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NSW Disability Advocacy Alliance

Response to the NSW Government's review of funding arrangements for independent specialist advocacy, information and representative organisations for people with disability in NSW.

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NSW Disability Advocacy Alliance
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The NSW Disability Advocacy Alliance (the Alliance) welcomes the opportunity to provide our input into the NSW Disability Advocacy Review. The Alliance is a coalition of independent disability advocacy and information organisations and peak representative bodies currently funded by the NSW Government. We influence and advocate for the rights of people with disability in NSW to ensure they get a fair go and a say in the policies and decisions that affect their lives. Our organisations work towards a better system where the rights of people with disability are protected and upheld; discrimination against people with disability is eliminated and people with disability are fully included, valued citizens in NSW community.

Members of the NSW Disability Advocacy Alliance:

Ability Advocacy - Northern Rivers
Action for People with a Disability - Northern Sydney
Blind Citizens NSW - Statewide
Community Access Western Sydney - West and South Western Sydney
Deaf Blind Association of NSW - Statewide
Disability Advocacy NSW - Hunter, New England, Mid North Coast, Nepean Blue Mountains, South Western Sydney, Central West, Western NSW, Far West NSW Regions, with offices in Newcastle, Taree, Port Macquarie, Coffs Harbour, Bathurst, Broken Hill, Dubbo, Tamworth, Armidale, Springwood and Parramatta
Disability and Aged Information Services Inc (DAISI) - Ballina
Ethnic Community Services Cooperative (ECSC) - Sydney Inner West
Family Advocacy NSW - Statewide
First Peoples Disability Network (FPDN) - Statewide
Information on Disability Education and Awareness Services (IDEAS) - Statewide; with offices in Tumut and Campbelltown
Intellectual Disability Rights Service (IDRS) - Statewide
Multicultural Disability Advocacy Association (MDAA) - Statewide
Muscular Dystrophy NSW (MDNSW) - Statewide
NSW Council for Intellectual Disability (NSWCID) - Statewide
Physical Disability Council of NSW (PDCN) - Statewide
People with Disability Australia (PWDA) - Statewide
Radio for the Print Handicapped (2RPH) - Statewide
Regional Disability Advocacy Services (RDAS) - Riverina and Murray Regions with offices in Albury/Wodonga, Griffith and Wagga Wagga
Spinal Cord Injuries Australia (SCIA) - Statewide
Stroke Recovery Association - Statewide
Synapse - Statewide

Introduction

Disability advocacy organisations in NSW provide individual and systemic advocacy, information and representation that protects and promotes the rights and needs of people with disability so that they have a voice, choice and control over their own lives. Providing advocacy to the families of people with disability is also a critical aspect of our commitment to people with disability as often advocacy is undertaken by this group with/or on behalf of their family members with disability and it is included whenever we talk about people with disability throughout this submission.

The work of disability advocacy organisations focuses on all domains of life including general state-based services that impact on the lives of people with disability such as education, justice, health, housing, transport and employment and access to appropriate disability supports and services.

Through advocacy organisations many systemic issues are identified and addressed, often saving the government significant time and cost. Further to this the systemic advocacy undertaken by the sector works on the protection of rights and progression of interests ensuring people with disability in NSW have the same everyday opportunities as those enjoyed by other NSW citizens.

We also know that discrimination affects the lives of people with disability in a myriad of ways hence disability advocacy organisations raise awareness and lead the way in countering discriminatory practices.

Disability advocacy organisations participate on NSW government advisory committees and boards and provide specialist expert advice on best practice principles for people with disability. Alliance member organisations are also the go-to, key point of access for individuals and communities of people with disability and their families. This provides government with opportunities for meaningful consultations with the people who are experts in their own lives, and the systems with which they come in contact.

Some disability advocacy organisations focus on individual advocacy, assisting people to solve individual problems, providing invaluable independent, unbiased information, linking them to mainstream services and supporting them to navigate these services when things go wrong. They also work to achieve justice for people with disability where their rights have not been protected and to ensure people with disability can respond effectively to discrimination.

