. I mean it cost us as an organisation about $200 000 to make that business work. And it's now working. And as an organisation we had like $220 000 reserves."

"And you need to get that money back?"

"Yeah. So our projections over 18 months will almost replace it. But getting to that is the hard part. Because if this bucket of money [TAFS] goes away, I have to make another $200 000 on top of that."

While many organisations were struggling, some spoke of having navigated the transition successfully, despite reservations.

"…that was how support coordination came about because people that had worked with us for 20 years were saying, well can't you do this? This is the stuff that you used to do. You used to help me to negotiate with services, you used to help me to find the service that I want, to make sure that that service is doing the job well. All of those things that are a support coordinator's job. So we then went down that path and said, well yeah ok we'll do it and we'll see what happens. And it's been very effective."

There were two organisations that reported having merged in order to secure their ongoing viability. Another had considered this but decided not to merge.

"Some have strapped two bricks together and chucked 'em in a pond. You know, like? That's really what our experience of the merger process was. They realised that they were strapping bricks together. Looking at that from a block funding point of view, you're already losing that dosh from a different part of the system from the NDIS, and then moving into outcomes based payment, fee for service and they're going to have to go through all of that, then you're strapping two bricks together."

There was both tacit and explicit recognition that the NDIS had fundamentally changed the way that organisations were operating and that, while there were advantages, there were also trade-offs.

"So I guess what the NDIS has done in a sense is that it's made it such a – almost like a business model of providing care. And for anyone to send a clinician a few hours out for one person, when you look at it from a business point of view it does – it's not economical to do that."

One participant expressed concern that the costs for the trade-offs would be borne by some people with disability.

"I certainly know the sector is being marketised. So the shift is moving towards big generalist providers, and that's great for convenience for people, but not particularly great for people who have very specific conditions, and rare conditions in particular."

"And a lot of the support coordination services, they provide great support coordination to a certain extent but it is, from the point of view of this is what you are buying and this is what we are selling, rather than it being about you are the most important person in this relationship and what you want is what we need to help you to find and building on that. So I think it is a very different approach."

Workforce

Workforce issues were also frequently spoken about, with many organisations having already made significant changes to their structure and services to adapt to the new operating environment. Most frequently reported were changes to management, increased numbers of part-time arrangements and loss of staff.

"We have a very flat structure. All of our workers, so one-on-ones. There are me, (name of staff member) and our specialist support coordinator are essentially the management team but everyone's, we work on the basis that everyone's on the same level. We don't have team leaders, we don't have all of those middle management levels that you've got to fund in some way."

"Everybody has become part time, because within NDIS, and as you know, the unit cost doesn't actually pay for the time people have to spend with a client. So that has been a huge impact on our organisation as a small organisation…most people have become part timers, because they are trying to meet the needs basically of the community."

Many were concerned that workforce changes, related to uncertainty of ongoing funding, would result in expertise being lost from the disability sector. Some mentioned that their expertise was being sought from other NDIS providers.

"They ring us … We'll get a support coordinator say, I've got a participant and they're having difficulty with Department of Housing and getting a service from Department of Housing of some sort, can you help? But we say, well no, you're the support coordinator, you do it. They're a mainstream service and that's part of what you should be doing is supporting people to negotiate their way through the mainstream systems."

One participant connected the changes under the NDIS with reduced access to training and development.

"You know staff have always ... a bit of a luxury of being able to get training through their agencies and services, and now that some agencies and services under the NDIS are saying to staff you have to pay for training yourself and then, staff are not updating training as much as they did before. That has a big impact on the services and the client and their carers as well but that, you know, it's a decrease in skilled workforce because staff are not getting the training as regularly as they had before."

Ongoing support for the intentions of NDIS - with concerns

Despite describing pressures and negative impacts on their organisations all participants expressed support for the intentions of the NDIS. There was a general consensus that the NDIS has improved things for many people with disability, however this acknowledgement was often qualified with statements related to complexity and access problems for all people with disability.

