

Policy Position Paper

Advocacy

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Background

JFA Purple Orange is an independent, social-profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families.

JFA Purple Orange adopts a 'partners in policy' approach. We strive to support, advise and work alongside governments and other decision-makers to ensure that their policies, programs and practices are inclusive and accessible for all.

We are producing a series of Policy Position Papers to present our position and ideas in key areas affecting the lives of people living with disability. These will be available on our [website](#) and will be updated over time.

We hope that these Policy Position Papers will assist governments, service providers, non-government organisations, people living with disabilities and their families, and the wider community to better understand how to break down the barriers that make our society disabling for some of its members.

JFA Purple Orange has worked closely with the disability community to ensure that our policy positions represent the voice of those with the greatest expertise: people living with disability and their families.

Introduction

Independent disability advocacy is critical for protecting and promoting the human rights and wellbeing of people living with disability. Advocacy can help to give people living with disability a voice, ensure they understand and can exercise their rights, and influence positive changes to systems, laws and practices to ensure these rights are upheld.

High quality, independent advocacy can support people living with disability to achieve positive outcomes in a range of areas, including social inclusion, employment, accommodation, education, access to justice, financial management, abuse and discrimination, health and wellbeing, access to the community, the exercise of choice and the pursuance of life goals.

JFA Purple Orange believes that individual advocacy services and self-advocacy programs must be available to, and accessible for, all people living with disability, irrespective of their age, gender, disability, NDIS eligibility, geographical location, place of residence, communication needs or cultural or linguistic background. It is vital that these services are independent and free from any conflict of interest.

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We need more trained advocates across all disability services.

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- Respondent to June 2020 survey on rights and attitudes

At a higher level, independent systemic advocacy must be adequately funded, supported and taken into account by governments. This will not only help to protect the rights of people living with disability, it will also improve the impact and efficiency of government policies, programs, and processes by ensuring that they genuinely reflect the circumstances, needs and ideas of people living with disability.

This paper will firstly explain the meaning of advocacy in the disability context, before considering why advocacy is important for people living with disability and their families, governments, service providers and the community in general. It will then set out JFA Purple Orange's vision for disability advocacy. The paper will consider individual advocacy, self-advocacy, and systemic advocacy separately, describing the current context and what needs to be done to achieve our vision.

The views in this paper are drawn from years of engagement with the disability community, desktop research, a 2019 state-wide consultation run by JFA Purple Orange on behalf of the South Australian Government and most recently, a 2020 survey with the disability community on rights and attitudes (including advocacy).



What is advocacy?

Disability advocacy is acting, speaking or writing to promote, protect and defend the human rights of people living with disability.¹ Advocates serve a vital role in supporting people living with disability to address discrimination, remove barriers to social and economic participation, and access services.

Key advocacy principles include independence, acting solely in the interests of the person living with disability, supporting participation in decision-making, supporting choice and control, and freedom from conflict of interest.

In Australia there are six broad models of advocacy: citizen advocacy, family advocacy, individual advocacy, legal advocacy, self-advocacy and systemic advocacy.² This paper will focus on the following:

1. Individual advocacy: a professional advocate acts on behalf of a person living with disability;
2. Self-advocacy: a person living with disability advocates for themselves, individually or as a group; and
3. Systemic advocacy: an individual or organisation advocates for changes to systems, policies, programs and/or processes to better protect and respect the rights of people living with disability.

¹ <https://www.dacssa.org.au/services/advocacy/>

² This has been taken and adapted from the definition of advocacy provided by the Department of Social Services on its National Disability Advocacy Program website, available at <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap>.

Why is advocacy important?

Individual advocacy, self-advocacy and systemic advocacy all serve to protect the rights of people living with disability. Yet the benefits of effective advocacy extend much further, also positively impacting on laws, policies, systems and processes. This section describes some of the many reasons why advocacy is important for people living with disability and their families, governments, service providers and the wider community.

Effective advocacy can help to:

Raise awareness

1. Build knowledge and understanding among governments, service providers, the community and other relevant stakeholders about the rights of people living with disability and provide reliable, first-hand information about the issues they are facing.

Solve problems

1. Develop a plan with people living with disability to resolve a particular issue or complaint;
2. Advocate for an outcome from government and non-government agencies with or on behalf of people living with disability;
3. Attend meetings with people living with disability;
4. Refer people living with disability to relevant services; and
5. Support people living with disability to navigate complaints processes.

Build confidence and knowledge

1. Build knowledge among people living with disability about their rights and responsibilities;
2. Inform people living with disability about formal complaints options;
3. Increase the confidence of people living with disability to speak out about their rights;
4. Ensure that people living with disability from culturally and linguistically diverse backgrounds understand Australian laws, systems, services and processes; and
5. Reduce the vulnerability of people living with disability to discrimination, violence, abuse, neglect and exploitation ³ including by:
 - a. Supporting them to gain confidence and knowledge to speak up for themselves about their rights and options;
 - b. Increasing reporting of violence, abuse, neglect and exploitation; and
 - c. Increasing accountability and deterring potential future perpetrators.⁴



³ During the consultation on South Australia's first State Disability Inclusion Plan, people living with disability suggested that more funding for advocacy services (and a greater understanding of their rights) would increase their safety. See South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/_data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.11.