Some organisations focus on groups of people with specific disabilities such as intellectual disabilities, developmental disability or particular physical challenges, as each group can experience their own unique form of discrimination and barriers that need specialised supports to address. Other organisations have particular expertise

in providing disability advocacy services to cultural groups such as Indigenous people or people who are culturally and linguistically diverse (CALD) or require legal expertise
Some organisations are cross disability and work to remove a range of structural and systemic barriers to all people with disability - realising their rights to live, participate and contribute to the community in NSW.

Particular Alliance members focus more on advising and shaping government policy with the aim of supporting the NSW and other Governments to improve systems as a whole, and to make them accessible and fairer for all people with disability, particularly those who are doubly disadvantaged, such as Indigenous people or CALD people. This work may include, but is not limited to, participating in departmental and research body advisory committees and boards, providing expert advice on best practice principles, and providing access to and representing people with disability for consultations.

Alliance members participate in face-to-face consultations, produce many written submissions and attend public hearings as expert witnesses in response to Parliamentary inquiries and state and commonwealth policy and regulation reviews. Action on behalf of the advocacy sector is also often required to bring important issues to the forefront and to seek broader societal change on behalf of people with disability.

The commonalities among us are strong and we are all committed to ensuring that the voices of people with disability are at the forefront of everything we do. The trust that people with disability demonstrate in their connection with our organisations continues to drive our work.

The following submission from the Alliance reflects our agreed input about the future of funding arrangements as we continue to provide independent specialist advocacy, information and representation to people with disability in NSW. Alliance members may submit separate organisational responses that expand on their specific areas of advocacy, or communities with whom they work. Where the Alliance chose not to comment on particular questions included in the review background paper, they have been removed from our submission.

Setting the scene for individual, self, citizen, legal, family and systemic advocacy, information and representation for people with disability in NSW

According to *Australian Bureau of Statistics Disability, Ageing and Carers, Australia: Summary of Findings, 2015*,[1] there are nearly 1.4 million people with disability living in NSW. This equates to nearly one in five citizens in NSW.

Research shows that on a range of measures people with disability experience greater disadvantage, exclusion, discrimination and marginalisation when compared to their non-disabled peers. The high levels of disadvantage that people with disability experience was recently confirmed in the *Australian Institute of Health and Welfare (AIWH) report "People with disability in Australia"*[2] which was released in September 2019.

This report highlighted that people with disability experience poorer health outcomes, are more likely to live in housing provided by state governments, and more likely to have lower levels of education and experience unemployment than people without disability. Research also shows that poorer social and well-being outcomes for people with disability are caused by the systemic barriers to access and inclusion across mainstream and specialist services and in everyday life activities.

In 2008, Australia ratified the *United Nations Convention of the Rights of Persons with Disabilities* (CRPD).[3] This represented a significant step forward in realising the rights of people with disability. To meet its commitments under the CRPD, Australia developed the *National Disability Strategy 2010-2020*[4] *(NDS)* through the Coalition of Australian Governments (COAG). The NDS was endorsed by all state and territory governments and the Australian Local Government Association in 2011.

To fulfil its own statutory responsibilities under the CRPD and the NDS, the NSW Government developed the *NSW Disability Inclusion Act 2014*.[5] In line with the CRPD, this Act highlights that "people with disability have the same human rights as other members of the community, and that the state and the community have a responsibility to facilitate the exercise of those rights". The Act also sets out the objectives and principles of "accessibility of mainstream services and facilities, the

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[1] *Australian Bureau of Statistics Disability, Ageing and Carers, Australia: Summary of Findings, 2015* https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

[2] Australian Institute of Health and Welfare (AIWH) report "People with disability in Australia https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/summary

[3] United Nations Convention of the Rights of Persons with Disabilities (CRPD) https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

[4] Department of Social Services *National Disability Strategy 2010-2020* https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf

[5] NSW Government *NSW Disability Inclusion Act 2014* https://www.legislation.nsw.gov.au/acts/2014-41.pdf

promotion of community inclusion and the provision of funding, support and services for people with disability".

In making this submission, the Alliance recognises that individual and systemic advocacy, information and representation play a key role in realising the rights of people with disability and enabling the NSW Government to meet its obligations under the CRPD, and under the *NSW Disability Inclusion Act 2014*.