> "Yes, undoubtedly there's a lot of people with intellectual disability now who are receiving supports, who didn't receive them before. There's a lot of people receiving better supports than they did before. On the other hand there's a lot of people who are having big problems ether getting the access to the NDIS or maintaining necessary supports that they had before."

> "The NDIS has been life-changing but it's been just so difficult to navigate. So it's given a lot more advantages and opportunities that this community has ever had before but, my god, it's so hard to navigate and to know what you're entitled to."

> "The NDIS is a great reform. It is one that most of our organisations in the advocacy sector truly believed in and lead the push for. And, umm within that, now that it is being implemented, it has very much added to the amount of work that we do and a good percentage of those are about how the NDIS, be it how they get access or how they manage the plan or how they deal with an issue."

> "People with disability, you know, some people are doing very well with their NDIS plans, but many others, particularly people who are either living in quite marginalised circumstances have experienced, you know, have been part of institutions for many years, and so then experience the effects of institutionalisation. People who are living in rural and regional areas, and or areas that are by virtue of postcode are disadvantaged, are possibly, you know, we are hearing that they're not getting the access to the NDIS that they may be entitled to."

Support for ongoing advocacy and information services

Organisations were very strong in asserting that there continues to be a need for advocacy services for people with disability in NSW, regardless of whether or not they were reliant on TAFS funding for their ongoing viability.

> "I think it would be a tremendous loss to the sector to lose advocacy services. I think they are needed, and they play a unique role in the community. We refer people to advocacy quite regularly because they, number one, their family maybe taking advantage of them. Number two, they might have a bad landlord or be in a discriminatory workplace, you know, there're so many examples of why an independent advocate is needed. I can't believe that this is even considered as a service that shouldn't be funded, I really can't."

Despite expressing uncertainty about ongoing state funding, many participants expressed determination to continue to deliver advocacy and information services.

“The families still keep in contact with us, and this is a trust relationship that we want to continue to provide the service to people, because it is about people. It’s not about a business model, you know. But that is where we are trying to fit into. Hopefully we will just do it, we can do it.”

Changes noticed by people with disabilities and their families

The interview included a question on what changes organisational leaders have heard the people they support have noticed. Key themes were identified across those responses.

Nine organisations reported that no changes to their service will have been noticed since the roll out of the NDIS. 25 organisations reported that changes had been noticed. Of these, nearly half deferred automatically to discussing challenges with service provision in the NDIS rather than to their own service provision. This may indicate the preoccupation these organisations are experiencing with supporting people through the NDIS service system.

Key Findings

- Most participants reported that service users had noticed changes; most notably that services are busier and that service users are experiencing more stress and confusion.
- Despite having described significant changes in their organisations and the disability sector in response to question two, some organisations reported that their clients would not have noticed any changes to their services.
- Many answered this question with descriptions of the challenges with service provision in the NDIS.
- Organisations identified that throughout the changing environment they have discovered that the people they support are likely to be very loyal to their organisation.
- A 'hard to reach' cohort is emerging; people with complex, intersecting support needs are finding it more challenging to engage with disability support service provision.

Themes

No change - continuity in service provision

> "…they won't have noticed any change in terms of service delivery, or I hope not.

> "Just on that last question, what do you think people with disabilities and families will have noticed any changes… they won't notice any changes until we are not here."

About a third of organisations said that their service provision was 'business as usual for clients'. Those that reported participants will not have noticed any changes represented a mixture of organisations. All provided services to both NDIS and non-NDIS participants and most mentioned the importance of independence of advocacy and information provision from direct service provision.

These organisations explained that they were doing their best to provide the same level of service to the people they support as they had in the past, regardless of the changing nature of their work and the environment. It was clear from the responses provided that organisations were committed to continuity in the levels of support and services they provide. Organisations described trying to 'weather the storm' of broad system change and remain present and available for their community, despite the challenges this was presenting. They feared the impact of the loss of TAFS on people with disability in the future and were thoroughly committed to preventing any reduction in their services.

“No. We try to still do everything that we were doing before. We are trying to support people with whatever issues they come to us.”