⁴ During a 2020 survey of people living with disability, family members and other stakeholders, we asked how access to free advocacy support could reduce how often people living with disability experience violence, abuse, neglect and exploitation. These three points summarise the main responses received.

Obviously it isn't a simple solution to prevent harm, but [if people had timely access to an advocate] they would feel they have someone to contact, to answer questions, to give support - emotional, information and practical. Otherwise, you are quite alone, and that is when you become vulnerable.

”

- Respondent to June 2020 survey on rights and attitudes

Support and encourage participation in decision-making

1. Support people living with disability to make their own decisions e.g. with respect to access to services and support; and
2. Give people living with disability the confidence, knowledge, skills and support to take part in future decision-making.

Increase social, cultural and economic participation

1. Support people living with disability to overcome barriers to social and economic participation, in line with key instruments, including:
 - a. The National Disability Advocacy Framework, the objective of which is for people living with disability to have access to 'effective disability advocacy that promotes, protects and ensures their full and equal treatment of all human rights enabling full community participation;' and
 - b. The NDIS Act, s4(13)(a), which recognizes that advocacy supports people living with disability by 'promoting their independence and social and economic participation'.
2. Support people living with disability – including but not limited to those from ATSI or culturally and linguistically diverse backgrounds

– to engage in cultural life, in line with Article 30 of the Convention on the Rights of Persons with Disabilities.

Facilitate access to services

1. Support people living with disability to access the services they need, noting that many people will not access services without advocacy support.

Deter mistreatment

1. Increase awareness among the general community, governments and services providers that the rights of people living with disability must be respected and promoted and that mistreatment does have consequences.

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[A]ny safeguarding system in the disability environment cannot operate optimally in the absence of a robust, dynamic and well-resourced advocacy system...

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- Commonwealth Ombudsman's submission to the 2017 review of the National Disability Advocacy Program

Reduce costs for governments

1. Resolve issues promptly and efficiently, preventing them from escalating and becoming costlier for governments to address.

A 2017 cost benefit analysis found that **every dollar used by Australia's independent disability advocacy agencies delivers \$3.50 in benefits**. These benefits include improved educational and employment outcomes, reduced load on carers and service providers, and more available resources in the justice system and in health and accommodation services.⁵

Influence change

1. Provide governments and other decision-makers with evidence-based recommendations as to how laws, policies and practices could be strengthened to better protect and promote the rights of people living with disability; and
2. Improve the quality of publicly funded services and the efficiency of government spending.

⁵ Daly, Barrett and Williams, 'A Cost Benefit Analysis of Australian independent disability advocacy agencies,' Disability Advocacy Network Australia, September 2017, available at <https://www.dana.org.au/wp-content/uploads/documents/Disability-advocacy-CBA-2.pdf>.

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Advocacy would give the necessary confidence, knowledge and support to provide the information needed to challenge and expose wrong doings.