Access to information and referral services, advocacy, and representation enable people with disability to navigate services, systems and environments that may not be accessible or inclusive of them. Advocacy and representation also ensure people with disability have a voice on the many issues in their everyday lives that impact on them - from access to education, health, housing, transport, employment, justice, democratic processes in NSW.

In this submission when we refer to the "rights of people with disability", we refer to the rights that are enshrined within the CRPD and to which the Australian Government and the NSW Government have responsibilities and obligations.

The Alliance looks forward to continuing to work with the NSW Government to enable all people with disability to be included and participate fully in the civic and community life in NSW.

We note that the United Nations Committee on the Rights of Persons with Disabilities, in its *Concluding Observations on the combined second and third reports of Australia* released on 23 September 2019, highlighted "the weak mechanisms and limited funding under the NDS and National Disability Agreement (NDA) for full and effective engagement of persons with disabilities through their representative organisations in the policy development, implementation and monitoring of actions relations to the Convention."[6]

This review of disability advocacy funding creates the opportunity to better resource and significantly improve the "full and effective engagement" of people with disability and improve life experiences and outcomes in NSW. We look forward to working with the NSW Government to realise the full rights of people with disability.

Key principles to underpin review recommendations

The Alliance acknowledges the importance of ensuring the review is based on sound principles. We give 'in principle' support to the draft principles, however believe there

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[6] United Nations Committee on the Rights of Persons with Disabilities, in its *Concluding Observations on the combined second and third reports of Australia* https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUS%2fCO%2f2-3&Lang=en

is room for improvement and further definition, hence we have listed below in order of priority, the principles that the Alliance members believe are most critical to underpin the review recommendations.

1. Protecting, upholding and promoting the rights of people with disability is a critical foundation block in enabling NSW to meet its statutory obligations under the human rights framework of the CRPD and associated domestic legislation including to ensure people with disability have a voice, choice and control over our lives.

Foremost, people with a disability are valued citizens with the same rights as everyone else. Rather than considering themselves as clients, people with disability across NSW are accessing advocacy to support their human rights including their right to choice and control over their lives. Advocacy is much more than providing services believed to be in the person's best interest, rather it is about supporting people with a disability to fulfil their human rights. The voices of individuals with disability must drive disability advocacy organisations and any changes in their funding or infrastructure.

2. *Using a rights-based approach to enable people with disability to determine their own will and preference.*
A central principle of the UNCRPD is supported decision making, where people with disability should get the support necessary to enable them to make and carry out the decisions that affect them.

3. Ensuring people with disability are able to access appropriate, specialist, independent, culturally sensitive, locally available disability advocacy supports and services which are available long-term.

4. Recognising the critical role that systemic advocacy plays in changing laws, policies and processes to uphold and protect the rights and aspirations of people with disability, remove discrimination and ensure inclusion for people with disability and build sector capacity to drive change.

5. Ensuring there is ongoing advocacy training and support to enable people with disability to lead public debate and government decision-making.

6. Ensuring disability advocacy is genuinely independent. *There cannot be an actual or perceived conflict of interest between independent disability advocacy and any provision of services.*

7. Specialist advocacy organisations are an essential aspect of the model to ensure the rights and voice of the people with disability who access them is upheld. *Specialisation meaning in terms of disability type and community type* *(cultural and geographical). It also means recognising the extensive and often long term expertise in advocacy and representation held by staff and boards in specialised services. Specialised disability advocacy organisations should be resourced to respond to the intersectionality of their community's complex needs.*

8. Embedding disability advocacy services in the local communities they serve so that trusted, independent, easily accessible, specialist advocacy is available locally for all people with disability.

Resourcing organisations should be undertaken with special consideration to rural and remote organisations which cover smaller populations spread across large distances, ensuring that advocacy is easily accessible in local communities.

9. Disability advocacy organisations should be fully resourced, long-term to deliver responsive, timely, competent support and services.

10. Valuing expertise, relationships and experience and ensuring their continuity is central to effective disability advocacy.

11. There should be a shared commitment from disability advocacy organisations and Government to work towards better ways of defining and demonstrating the outcomes and impacts of disability advocacy work.