“Basically we've been doing what we've always done with that [TAFS] money... which is direct advocacy and citizen advocacy, but we've just been trying to struggle with doing it with a hundred thousand less money.”

“…[we are] an organisation established to advocate on behalf of people who are more disadvantaged, or less fortunate, and we are living by the legacy.”

“I think for a lot of the advocacy organisations, but I can only speak for ours… you realise that some things you actually have to fight until the end… because there’s just too much to lose.”

These quote illustrate that many organisations are driven by a clear mission. Some had already lost a proportion of their TAFS in the process of gaining ILC grants, others had diversified funding sources and service portfolios. Regardless, the indelible right of people to access advocacy and information was at the core of their purpose.

People with disability and their families will have noticed changes

The intent of this question was to report specifically on the changes to information and advocacy supports, rather than challenges associated with the implementation of the NDIS. However, it is important to highlight that among several changes noticed, the most commonly cited change was stress and confusion at the complexity of receiving support through the NDIS. Busyness, decreased availability, increased loyalty and the impact of compounding disadvantages were also cited by a large proportion of organisations.

Confusion, stress and complexity

Consistent with organisational changes, the complexity of the NDIS system for people with disability and families was a key theme reported by organisations. Stress and confusion at NDIS complexity, and challenges with inconsistencies were the most commonly change observed for people with disability and their families.

“So all these rules that are coming up are complicating the lives of people with disabilities. They don't make it easier.”

“[The NDIS is] really is like it’s just another giant typical bureaucracy and it’s not any different. There’s no one you can ring there. So, they need a middleman often to figure out what they’re supposed to do.”

“The biggest issue and challenge, I think, for people with disabilities is it’s a big scheme.... I think a lot of people struggle with its entirety and not fully understanding it… They’re expected to tell them what they need, they’re expected to know what’s in the plan, expected to know what the funding is, what it's being used for. However, a lot of people just – they haven't been provided the tools or the information on how to do it."

"I think from my perspective, as an advocate, what I see is a lot of confusion and that if someone didn't have an advocate, I could see how the process of trying to for example get maybe a review, would just exacerbate a person."

Busier with reduced capacity

As a direct impact of the complexity of the scheme, participants talked about the NDIS having created various new workloads for their organisations. Where some received NDIS Appeals funding to deal specifically with some of that work, the majority did not. It was reported that people are experiencing longer waiting periods to access advocacy and information and that people they support would notice that the staff are busier and less available. It was also reported that people would have noticed changes in the way that the organisations has to prioritise delivery of services.

"I might seem more harried than I ever did before… that might be something!"

"They're saying, well, it's taking you longer to get into the service because you're getting busier and busier all the time."

An increased workload meant that some 'products' such as newsletters had to be discontinued, because other supports needed to be prioritised. These changes were considered to be having consequences for people with disability.

"Participant: So yeah I have one particular couple who like to drop in regularly and I've had to sometimes say, and much more than what I ever used to, I'm sorry but I really don't have much time today. They'll just drop in out of the blue. They, the only change they will have noticed, which isn't really NDIS, but it is, we made the decision a year, almost a year ago, that we would stop doing a printed newsletter. Because it took an inordinate amount of my time... So that is something that has changed. And that they could keep dropping [in] to help us get it together for mail out. It is only a small, small thing, and it isn't really what you're asking.
Interviewer: Well, no I think it is significant. It's indicative of…
Interviewer 2: Well big for them.
Participant: Well it is actually. They actually really enjoyed giving back."

More responsibility for people with disability, their families and carers

A third of the participants reported that people with disability, their families and carers will have noticed an increase in the level of responsibility they carry for the receipt of support services. This was noted as positive and negative.

"Customers are now taking an active approach to their service provision, compared to passive approach."

Where a NDIS participant had complex needs in several facets of life, the increase in responsibility for service coordination was experienced as challenging, a negative impost and a risk. For some people with disability and informal carers, it was reported that the increase in responsibility appeared to be very stressful.