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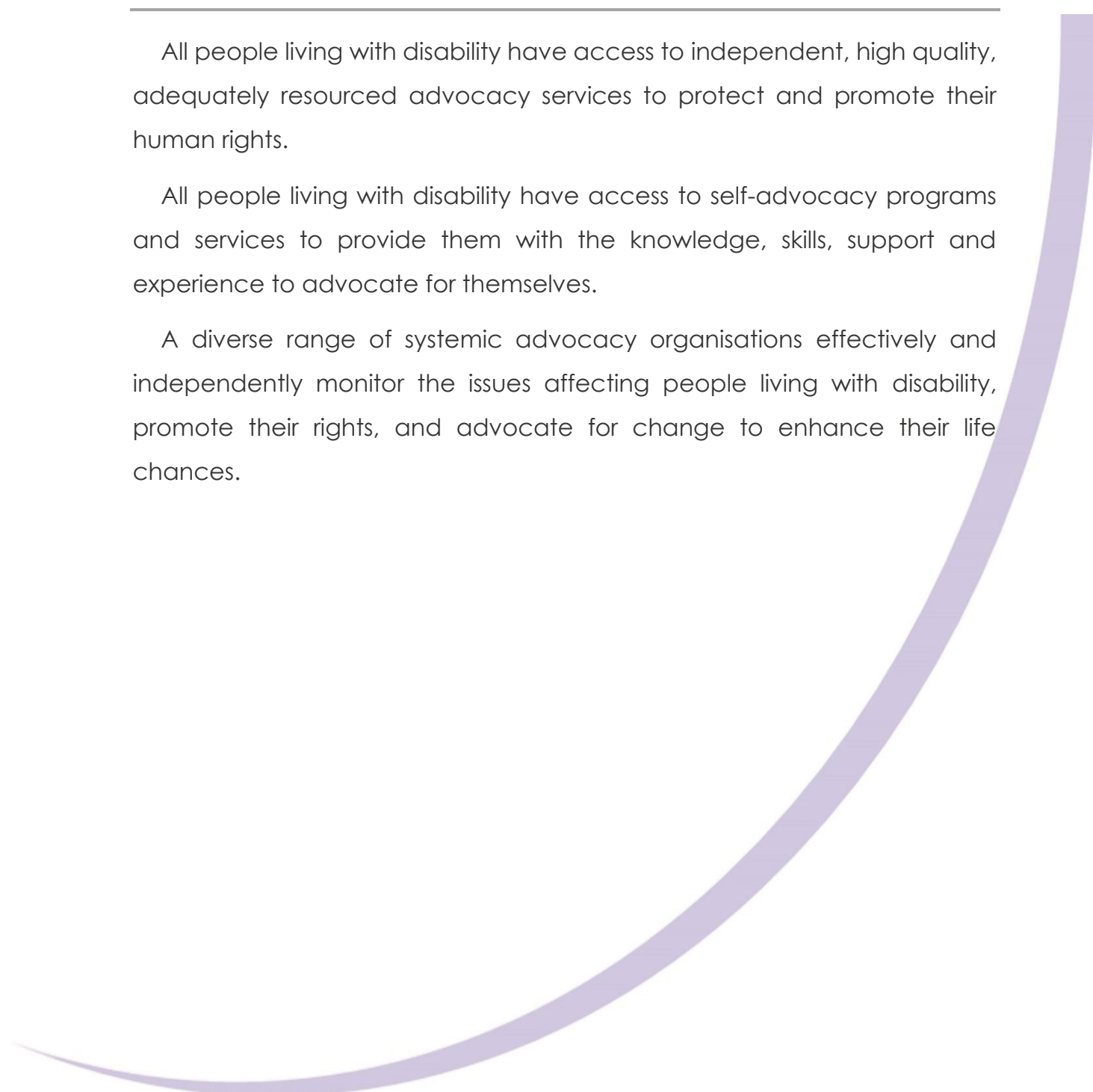
- Respondent to June 2020 survey on rights and attitudes

What is our vision for advocacy?

All people living with disability have access to independent, high quality, adequately resourced advocacy services to protect and promote their human rights.

All people living with disability have access to self-advocacy programs and services to provide them with the knowledge, skills, support and experience to advocate for themselves.

A diverse range of systemic advocacy organisations effectively and independently monitor the issues affecting people living with disability, promote their rights, and advocate for change to enhance their life chances.



Individual advocacy

This section explores how our vision could be achieved with respect to individual advocacy. It sets out the current context including key issues, describes our vision in detail and makes recommendations for change.

What is the current situation?

According to recent consultations undertaken by JFA Purple Orange in South Australia, advocacy services work well and advocates support people living with disability with a diverse range of issues.⁶ In May 2020, the Disability Advocacy Network of Australia reported on a survey conducted with advocacy organisations around Australia. The most common issues raised by advocacy clients were government payments and NDIS access/planning, closely followed by abuse/neglect/violence, NDIS internal review and NDIS implementing plan/accessing services.⁷

Funding

The main issue with respect to advocacy is a lack of funding to meet demand. There are often long waiting times to receive services, which are then only available for a limited time. There are also gaps in advocacy coverage in regional areas.⁸

⁶ 2019 consultation on South Australia's first State Disability Inclusion Plan and 2020 survey on rights and attitudes (including advocacy).

⁷ <https://us9.campaign-archive.com/?u=549c507664a643e2890c363a4&id=9eefab00b0#SnapshotSurvey>.

⁸ South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/_data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.10.

In 2019, the United Nations Committee on the Rights of Persons with Disabilities considered Australia's compliance with its obligations under the Convention on the Rights of Persons with Disabilities. The Committee expressed concern about 'the unsustainability and inadequacy of resources for continuous, individual and independent advocacy programmes.'⁹

Responsibility for funding disability advocacy is currently shared between the Commonwealth and state and territory governments.¹⁰

The Commonwealth Government funds approximately half of all disability advocacy services across Australia through the National Disability Advocacy Program (NDAP). Organisations receive funding for individual advocacy, self-advocacy, citizen advocacy, family advocacy, legal advocacy and/or systemic advocacy. According to a 2017 review of the NDAP, '[t]here is no pattern or consistency in how much is funded to each model in each region, and this means there are gaps in the choice of models and the availability of support for people with disability'.¹¹

Some states and territories have reduced or ceased advocacy funding in recent years, often based on the assumption that the NDIS will reduce the need for independent advocates.¹² This is not correct. While the NDIS funds various supports that can build the skills and knowledge of people

⁹ Committee on the Rights of Persons with Disabilities, Concluding observations on the combined second and third periodic reports of Australia, CRPD/C/AUS/CO/2-3, 15 October 2019, para 5(g).

¹⁰ Until recently, the South Australian Government was the only state or territory not to provide funding for advocacy. In September 2020, the South Australian Government announced that it will fund a new state-wide advocacy service \$400,000 per year for three years, with the service commencing in December 2020.

¹¹ Review of the National Disability Advocacy Program, Consultation Report, July 2017, p16.