In response to the other sections of the Review we provide the following:

Patterns of need for people with disability in NSW

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

The landscape, including the many systems that sit within it, are constantly changing for people with disability, requiring ongoing monitoring, assessment and responses by the disability advocacy sector. A slight change in government policy, for example, can extremely affect people with disability, leading to further disadvantage.

The introduction of the NDIS is still in its infancy. The NDIS provides support for around 10% of people with disability in NSW, up to the age of 65. The other 90% of people with disability which includes children, young people and older people continue to rely on mainstream and specialist services most often delivered by the NSW Government and associated agencies. Reports, such as the Productivity Commission's Inquiry into the National Disability Agreement released in 2019, identify significant ‘interface’ issues between the supports delivered through the NDIS and mainstream services such as health, housing, and education.

In relation to the NDIS, there are many barriers that will continue to need to be addressed as people with disability learn about the scheme, seek to access it as well as create and implement their NDIS plans. Information, advocacy and representation for people with disability in NSW will be required over the long term. Interactions with disability service providers also form a large component of this work as many people with disability experience a heightened level of vulnerability due to the current changing service system and a newly emerging service system. Again this work of monitoring, assessment and response is critical to safeguarding and protecting the rights and interests of people with disability going forward and over the long term.

Additionally, with an ongoing ageing population, it should be noted that there is a significant and unresolved discrepancy between My Aged Care and the NDIS for people with disability over the age of 65 that still needs to be addressed.

More broadly, the policy and service delivery areas for which NSW Government and its associated agencies is responsible continue to undergo review, reforms and improvement. Under the NSW Disability Inclusion Act 2014, the NSW Disability Inclusion Plan and government agency and local government Disability Inclusion Action Plans, review and implementation of plans must include consultation with people with disability and their representative organisations. This also involves the development of information and advocacy supports to navigate change.

A snapshot of policy reform areas that impact on people with disability includes but is not limited to: health, mental health, early childhood education, school education, TAFE, transport, social housing (including the devolution of large institutions), planning and the built environment, sporting, recreation and cultural activities, access to justice, access to voting, violence prevention, child protection, out-of-home care, juvenile justice and the adult justice system, trustee and guardianship. Consideration of any one of these areas involves legislative, policy and practice frameworks that impact on people with disability and the need for better and improved approaches to realising the rights of people with disability.

Finally, we are beginning to work with people with disability who are engaging with the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. The Disability Royal Commission will go for three years and will investigate what has led to the widespread and systemic violence against people with disability including in the state of NSW. The roll-out of findings and recommendations from the Royal Commission will create the need for ongoing change and improvement on the way that NSW Government programs are delivered. This will have considerable impact on advocacy organisations and their resources as we work with people with disability to navigate changes as well as provide advice to government to implement changes and reforms in meaningful and effective ways to realise the rights of people with disability.

What are the areas of focus, mechanisms and kinds of activities that come under the broad heading of 'advocacy'?

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

It is important to describe advocacy in a transparent manner. However, the proposed model that names different focus areas, and advocacy mechanisms, appears to be a linear structure and runs the risk of inflexibility. It is misleading as the separation doesn't reflect the complex inter-relatedness and diversity of needs experienced by people with disability. Nor does it reflect organisations working together to provide disability advocacy in the way most appropriate to the people they serve. Advocacy organisations with the knowledge and community connections, are best placed to allocate their time and resources appropriately. This flexibility has been described well in the National Disability Advocacy Program (NDAP) model. (It should be noted that the NDAP itself is currently under review, with no clear direction on where it too is heading, leaving both State and Federal systems in a state of flux.)

Categories are not an appropriate nor in any way adequate way to differentiate the work undertaken by disability advocacy organisations. In addition, the representational work done by some organisations, for example Disabled People Organisations and Disabled People and Family Organisations is not reflected at all in the currently suggested categories and would need a separate stream should categories be applied.

A differentiation between individual advocacy and self advocacy/self representation, best described in the Convention on the Rights of People with Disabilities, is needed, and terms such as 'supported advocacy' which are not well recognised, should be avoided.

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

The Alliance notes the inadequacy of this approach and suggests that a description of the continuum of disability advocacy is required with an emphasis on supporting people with disability to exercise their rights and voice, choice and control of their own lives. The Alliance would like to see this revisited and offers to work with the Commissioner on this issue.