> "These days most of the calls will be fielding NDIS questions. In the last couple of months, crisis and overwhelmed calls, people just feeling at their wits end, don't know what to do… they've been approved for packages but they don't know what to do next."

Organisations were concerned about the stress they observed people with disability their families and carers experiencing with some reporting 'stepping in' to prevent crises emerging or people falling through service system 'gaps'. This was identified as a particular risk for NDIS participants without informal supports.

> "We find… we have a lot of people contacting us who are completely isolated and don't have anyone to help them to apply for NDIS. So we find we do quite a bit of that work in helping people to do their access request and sometimes we go to their, well, almost always if they don't have anybody else, we go to their planning meetings with them and do some pre planning work with them because that just seems to be a gap, although really the, that gap's meant to be filled. But what we find is that if you're on your own as a person with an intellectual disability it's just not enough and so people are missing out."

Two organisations reported that people with disability and families were stressed and concerned about the prospect of the organisations supporting them having to close in June 2020.

> "We are continually hearing the concerns, dismay and the effect of resulting stress from people with disability and their supporting families in regards to the ceasing of NSW Government funding."

> "Yeah, and I guess, I mean, partly because we've been talking about it a lot in the media, people are quite worried in regional areas in particular about losing all their services, particularly advocacy, because they're already struggling."

Falling through the gaps

> "But that cohort of people we're finding harder to reach, if I say it that way, even though we know that they have issues but they're ... we're actually finding that this is mainly through ... you know, it's actually for them I think they're giving up a bit so by the time you've connected with them they are actually in real crisis because they're not getting much service or support and they're really falling through gaps.... but it's that they don't believe there's anything there for them."

Organisations expressed concern and frustration for people who have numerous, intersecting disadvantages and barriers. Examples were provided of people with disability, not necessarily eligible for the NDIS, who were experiencing problems such as homelessness or insecure housing, mental health issues, substance misuse problems, trauma, social isolation and family issues. It was reported that some people with disability were in situations characterised by complex disadvantage and unable to access supports. There was also concern expressed that some were giving up on seeking supports.

Those living with economic and other disadvantages, including some Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, those in remote areas, people with comorbid diagnoses and people generally disempowered were described as becoming more difficult to locate, engage and find support for.

> "If you take that conversation another layer back to Aboriginal and Torres Strait Islander People, we would say those with a disability are the most disadvantaged groups today. Being Aboriginal is a disadvantage in Australia today, and being a person with disability, we would say is a double disadvantage."

> "For our communities, it's another system that they'll miss the boat on. They were promised the Holy Grail, everyone is included, everyone can jump on this boat and be part of new changes... Again, the lower hanging fruit which are ATSI communities, and CALD, the ones that are most vulnerable and disadvantaged are the ones that are missed."

> "We totally support making the person at the centre of decision making, but at the same time, I really strongly believe that this system is for English speaking, middle class people with physical disabilities. That works really well, you know, people can speak up for themselves. But when it comes to people with disabilities from culturally and linguistically diverse backgrounds, especially intellectual disabilities, it becomes more and more complex, and that hasn't been taken into consideration at all in setting up the system."

> "A lot of work goes into stopping people from falling through the cracks, identifying people who, yes, who might be at risk, working with them, doing social work and case work with them, which is another thing we don't get paid to do. But yes, a lot of that type of work to stop people from missing out… because a lot of those are people from culturally and linguistically diverse backgrounds, people who are living in poverty. It's very, very disadvantaged people, and disempowered and extremely hard to engage with. We put a lot of effort in trying to be near the culturally and linguistically diverse community, building relationships in the culturally and linguistically diverse community, so that when it comes down to it, we can approach them and they trust us."

The quotes reflect observations made by organisations that disability services are for some becoming less universal and less accessible. The suggestion is that one of the most concerning change for people who did not easily fit the NDIS model was the increased risk of 'falling through the gaps'. Several participants stated that they had predicted that this would be the impact of the NDIS, citing the complexity of its implementation.