¹² 'Disability Rights Now 2019, 'Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities: UN CRPD Review 2019, p.12, available at <https://dpoa.org.au/wp-content/uploads/2019/08/CRPD-Shadow-Report-2019-English-PDF.pdf>.

living with disability to make decisions, stand up for their rights and make complaints, this is not the same as independent advocacy support.¹³

The Commonwealth Government holds the view that responsibility for advocacy funding lies with all levels of government. In its 2019 response to an inquiry into transitional arrangements for the NDIS, the government explained that '[a]ll levels of government have a responsibility to support advocacy for people with disability to ensure they can exercise their rights. A national system of disability advocacy support requires ongoing investment from states and territories to ensure their citizens can resolve issues with state-run services, and advocates can participate effectively in state-based planning.'¹⁴

In Australia, Local Area Coordinators do not engage in advocacy with or on behalf of NDIS participants.¹⁵

The NDIS

The NDIS has increased, rather than decreased, demand on independent advocacy services. For example, according to a 2018 report, some disability advocacy services in New South Wales saw a 100% increase in demand over two years as the NDIS rolled out and the state government wound back disability services.¹⁶

¹³ See Department of Social Services, Disability Advocacy factsheet, available at https://www.dss.gov.au/sites/default/files/documents/12_2018/disability-advocacy-factsheet.pdf.

¹⁴ Joint Standing Committee on the National Disability Insurance Scheme, Progress Report, March 2019, p.101, available at [file:///C:/Users/rebeccad/Downloads/Report%20\(4\).pdf](file:///C:/Users/rebeccad/Downloads/Report%20(4).pdf)

¹⁵ The local area coordination model in the United Kingdom allows independent local area coordinators, acting purely in the interests of people living with disability, to support people to have a voice in self-advocacy and/or advocate alongside or for them. See Inclusive Neighbourhoods website, <http://inclusiveneighbourhoods.co.uk/how-does-it-work/>.

¹⁶ NSW Disability Advocacy Alliance, 'The Gaps are Getting Bigger for People with Disability in NSW,' 2018, p11.

Advocacy needs extend beyond the NDIS and the majority of Australians living with disability will not be entitled to access the scheme. It is important to ensure that NDIS participants are not advantaged in their ability to access advocacy services over non-participants.

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Of course, the biggest single driver of additional demand for independent disability advocacy – now, and into the foreseeable future – is the introduction of the NDIS. The NDIS is both an expansion of the current disability service system and a significant restructuring of existing service models. Both impacts – growth and change – will impact on demand for independent advocacy.

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- *Disability Advocacy Network Australia, Submission to Australian Government Community Consultation, January 2013*

The impact of COVID-19

The COVID-19 pandemic, which began in 2020, has further increased the demand for advocacy services. In May 2020, the Disability Advocacy Network of Australia reported on an online survey conducted with advocacy organisations throughout the country. Over half of responding organisations had experienced increased demand due to COVID-19, with

a quarter of organisations indicating that their capacity to take on new clients had decreased during the pandemic.¹⁷

Services for marginalised or isolated groups

Advocacy services are particularly important for those who struggle to access and understand information, connect with services and speak out for themselves.

A 2017 review of the National Disability Advocacy Program highlighted a need for increased advocacy support for people living with disability from hard to reach groups that may be marginalised or isolated. This included Aboriginal and Torres Strait Islander (ATSI) peoples; culturally and linguistically diverse (CALD) communities; those living in rural, regional and remote locations; and those who are very socially isolated, including people with communication difficulties and people residing in institutional care.¹⁸

The Australian Civil Society Shadow Report to the UN Committee on the Rights of Persons with Disabilities in 2019 noted a particular need for more advocacy services for Aboriginal and Torres Strait Islander people in rural and remote areas.¹⁹

Promotion of services

¹⁷ Disability Advocacy Network Australia, 'DANA's COVID-19 Advocacy Snapshot Survey', available at <https://www.dana.org.au/advocacy-snapshot-survey/>.

¹⁸ Review of the National Disability Advocacy Program, Consultation Report, July 2017, p6.

¹⁹ 'Disability Rights Now 2019, 'Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities: UN CRPD Review 2019, available at <https://dpoa.org.au/wp-content/uploads/2019/08/CRPD-Shadow-Report-2019-English-PDF.pdf>.

Many people in the disability community do not know that advocacy services exist or are not comfortable accessing them. Some people from culturally and linguistically diverse backgrounds might not realise that it is possible to make complaints about services if this is not the norm in their country of origin.

The commitments made by governments

By committing to the National Disability Advocacy Framework, governments have agreed to strive towards the following objective: 'People with disability have access to effective disability advocacy that promotes, protects and ensures their full and equal treatment of all human rights enabling full community participation.'²⁰

The Framework recognises that the provision of advocacy will contribute to a number of key outcomes including economic participation, social inclusion, choice, wellbeing, and support to pursue their life goals.²¹

Pursuant to the Framework, governments committed to improve access to advocacy: 'All governments agree to improve the administration of advocacy support, with a focus on improving service delivery and access to advocacy for people with disability.'²²

The National Disability Strategy 2010-20 similarly recognises that disability advocacy services enable and support people with disability to safeguard their rights and overcome barriers that impact on their ability to participate

²⁰ National Disability Advocacy Framework (2012), para 11, available at https://www.dss.gov.au/sites/default/files/documents/11_2014/attachment_a.2_-_national_disability_advocacy_framework.pdf.