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

Is this a useful approach to analysing advocacy?

No it is not.

The Alliance acknowledges the review team's understanding of the complex nature of the skills, experience, and knowledge required in advocacy work and the high degree of ongoing support people with disability also require in order to engage in advocacy work. The use of the word "activities" is not helpful.

Work undertaken by disability advocacy organisations is challenging on many levels and that there are multiple overlaps. This recognises that advocacy is about fulfilling the needs of people with disability, and that the complexity of people's lives may result in them requiring supports and skills development in a way that is not described well within the current categories. The Alliance believes that there are more effective ways of describing advocacy work than the current listing and offers to work with the Commissioner on this issue.

Need to Measure Outcomes

How could NSW best measure the outcomes of advocacy organisations?

The Alliance agrees that there is a need for improved methods for reporting on the quality of disability advocacy across NSW. This has the potential to improve information sharing between advocacy services and to inform the work of the sector and the NSW Government. Outcomes measures need to move beyond compliance measures and outputs. They need to be truly person-centred, remain accountable to the person with disability and be focused on agreed standards of disability advocacy practice.

In developing a system for measuring outcomes careful consideration needs to be given to the workload and complexity of data collection and reporting. Disability advocacy organisations need to be resourced to undertake this work and the reporting requirements need to be proportionate to the size of the organisation. Collecting data to demonstrate outcomes shouldn't be onerous.

The Alliance notes that the outcomes required for individual advocacy will differ significantly from those required for systemic advocacy that focuses on influence and policy change, and supporting people with disability to be at the forefront of that are longer term by nature. Standardised outcome measures may be useful for some outcomes, but more specific outcome measures may be needed in specialist advocacy.

There is also a difference in the outcomes for self advocacy, citizen advocacy and individual advocacy. While it may be possible to develop some standardised outcomes measures they also need to be flexible enough to take into account the continuum of work required to achieve an outcome. All outcomes, and outcome measures, need to be developed in consultation with disability advocacy organisations and the Alliance would be willing to work closely with the government on this issue.

Should outcomes reporting use the same indicators as NDAP?

The Alliance supports the development of outcomes that align closely between NDAP and disability advocacy in NSW, acknowledging that the aim is improved outcomes for people with disability no matter which organisation they interact with and, irrespective of the funding source. When this work is completed for NDAP (it is not currently in place) their indicators will be a useful tool for consideration by the disability advocacy outcomes working group. Importantly there should not be an excessive data collection burden on organisations who receive resourcing for both.

As noted above the NDAP program is still to finalise an outcomes-based reporting framework. We also note that reporting requirements for nationally funded Disability Representative Organisations (DROs) that undertake systemic advocacy and representation still report on activities undertaken through an agreed Activity Work Plan. At this stage, a specific outcomes framework is yet to be developed for DRO funded organisations at the national level. Again, we would support alignment between a NSW state-based outcomes framework and nationally based outcomes when they are developed. We believe a new outcomes-based monitoring and reporting framework should be linked to a redeveloped National Disability Strategy (NDS) and National Disability Agreement (NDA).

What assists or prevents advocacy organisations from measuring their outcomes?

- Work needs to be done on definitions of “outcomes”.
- Time and money for staff to undertake the work involved in collecting data and reporting on the data in a timely manner.

Disability organisations also require an efficient, effective and consistent data collection system within their organisations to capture this, along with a commitment from the funding body to disseminate this outcome information.

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

The Victorian report appears to focus on output measurements rather than describing person-centred outcomes, or ways of measuring these outcomes. NSW has the opportunity to be a leader in developing outcome-based measures which could be strengthened with a focus on the CRPD. The Alliance will be pleased to collaborate in this process.

Developing a new system for the provision of funded advocacy services in NSW

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

There are eight key factors that should guide disability advocacy provision to ensure that the future needs of people with disability in NSW are met. They are listed below and discussed further in this section.