> "We said this… and we identified these issues right from the beginning. You know, those who know how to work a system, like everything in life, will be enabled to have a better quality of life. Those who are the most vulnerable and the most disadvantaged that will be left behind."

“They won’t go” – continuity and change

Many organisations reported that the people they support have a fierce loyalty to their organisations in the face of the changes described in this report. This loyalty was attributed to having built relationships of trust over time through the organisations being embedded in, and known, by their community, and by having a ‘track record’ of providing appropriate and expert support. This was expressed particularly strongly by specialist culturally and linguistically diverse organisations, organisations working with Aboriginal and Torres Strait Islander Communities and by organisations that had an open shopfront and had been part of a community for several years.

> “I talk about people having access to a phone call, but more important for our communities, for Aboriginal communities is that face to face contact is vitally important. That people feel that they’re being heard.”

> “… Because it takes many years to develop, like any friendship, like any network. It takes time, particularly for Aboriginal people, all across the sector connecting and feeling comfortable and feeling like they’re not being judged. That’s a time effort that you can’t buy.”

Organisations described encouraging people to use their NDIS plans to try different service providers. Many found though that existing clients prioritised their relationship with their organisation over the freedom to choose something new. Some organisations reported that the reluctance of their existing clients to move to other service providers, including private providers, had informed their decision to transition to NDIS service provision (mostly in indirect supports). Other organisations reported that existing relationships and respect for the choices of people with disability resulted in them continuing to work to provide appropriate supports.

> “I know, even the same sort of people went back to [their familiar advocates] because that is where they feel comfortable, that’s where they feel trusted. You know, trust is one thing that is something that cannot be built overnight. That is why people need such a long time of an ongoing service. One of our project officers, I said why do they think that they come back to us all the time, and he said a long history and reputation, and we provide culturally and linguistically appropriate services for them. When someone doesn't speak the language, we just make every effort to actually find someone. If we don't speak the language, we will find an interpreter service. It doesn't matter what it is, we will just try our best to support them.”

> “[Colleague]’s nodding ‘yes’ because they keep coming back because they know you and they trust you. Sometimes you’re not resolving any issue but you’re listening. Then they’ll go away having, just happy to talk to someone.”

> “Look, normally I should refer them to another agency, but even if I do that, they wouldn't accept it, one because of let’s say because of the acquaintance and because we know each other for a long time, and they rely on our support, and it’s sad to say we can’t do this, you have to go there. It’s very, very hard…There are families that say no, I will only speak to you,

I don't want to speak to anybody else… I've been part of their lives for many years. This is the cultural issue. Sometimes it’s a matter of trust, you know, and if you prove yourself to them that you are a person that can be trusted and you are knowledgeable, they want you, they want you, they want you, and there is nothing else that you can do. I do encourage them to do a lot of things for themselves. I guide them how to do it, this and that, but there are different cases.”

Plans for the expiration of the TAFS funding

At the time of interviews there was no indication from the NSW Government that funding would continue for disability advocacy and information organisations after 2020. While the issue of the TAFS expiry was a feature of all interviews, discussions of specific plans for services post-TAFS were challenging. In one case the question was not initially received well.

> "…you said - what will you do **when**? What do you mean by **when**? If we start talking about when it [TAFS] ends then we may as well just pack up and go away now. How ridiculous is that question?"

This quote illustrated the determination expressed by many participants and their organisations not to 'give up' on securing funding for advocacy and information. Despite this the data from interviews revealed that most organisations had considered how to operate without TAFS.

Key findings

- Almost all leaders of organisations had been working with their boards, management committees and membership and discussing plans for the expiration of the TAFS funding.
- Eight organisations had plans in place that included an option to close the organisation, including two regional service providers. Two organisations indicated a clear intention to close.
- Organisations that plan to continue to operate were often those with alternative funding sources. Many advised that the expiry of TAFS funding would result in structural changes, including reduction of staff, and withdrawal of standalone advocacy services (including in regional areas).
- Almost all indicated that their boards, membership and communities would mobilise to support them in advocating for continued funding for advocacy services.
- NDIS pricing and short term funding were impediments to ongoing viability of services.