²¹ National Disability Advocacy Framework (2012), para 12, available at https://www.dss.gov.au/sites/default/files/documents/11_2014/attachment_a.2_-_national_disability_advocacy_framework.pdf.

²² National Disability Advocacy Framework (2012), para 15, available at https://www.dss.gov.au/sites/default/files/documents/11_2014/attachment_a.2_-_national_disability_advocacy_framework.pdf.

in the community.²³ One of the areas for future action by governments is to '[s]upport independent advocacy to protect the rights of people with disability.'²⁴

The impact of inadequate advocacy services

If a person living with disability is unable to find the advocacy support they need, they are likely to either leave their issue(s) unresolved or turn to people they know and trust for advice. Those people will not necessarily have the expertise and technical knowledge required to find the best solution and might unintentionally mislead or misinform the person living with disability.

A lack of independent advocacy services can also result in service providers offering their own internal 'advocacy' services, resulting in conflicts of interest that pose safeguarding risks for the people living with disability involved.

Further, a lack of funded advocacy has reportedly resulted in a significant rise in fraudulent activities by providers.²⁵

What would our vision for individual advocacy look like in practice?

VISION: All people living with disability have access to independent, high quality, adequately resourced advocacy services to protect and promote their human rights.

²³ National Disability Strategy 2010-2020 (2011), p40.

²⁴ National Disability Strategy 2010-2020 (2011), Area 2.11, p41.

²⁵ 'Disability Rights Now 2019, 'Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities: UN CRPD Review 2019, footnote 31, available at <https://dpoa.org.au/wp-content/uploads/2019/08/CRPD-Shadow-Report-2019-English-PDF.pdf>.

In practice, this would mean that individual advocacy service providers:

1. Receive adequate funding from Commonwealth and state/territory governments to meet demand;
2. Have enough appropriately trained staff to dedicate the time required to resolve each matter thoroughly;
3. Are independent from disability service providers and the NDIA;
4. Do not have any conflict of interest, either personally or at an organisation-level (i.e. the advocate and his/her employer would not benefit in any way from influencing the outcomes of the matter);
5. Act exclusively in the interests of the person living with disability they are supporting;
6. Are available to all South Australians living with disability, irrespective of their location, either in person or via phone/internet;
7. Are free for people living with diagnosed disability;
8. Have reasonable waiting lists, with flexibility to respond to urgent matters quickly;
9. Proactively reach out to people living with disability who are isolated and less connected including people with additional or complex communication needs, people living in institutional settings, and people from CALD or ATSI backgrounds, and tailor their services to meet their needs;
10. Have accessible websites, including for screen-readers;
11. Provide information in different accessible formats, including Easy English;
12. Set targets for the recruitment people living with disability as advocates;
13. Involve people living with disability in decision-making about changes to service delivery;

14. Provide regular disability inclusion and cultural competency training to all staff; and
15. Promote their services widely, so that people living with disability and their family members know what is available and how to access them.

What needs to be done?

To ensure the provision of quality, timely, independent individual advocacy services, JFA Purple Oranges makes the following recommendations:

Recommendation 1

The Commonwealth Government to **clarify how jurisdictional responsibility for advocacy** is allocated among states, territories and the Commonwealth, to reduce the possibility of funding gaps.

Recommendation 2

The Commonwealth Government to undertake a review of national advocacy funding and **introduce a new, long-term funding model** that accurately reflects the need for individual advocacy services for people living with disability, including but not limited to NDIS participants.²⁶

²⁶ The Committee of Inquiry into Transitional Arrangements for the NDIS recommended that 'the COAG Disability Reform Council work with the Department of Social Services to address the expended funding shortfalls for advocacy services beyond transition.' See Transitional Arrangements for the NDIS report, 15 February 2018, Recommendation 19, available at https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/Transition/Report.

In 2019, the UN Committee on the Rights of Persons with Disabilities recommended that Australia '[e]nsure that persons with disabilities are able to access continuous, sustainable and adequately resourced individual and independent advocacy programmes, particularly those not part of the National Disability Insurance Scheme.'

Recommendation 3

State and territory governments to undertake a review of current advocacy funding and **introduce a new, long-term funding model** that complements the Commonwealth's model and ensures that the need for individual advocacy services for people living with disability, including but not limited to NDIS participants, is fully met. This would necessarily require state and territory governments that have reduced or ceased advocacy funding to restore funding to independent organisations at least to previous levels.

Recommendation 4

The Commonwealth and all state and territory governments to undertake a review of the availability of advocacy services in **regional and remote areas** and take steps to ensure access to all people living with disability. This could include:

1. Establishing more local advocacy services in regional and remote areas;
2. Providing funding for outreach for non-local advocacy organisations;
and

3. Providing support (for advocacy organisations and people living with disability) for non-local advocacy services to provide support online.