1) A commitment to long-term funding for advocacy provision in NSW so that people with disability can have certainty about the advocacy they can access.
2) Advocacy funding being based on need rather than the current rationed system.
3) A disability advocacy sector that is free from perceived and actual conflicts of interests and that any ‘perceived conflicts’ are mitigated and managed accordingly in order to ensure that organisations are serving the rights and interests of people with disability alone.
4) Recognition of the specific needs of different communities and disability types.
5) Recognition of DPOs and DPFOs and the role of representation.
6) Commitment to not for profit and independent specialist organisations.
7) Explicit recognition that advocacy is needed to address issues within mainstream services, legislation and the NSW community and that it helps government to fulfil their own commitments under the Disability Inclusion Act, Disability Action Plans, National Disability Strategy and CRPD.
8) Explicit recognition that advocacy is needed to enable people to get fair access to and adequate support from the NDIS.

Designing the disability advocacy system for the long term needs to be a transparent process and include the voices of people with disability at every step. The main focus should always be about maximising benefits for people with disability in a way that supports their voice, choice and control and mitigating conflicts of interests within organisations. A commitment from the NSW Government about long-term funding for advocacy services is the first step in this process. People with disability deserve to know that their current, and future, advocacy needs will be provided in a way that is accessible and appropriate according to their individual or population needs.

Any design process for the future of individual and systemic advocacy should occur in consultation with the Alliance, within agreed parameters, and must include people with disability. In NSW a disability advocacy infrastructure currently exists, with many aspects having been shown to be effective, even within the limited funds available. Appropriate funding is essential to ensure continuity and further development of expertise and relationships which will allow for a systematic, inclusive consultation. This will also ensure that a process of development will acknowledge the voices of people with disability, and the wisdom and experience of people currently working within the sector.

While the Alliance welcomes the federal government's commitment and role in funding information, linkages and capacity building initiatives, continued involvement of the NSW Government is critical. This will allow a focus on services that are the responsibility of the NSW Government. There is a clear conflict of interest between the funding of organisations who provide traditional services to individuals (such as supported accommodation, day programs, personal care etc) and organisations who provide individual and systemic advocacy.

There cannot be an actual or perceived conflict of interest between independent advocacy and any provision of services.

The Alliance acknowledges the role of the ILC in funding information and linkages (but not advocacy). There is a place for short term, project-based funding to the NDIS for ILC. There is also a place for funding for information and referral undertaken by Alliance members. As we believe in a holistic approach to advocacy, information provision and referral will remain part of the work we do. When a person with disability calls us we are there for them. If, as part of their individual advocacy, they require information then we must provide it. Individual advocacy is provided to people with disability across their life span. Our relationships are often long term and we are committed to ensuring these advocacy needs are met, at whatever age.

Until there is evidence that the federal model is able to support easy access to state and locally based information for people with disability and their families the NSW Government needs to continue to be involved.

When disability advocacy is funded by the federal government there is also risk that the value of smaller state-based organisations is diluted. Advocacy knows no boundaries, therefore there will always be a long-term role for the NSW Government in funding disability advocacy, particularly that provided by smaller state-based organisations. There has never been any indication that the Federal Government will fund state based systemic advocacy.

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

The design of an advocacy system must recognise the intersectionality of the people for whom we provide advocacy services and recognise that there will always be a place for funding specialised services that provide services to specific groups. This may be people with a specific disability type, or for people from cultural and geographic communities. Specialist advocacy organisations are an essential aspect of the model to ensure that the rights and voice of the people who access them are upheld. Design factors should include recognising the expertise in advocacy and representation held by staff and boards in specialised services. Disability advocacy which is easily accessible and embedded in local communities is critical to the quality and effectiveness of advocacy. Specialisation meaning both in terms of disability type, and community type (cultural and geographical). Responding to the intersectionality of the advocacy needs of people with disability is also critical to effective advocacy.

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

Maintaining independence is an important principle in providing advocacy services for people with disability and their families. A model that integrated funded advocacy with traditional service provision would not be supported. Independence enables disability organisations to serve the interests, will and preference of people with disability alone and enables advocacy supports to be at ‘arms length’ from the systems and services that they may be required to advocate against.

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

Ability to advocate for individuals with disability, and for systemic change requires independence from direct/traditional service provision such as accommodation services or day programs, and will continue to do so. The programs provided under ILC funding may also include individual capacity building through, for example peer support, peer-led groups, and self advocacy. However, this capacity building differs greatly from individual or systemic advocacy, which are not fundable under the ILC.