Themes

Funding expiration plans

> "(TAFS) …is the majority of our funding so we have found that we will be dead in the water if we don't find another source. We have and will do one of two things. One is to commit to past that time because we do have funds in the bank that would allow us to continue for a couple of years at a very limited, in I suppose a limited way."

Almost all participants indicated that they, and their management committees or boards, had been actively engaged in planning that included consideration of TAFS expiration. The options being canvassed that were described most often during the interviews were service closure, reduction of services and finding ways to continue advocacy work in the NDIS system. Some reported having multiple plans.

> "We will struggle without that money, if we don't make up the difference we won't be there. I am running 3 strategic plans at once. One is about growth. One is about funding development, business development. And one is about how we shut the doors."

Most plans included at least some consideration of closing. Eight organisations indicated that plans being considered included closure. Two of these were located in regional areas, and at least one had already come to a decision.

> "We do have a plan in place for ours. And yes we will be shutting the doors and selling the building. I set up a scholarship years ago. So all our assets will actually go into that part."

While more than half of the organisations had no plans for closure, changes to organisational structure, including reduction in current levels of staffing, were being actively considered. All but one of this group stated that without funding the service would cease providing standalone advocacy services.

> "…we'd be closing Armidale, Dubbo, probably we'd have a few. Basically, we'd lose eight advocates so we'd have to then … A couple from Newcastle, some from the mid-North Coast, Armidale office would definitely close, one of the offices on the Mid-North Coast would close. We'd have to really think about our presence in Broken Hill again or Dubbo and cut down our staff at Bathurst as well so we'd probably have to lose some offices and retrench some staff."

For organisations contemplating closure of advocacy services the issue of how to communicate this change to their members and communities was complex.

> "The issue with that is I think we have to shut our doors physically and become mobile to avoid, to abandon the community. Because the reality is we have no money to provide that sort of support and people will expect it. They will keep coming through our door. And if we just become an NDIS service provider I think we actually have to… we can't have the shop front, we can't be there."

"Planning" for closure was discussed as a necessary responsibility. Some participants clearly stated that despite planning for closure they intended to continue to lobby for advocacy services and had no intention of withdrawing from the disability space.

> "Well of course from the first of January there will be, a closing plan in place, of course. You know the staff will take all of their leave by the 30th of June, as required by the management committee of course. And there will be ah, a closing down process document entered. But I believe the membership is very clear that if they need to on a voluntary basis, they will continue to lobby for advocacy funding. The management committee and the membership are going to continue to lobby for advocacy funding."

Even those without plans to close indicated strongly their commitment on ongoing lobbying for advocacy.

> "Tell them we won't go quietly."

Most participants expressed distress, anger and disappointment about the impact the loss of advocacy services would have on people with disability in NSW.

> "Well, for the community they'd get less support from us and for ourselves as an organisation we, again, we'd find ourselves what things were like 12 months ago, you know, what are we going to do? Are we going to drop hours or are we going to have to lay people off, are we going to, you know? I think Governments have got to realise that advocacy plays a big role in assisting people with the NDIS and they need to say, well, we've got to continue to fund this."

A small number of organisations indicated that they did not have any plans for the expiration of TAFS. This is not to say that organisations were counting on the funding continuing, more that their present focus was on finding ways to continue to operate.

> "We're focused on survival, and good survival. But of course the non-survival option is always there. But if you start focusing on it, it start becomes a fait accompli."

> "…we're not ready to go there yet. Now that's not because we are being delusional in nature in relation to what the end result is going to be, but it's actually, if you want to call it a fight, which I probably wouldn't, it's not something that we're willing to lose. Because it's actually not about what **we** would lose..."

Participants spoke often about the commitment of their communities and membership to continuing to lobby for advocacy funding and their willingness to mobilise. Many organisations reported having links with their local MPs, some of which reported that MPs offices were a source of referral for advocacy. It was clear during the interviews that regardless of the decision of the NSW Government many organisations would continue to 'advocate for advocacy'.