Recommendation 5

The Commonwealth and all state and territory governments to undertake a review of the availability of **culturally appropriate advocacy services** for people living with disability from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse communities, and take steps to ensure sufficient access and availability.

Recommendation 6

The Commonwealth and all state and territory governments to undertake a review of the availability and accessibility of advocacy services for **people living with disability who are socially isolated, including those with additional or complex communication needs and those residing in institutional care (including aged care facilities)**, and take steps to ensure sufficient access, availability and awareness of services.

Recommendation 7

The Commonwealth and all state and territory governments to explore the merits of funding more **specialist advocacy agencies** for particular hard to reach groups, such as people from CALD or ATSI backgrounds, people with communication barriers and people residing in institutional care, and allocate funding accordingly.

Recommendation 8

The Commonwealth Government to commission an **independent review of the National Disability Advocacy Framework, including levels of implementation**, with recommendations as to how the Framework could be

updated and how implementation could be better monitored in future, to ensure greater commitment to advocacy and a more consistent approach by governments.²⁷

Recommendation 9

The Commonwealth Department of Social Services and the NDIA to **clarify the extent of the role of Local Area Coordinators** in providing advocacy and self-advocacy support to people living with disability, noting that at present Local Area Coordinators are not independent of the NDIA.

Recommendation 10

The Commonwealth Government to work with NDAP-funded agencies throughout Australia to develop a **consistent approach to collecting and sharing data and information about systemic issues** (independently informed by individual issues) among agencies and with other key stakeholders, such as governments.²⁸

Recommendation 11

Advocacy providers to **better promote general and context-specific (e.g. NDIS or DRC) advocacy services** in the disability community, including through the NDIS and local area coordinators. This would include tailored

²⁷ Within the current Framework, governments agreed to 'work together to review the key policy directions from time to time in light of emerging priorities at the national and local level.' See National Disability Advocacy Framework (2012), para 16, available at https://www.dss.gov.au/sites/default/files/documents/11_2014/attachment_a.2_-_national_disability_advocacy_framework.pdf.

²⁸ Raised as an issue in Review of the National Disability Advocacy Program, Consultation Report, July 2017, p22. Under the National Disability Advocacy Framework, governments committed to '[improve] coordination and communication between the disability advocacy, mainstream sector and governments to develop the overall capacity of the sector, including promoting linkages between individual and systemic advocacy.' See National Disability Advocacy Framework (2012), para 15(f), available at https://www.dss.gov.au/sites/default/files/documents/11_2014/attachment_a.2_-_national_disability_advocacy_framework.pdf.

outreach to marginalised groups including ATSI peoples, people from CALD backgrounds, people living in regional and remote areas, people with communication difficulties and people living in institutional settings.

Recommendation 12

Advocacy providers to **better promote their services in the general public** so that people living with disability, family members and friends and the wider community are aware of available support.

Recommendation 13

Advocacy providers **to employ more people living with disability as advocates (including people from culturally and linguistically diverse backgrounds)** and include people living with disability in decision-making about their service provision.

Recommendation 14

Advocacy providers to **train all advocates on key values and principles** that must be applied in providing advocacy services to people living with disability.

Recommendation 15

Advocacy services to **train all advocates on supporting people from ATSI and CALD backgrounds.**

Self-advocacy

This section explores how our vision could be achieved with respect to self-advocacy, whereby people living with disability advocate for themselves. It sets out the current context including key issues, describes our vision in detail, and makes recommendations for improvement.

What is the current situation?

Self-advocacy programs provide an important source of information and support for people living with disability to build the skills, knowledge, and confidence to advocate for themselves. Such programs are commonly provided by advocacy services or through self-advocacy groups and peer networks.

The importance of self-advocacy groups was summarised in the September 2020 report of Our Voice SA, a peer-led self-advocacy group based in South Australia: 'they provide opportunity to share information, meet new people, work together on common issues and to make changes in the local community.'²⁹

While there are many self-advocacy programs throughout the country, these do not reach all people living with disability who would benefit from being involved, particularly in regional areas.

Knowledge of rights

²⁹ Our Voice SA, 'Stronger and Louder: Exploring the emerging priorities of South Australians living with intellectual disability,' (2020), p.18.

When consultations with the disability community are held, people living with disability typically say they do not know enough about their rights.³⁰ This is the basic starting point for self-advocacy. Without such knowledge, people will struggle to identify rights violations, let alone know which action to take in response. Knowledge of one's rights is also empowering, giving people the confidence to speak out.

In 2018-19, the Australian Human Rights Commission received 891 complaints about disability discrimination, accounting for almost 44% of all complaints received. The number of complaints to the Commission about disability discrimination has gone up every year over the last five years.