There cannot be an actual or perceived conflict of interest between independent disability advocacy and any provision of services and the Alliance considers that the disability support system and independent advocacy organisations are and should continue to be different entities for funding purposes

Advantages and disadvantages of alternative funding arrangements

As a general principle the Alliance recommends that any future funding for the disability advocacy sector should be held at arm's length to the systems we may be required to advocate against.

One suggestion for this could be administration of future funding by the Ageing and Disability Commission (ADC), which is widely considered to be well informed, independent and able to avoid conflict of interest, and may have significant advantages. Funding for individual and systemic advocacy with NSW could be quarantined within the Commission, thereby providing certainty and sustainability of funding. It also has the potential to create greater connection between disability advocacy across the state.

Another suggestion the Alliance proposes is for funding administration to be held within the Department of Premier and Cabinet (DPC) as they are uniquely placed within the centre of NSW Government. Much of our advocacy work requires addressing issues and barriers across NSW systems and departments, enabling effective collaboration between the advocacy sector and NSW government.

Our strong recommendation is that any future funding arrangement would need to be transparent, ensuring advocacy provision is independent, specialist and embedded in local communities and remain accountable to people with disability.

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

There will always be on ongoing role for known organisations trusted by people within the communities they serve, in particular for Indigenous, CALD and LGBTIQ people with disabilities.

Resources for providing effective and efficient funded advocacy services in NSW

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

In addition to the population-based funding required for high quality advocacy services, an effective and efficient sector needs to have the capacity to operate collaboratively. The sector would benefit from regular communication among disability advocacy organisations, sharing of information, examples of better practice, and sector capacity building. Consideration could be given to establishing an advocacy unit within the funding body similar to the NDAP. This unit would act as a portal for communication with the sector. One model for consideration is an improved version of the Victorian Disability Advocacy Resource Unit.

Strengthening the capacity of the peak bodies would also provide an opportunity to ensure that the sector is well resourced to fulfil its role across the advocacy continuum.

Formalisation of our Alliance, as a communication and information/skills sharing hub could also be considered and appropriately resourced

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

The Alliance acknowledges that resource deficiencies exist in the current disability advocacy service system. Foremost, current funding doesn't meet the level of community need for disability advocacy nor the resourcing, collaboration and capacity building required to support it.

Significantly, there is an absence of a formal infrastructure to support coordination and collaboration, and capacity building, across the sector. There is no funding available to maintain a structured network.

Across the sector systematic methods for the collection and collation of data, and the valuable stories of people with disability, to inform systems development and evaluation is an area that would benefit from investment. Limited investment in developing the sector's knowledge, skills and experience in data collection and analysis has resulted in a lack of evidence-based data.

The development of a system to collect, and report on, data and the experiences of people with disability and their families, needs to occur in collaboration with the communities we serve. Systematic data collection will provide the basis for targeted systemic advocacy and assist collaboration across advocacy organisations. It will allow the sector to analyse where people with disability and their families are interacting with crisis and specialist services eg: justice system/ child protection, and the effectiveness, or otherwise, of those mainstream service responses. Additionally, it provides a basis for tracking and funding emerging needs trends and areas for improvement within, and across agencies. Lastly, it demonstrates what is working well and where improvements need to be made.

Reliable data is required to support a whole of government approach to disability advocacy and is critical to inform government policies and ensure government remains accountable to people with disability and meet their obligations under the NSW Disability Inclusion Plan.

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

The NSW Government, and the Australian Government, both have a part to play in ensuring all people with disability have equal access to services and supports, and that those not eligible for the NDIS don't fall through the gaps. NSW Government funding will be required for the development of a systematic approach to capacity building.

In closing, and noting the many areas under consideration within this review that may affect the way advocacy is delivered post June 2020, the Alliance believes that in order to consider the outcomes proposed by the review, make decisions on any changes to current systems, and then implement these changes, that the time factor to do so would extend beyond the current NSW advocacy funding arrangements.

Therefore, in order to enable the time required for individual organisations to administer any changes and ensure that continuity of services remains for the people with disability whom require them during this time, the Alliance requests that current funding arrangements are continued for a further two years (to June 2022) to allow for this.