Consideration of alternative funding sources

Most organisations had either considered or applied for other funding, including Support Coordination (the 'line'). Reservations about conflict of interest and alignment with values were not the only reasons given for being cautious about transitioning to NDIS.

> Interviewer: "Would you be looking at support coordination?"

> Participant: "Yes. Hmm. Yes, I mean one of my qualms with all of that is that you need to have a lot of customers to pay the rent. Because you only get 10 or 12 hours a year if you're lucky. From what I understand if you're really brutally commercial about it, 12 hours comes, "that's it sorry I can't do any more now until next plan." Others work for free to support their customers and that can't be economically sustainable a lot of the time."

The quote above reflects what organisations reported on their experience of providing support coordination services and what they have heard or seen of the experiences of other services in their areas. As discussed previously many expressed concern about the NDIS pricing arrangements and questioned whether these would allow them to maintain a viable service. Additionally withdrawing supports when plan funding ran out was not considered to be consistent with the ethos of many organisations.

Accounts of experiences heard from others were consistent with first person accounts shared during interviews. At the time of interview many organisations providing Support

Coordination reported that they were not 'breaking even' and shared that they knew of other organisations in 'deficit'.

> "It is really, and as you know, a lot of small organisations have folded up because they can't. We actually, I know some of the disability organisations, they could not actually carry on with their support coordination because they are all in deficit. Everybody is in deficit [chuckles]. NDIS have made a billion dollars and they think that's a surplus [chuckles]. So yes, it is a huge gap in our service delivery, but we are still continuing service delivery as it was prior to. In between we had a bit of a gap when we were really trying to set up the system. But we are still going through the system, because it's a huge demand on a small organisation like ours."

During interviews two organisations, including one planning for closure, mentioned trying to run an advocacy service sorely staffed by volunteers.

> "…for myself if advocacy funding is closing, I said I will volunteer. (Service) owns the building so we have a few people who put their hand up to say we will volunteer, we will continue working on advocacy if we have to."

> "At the moment, we do not know if we're going to be able to apply, or if we want to apply for further funding, officially, under the ILC or anything else. What we are thinking is that we might not apply for any other funding, so when the next year comes, the period of June 2020, the funding is finished, but we're going to leave the premises where we are, obviously because it's expensive, we're going to keep the organisation, and on a volunteer basis, of course it's not going to be the same."

That organisations would be willing to provide services that were previously funded on a volunteer basis was interpreted as an indication of their commitment to their communities, rather than a plan. It is worth noting that these organisations were delivering services to CALD communities.

> "I will find it very difficult to let go and say we can no longer provide that service and you know isn't that what government is banking on? That their expectation will be that services like ours continue but they don't fund us. So, I'm struggling with that issue and that is something that I talk with our board about all the time."

The quote above illustrates a view that there was an expectation from government that services provided by NGOs under previous funding arrangements would continue to be provided for free even if funding ceased. This may be indicative of a cynicism, or mistrust, held by some providers regarding the intention of funding policy. While there is no evidence that this is the case this perception is understandable.

> "Well, it is hard to imagine at this stage, because that is one program (TAFS), it has nothing to do with NDIS, but that is the program actually, we really cannot even comprehend how government is planning to support CALD people with a disability, navigating the services, accessing services that are appropriate to their needs. We can't even comprehend it."

Conclusion

Disability advocacy and information organisations in NSW are facing an uncertain future. Most organisations are operating with limited resources in an environment that has been completely transformed by the NDIS.

From the accounts provided by organisations it is clear that there is an ongoing need for disability and advocacy support in NSW. Support to access mainstream services for all people with disability coupled with assistance in navigating the NDIS system for NDIS participants are but two of the reported drivers of increased demand on organisations.

It is not surprising that the NDIS has contributed to increased demand on services given the size and scale of the reform. It is widely recognised that the NDIS has presented challenges for many participants[31] and that further work is required to refine the system. It is noted that work to improve the NDIS is ongoing.