Participation in decision-making

People living with disability are often less involved in decision-making than their non-disabled peers. This is a particular concern for people living with intellectual disability and people with communication difficulties. Family members, support workers or service providers often make decisions for them – from small things, such as what to wear or when to eat, to larger matters such as where to live and with whom, where to study, where to work and which social activities to take part in. Self-advocacy programs help people to overcome barriers to participation in decision-making.

³⁰ 2019 consultation on South Australia's first State Disability Inclusion Plan and 2020 survey on rights and attitudes (including advocacy).

The particular needs of people from ATSI and CALD backgrounds

People from ATSI and CALD backgrounds, particularly new arrivals, may have limited English proficiency and a limited understanding of their rights and entitlements. There are many factors that can limit these people's ability to become effective self-advocates, including language barriers, cultural attitudes, traumatic past experiences, and limited experience with complex service models.³¹

Sources of funding

The NDIS recognises that it has an important role to play in providing decision-making supports and building individual capacity for people to advocate for themselves. The NDIS funds self-advocacy and peer support programs through the Information, Linkages and Capacity-Building (ILC) Program. ILC-funded programs are encouraged to include people who are not eligible for the NDIS. These programs are only funded for relatively short periods of time (1-3 years) and grant recipients are told that they will need to find alternative funding into the future.



The promotion of advocacy by and empowerment of persons with disabilities are key components of their participation in public affairs; they call for the development of technical, administrative and communication skills, and the facilitation of access to information and tools concerning their rights, legislation and policymaking.

³¹ FECCA submission regarding the National Disability Advocacy Framework, 23 July 2015, p.4, available at: <https://fecca.org.au/wp-content/uploads/2015/07/FECCA-Submission-National-Disability-Advocacy-Framework.pdf>.

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- *United Nations Committee on the Rights of Persons with Disabilities*

General Comment 7 (2018) para 58.

What would our vision for self-advocacy look like in practice?

VISION: All people living with disability have access to self-advocacy programs and services that provide them with the knowledge, skills, support and experience to advocate for themselves.

If our vision were achieved, all people living with disability would:

- Have access to culturally appropriate self-advocacy programs and services, irrespective of their age, gender, disability, NDIS eligibility, geographical location, place of residence, communication needs or cultural or linguistic background; and
- Understand their rights and responsibilities, know how to make complaints, and have the confidence and skills to speak up for themselves.

“

Joining Our Voice SA has helped me grow, I now have the confidence to speak up about things that matter to me.

”

- *Person living with intellectual disability*

interviewed by Our Voice SA for a needs assessment (2020)

What needs to be done?

To strengthen self-advocacy services and ensure they reach those in need, JFA Purple Orange makes the following recommendations:

Recommendation 1

The Commonwealth Government to **increase its investment in self-advocacy and peer networks** through the NDIS Information, Linkages and Capacity-Building program and fund programs on an ongoing basis, or for at least 5 years.

Recommendation 2

State/territory and Commonwealth governments to provide an increased level of **funding for self-advocacy and peer networks** outside the NDIS for at least 5 years.³²

Recommendation 3

The Commonwealth and state/territory governments to **map out funding provided for self-advocacy across Australia** and ensure needs are met and there is adequate coverage in terms of geographical location, disability type, living situation and cultural and linguistic background, then take steps to fill any gaps.

³² Support for self-advocacy programs and peer support networks was also called for during the 2019 State Plan consultation. See South Australia's First Disability Inclusion Plan 2019-2023, Community Consultation: Summary Report (2019) available at https://dhs.sa.gov.au/_data/assets/pdf_file/0017/84113/disability-inclusion-plan-consultation-report.pdf (accessed 29 June 2020) p.10.

Recommendation 4

All organisations providing self-advocacy programs to **involve people living with disability in the design and delivery of activities**,³³ providing appropriate reimbursement for their advice and time.

Recommendation 5

Governments providing funding for individual advocacy services to require all services to report on measures taken to **strengthen clients' self-advocacy skills**.

³³ See Our Voice SA, 'Stronger and Louder: Exploring the emerging priorities of South Australians living with intellectual disability,' (2020) Recommendation 4, p.8.

Systemic advocacy

This section explores how our vision could be achieved with respect to systemic advocacy. It sets out the current context including key issues, describes our vision in detail, and makes recommendations for improvement.

While this section refers only to systemic organisations, it should be noted that many such organisations provide different types of advocacy in addition to undertaking other work.

What is the current situation?

Systemic advocacy organisations play a vital role in promoting the rights of people living with disability, monitoring issues that affect their lives and advocating for positive change. They represent the voice of people living with disability, ensuring that key stakeholders and decision-makers are informed of their rights, needs and aspirations.

Funding arrangements

At present, eight organisations are funded under the national Disability Representative Organisations program to provide systemic advocacy and representation for Australians with disability. Organisations are funded to:

- Promote an understanding of the lives of people with disability;
- Promote and protect the rights and dignity of people with disability;
- Support service providers in delivering services to people with disability; and

- Foster support for the participation of people with disability in all aspects of community life.³⁴

These peak bodies provide advice to the Government on breaking down barriers and improving social and economic participation by engaging with a range of ministers and portfolios.