The withdrawal of services previously available in NSW to people with disability who are ineligible for the NDIS is likely to pose ongoing issues for people with disability, their families and organisations. It is also clear that people with disability continue to face challenges accessing mainstream services such as education, justice, housing and transport. Support continues to be sought from advocacy organisations from people with disability, regardless of eligibility for NDIS.

People with disability from culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander people and those requiring support for social and communication issues were identified by organisations as needing additional, and sometimes specialised, advocacy supports. Concern was also expressed about ‘thin markets’ and lack of services for people with disability in regional and remote communities.

There was universal agreement, and concern expressed, about the absence of ongoing funding for advocacy and representation in NSW. This was experienced as an additional pressure on organisations, most of whom reported operating with limited resources. Resource constraints resulted in changes to working arrangements, staff moving from full-time to part-time, as well as changes to organisational structures and service capacity.

Independence was a key issue that emerged during all of the interviews. The need for advocacy organisations to maintain independence as a prerequisite for advocacy was a barrier for many organisations, when contemplating transitioning to NDIS service provision. This may have contributed to the concerns expressed about programs that sought to encourage advocacy organisations to ‘transition’ to the NDIS. It is clear that this issue is ongoing and will require further consideration.

The commitment expressed during the interviews to the rights of people with disabilities was striking. During the interviews all organisations described experiences that

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[31] Commonwealth of Australia (Department of Social Services) 2019 ‘*Improving the NDIS Experience: Establishing a Participant Service Guarantee and Removing Legislative Red Tape – Discussion Paper*’

demonstrated their significant expertise in navigating services systems and in providing supports to people with disability to assist them to exercise choice and self-determination.

NCOSS would like to thank all of the organisations that participated in this research for their time and generosity in sharing their experiences and expertise. It is hoped that this report provides an insight into the contribution these organisations make to the lives of people with disability in NSW.

Attachment A

Summary of supports under NDIS

Direct supports

Direct supports are services provided under the NDIS that are chosen and purchased by participants through their NDIS plan to assist them to live independently, participate in the community and achieve their goals.

Support coordination and plan management are not direct supports. Plan managers and support coordinators have a brokerage and/or advisory role with participants about the services they wish to choose. They are involved in the location, negotiation and purchase of direct supports. NDIS service providers can offer both direct supports and plan management and support coordination. It is therefore incumbent upon these providers to proactively manage perceived and actual conflicts of interest when recommending direct supports (including those not delivered directly by that same provider).[32]

Early intervention support

Supports are available to children and adults who meet the requirements. The intention of early intervention is to alleviate the impact of a person's impairment upon their functional capacity by providing support at the earliest possible stage and reduce their future needs for support.[33]

Support Coordination

Support coordination aims to strengthen the ability of NDIS participants to self-direct their packages and participate more fully in the community. This may include initial assistance with linking participants with the right providers to meet their needs, assistance to source providers, coordinating a range of supports both funded and mainstream, building on informal supports, resolving points of crisis, parenting training and developing participant resilience in their own network and community. Support Coordination is funded in an NDIS plan if it is deemed by the planner to be reasonable and necessary, for example if a person has complex needs where multiple service systems are involved. Support coordination is included in the plan as a fixed amount, priced per hour of support.

Specialist Support Coordination

Specialist Support Coordination is for participants with more complex needs and is time limited. It may also involve development of an intervention plan which will be put in place by disability support workers. For Specialist Support Coordination to be included within a plan there must be clear benefits to the participant.

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[32] National Disability Insurance Agency 2017, *NDIA Terms of Business for Registered Providers*, Geelong. p.3

[33] https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-early-intervention-requirements

Plan Management

Plan management refers to the financial management of a participant plan. The NDIA is the plan manager for most participants. Others may manage their own plans, have a family member manage it on their behalf or engage a plan manager to do so. Plan managers administer payments to providers, process expense claims, provide monthly statements for participants and claim payment from the NDIA. Plan Managers also liaise with providers and participants to implement and manage the plan.