Systemic advocacy is not adequately or equitably funded.³⁵ Systemic advocacy is funded outside the NDIS, yet there are many consultations and commissions of inquiry on various aspects of the NDIS that benefit from the input of systemic advocacy organisations. Given the limited selection of organisations receiving funding, it is also difficult for them to sufficiently represent the diverse voices and experiences of people living with disability throughout Australia.

The legal and policy framework

Article 29 of the Convention on the Rights of Persons with Disabilities recognises a role for governments to encourage people living with disability to form and join 'organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels'. The UN Committee on the Rights of Persons with Disabilities has further called on States parties to the Convention to '[prioritise] resources to organizations

³⁴ See Department of Social Services website, National Disability Representative Organisations, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/national-disability-peak-bodies>.

³⁵ See Australian Federation of Disability Organisations, Pre-Federal Budget Submission 2020-21, 31 January 2020, p.9, available at <https://www.afdo.org.au/wp-content/uploads/2020/02/AFDO-Pre-Budget-Submission-2020-2021.pdf>. This submission explains that Disability Representative Organisations forming part of the AFDO-led consortium receive only \$27,000 per year.

of persons with disabilities that focus primarily on advocacy for disability rights.³⁶

Pursuant to the National Disability Strategy, governments 'will work collaboratively with people with disability and their representative organisations, their families and carers, communities, unions, businesses, service providers, advocacy and other organisations in the development of programs, policies and systems that affect people with disability.'³⁷

What would our vision for systemic advocacy look like in practice?

VISION: A diverse range of systemic advocacy organisations effectively monitor the issues affecting people living with disability, promote their rights, and advocate for change to enhance their life chances.

For our vision to be achieved, a diverse range of systemic advocacy organisations would:

- Receive adequate, long-term funding that reflects the complexity of the disability system and the need for up-to-date information and advice;
- Be independent of service providers, the NDIS and other interested parties to minimise conflicts of interest;
- Participate in independent individual advocacy so that recommendations are based on identified individual experiences;

³⁶ Committee on the Rights of Persons with Disabilities, General Comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention, CRPD/C/GC/7, 9 November 2018, para 61(b).

³⁷ National Disability Strategy 2010-2020 (2011), p67.

- Have enough qualified staff to provide high quality, reliable, evidence-based information on key issues relating to the rights of people living with disability; and
- Have a cohesive, efficient system of information sharing among organisations at a state/territory level and nation-wide.

Further, all governments (state/territory and Commonwealth) would:

- Work collaboratively and systematically with advocacy organisations and self-advocacy programs, people living with disability and their families, and other relevant stakeholders in the development of policies, programs and systems that affect the lives of people living with disability.

What needs to be done?

To ensure that systemic advocacy organisations can provide communities, governments and other stakeholders with the information and support required to effectively enhance the life chances of people living with disability, JFA Purple Orange makes the following recommendations:

Recommendation 1

The Commonwealth Government to commission an **independent review of current systemic advocacy funding**, to assess whether funded organisations are able to adequately respond to need and whether they represent sufficient diversity (e.g. age, gender, disability, NDIS eligibility, geographical location, place of residence, communication needs and cultural or linguistic background). This would include an assessment of the resources used for NDIS-related advocacy.

Recommendation 2

The Commonwealth Government to **modify its funding arrangements** in line with the recommendations of the independent review.

Recommendation 3

The **Commonwealth Government to provide additional funding for systemic advocacy related specifically to the NDIS**. This would provide the NDIA with valuable feedback on its policies, programs and processes.

Recommendation 4

State/territory governments to **fund local systemic advocacy organisations** to provide information and advice on state/territory-level policies, programs and processes.

Recommendation 5

Commonwealth and state/territory governments to develop mechanisms to **engage more closely with systemic advocacy organisations** to inform their policies, programs and systems. This would include a formal role for systemic advocacy organisations in monitoring implementation of the National Disability Strategy and state/territory-level access and inclusion laws, policies and action plans.

Conclusion

The purpose of the UN Convention on the Rights of Persons with Disabilities is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.'³⁸ For Australia to achieve this, it is essential that all people living with disability have access to well-resourced, high quality, independent individual and self-advocacy services. It is also vital that independent systemic advocacy organisations are sufficiently funded to monitor and report on the issues faced by people living with disability, and that the information they provide is considered and acted upon by decision-makers.

JFA Purple Orange urges the Commonwealth, state and territory governments of Australia and other relevant stakeholders to pay close attention to the information provided in this policy position paper and work towards implementing our recommendations.

If you would like to discuss any element of this policy position paper, or find out more about our work on advocacy, please contact us at admin@purpleorange.org.au.

“


Well trained, independent advocates... may be the only voice a person living with disability has.

”

- Respondent to June 2020 survey on rights and attitudes

³⁸ Article 1.

Additional JFA Purple Orange sources

- Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation on rights and attitudes, September 2020, available [here](#)
 - Submission to the South Australian Civil and Administrative Tribunal regarding AGAC Draft Guidelines for Australian Tribunals: Maximising the Participation of the Person, 7 January 2019, available [here](#).
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