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Response to the Stage 2 Consultation on the National Disability Strategy

Introduction

Advocacy for Inclusion (AFI) is pleased to provide a submission in response to the proposed National Disability Strategy ('the Strategy').

AFI provides individual advocacy where the rights and attitudes towards people with disabilities are notably unequal to their peers without disability in society and systems. Our advocacy approach is broad, representing issues that impact people with disabilities in a range of areas including equal access to justice, NDIS gaps, mental health, guardianship, supported decision-making, access to inclusion, education, child protection, access to healthcare, accessible housing, access to appropriate services. We also provide training on human rights in a disability context, disability awareness for organisations or small community groups, and develop resources to aid information sharing for people with disabilities to engage independently.

We also provide expertise in our systemic advocacy representation of people with disabilities in the ACT on a national and local platform. We work within a human rights framework in acknowledgment to the *United Nations Convention on the Rights of Persons with Disabilities (CRPD)*, the *Optional Protocol to the Prevention of Torture (OCPAT)* and is signed onto the *ACT Human Rights Act 2004*.

The *National Disability Strategy 2010-2020* is the foundation of Australia's work to advance disability rights and recognises the experiences and needs of people with disabilities and their families are central to the Strategy, its vision, and its principles.¹ The Strategy is the national policy framework for guiding Australian governments to meet their obligations under the *UN Convention on the Rights of Persons with Disabilities (CRPD)* and to implement the CRPD across a range of key outcome areas.

The vision and outcome areas being proposed for the new Strategy

The *National Disability Strategy 2010-2020* indicated the following six outcomes areas of policy actions under the current strategy is still appropriate:

1. Economic security
2. Inclusive and accessible communities
3. Rights, protection, justice, and legislation
4. Personal and community support

¹ Commonwealth of Australia (2011), *National Disability Strategy 2010-2020*, Canberra

5. Learning and skills
6. Health and wellbeing

The current strategy is still appropriate, however over the past ten years, the Strategy needs to reflect remaining and emerging gaps people with disabilities experience. Since the introduction of the current plan and the National Disability Insurance Scheme (NDIS), the AFI advocacy model has changed and now reflects broader provisions in the policy.

It is welcoming to see that the new Strategy will focus on measurable outcomes to address systemic human rights gaps, resourcing in implementation, and monitor and evaluation across its policy outcome to address accountability and implementation mechanisms.^{2 3} It also acknowledged that DSS has taken the recommendation of the UN Concluding Observations to account and it is demonstrated in the position paper.

We recommend that new policy targets are included to strengthen the Strategy's purpose and delivery over the next ten years. During the current Strategy, two key areas of focus have emerged for AFI which we believe must be placed as a priority of government policy and decision-making for the next ten years.

Advocacy

We note that the current Strategy refers to advocacy support in a loose, unprioritized fashion. It is not new for AFI to be praised, like other community sector organisations, for our 'hard work', 'dedication' and 'commitment to people with disabilities', but remain under-funded and over-capacity in the number of clients that we can take on. With the steady change to AFI's advocacy models to accommodate the NDIS in the past five years, the rights and attitudes of people with disabilities have continued to be communicated through our systemic advocacy and development of training and resources designed on disability human rights to a tailored audience or supported decision making.

AFI is funded to provide individual advocacy in the ACT by the ACT Government and faces the 'renewal' of funding each financial year without guarantee of continuance. AFI's systemic policy funding is funded through DSS. In three years, AFI's advocacy team has expanded from one individual advocate to three, with one staff member dedicated to NDIS Administrative Appeals Tribunal (AAT) cases. With four individual advocates, AFI has reached maximum capacity taking on only urgent and complex cases. Each year, there is the uncertainty of funding for individual advocacy provided by the ACT Government.

AFI's systemic policy funding is provided through the National Disability Advocacy Program (NDAP). It was previously reviewed in 2016 but to date, identified reforms are yet to be implemented. The ACT Government is included where State and Territory Governments have actively reduced or ceased funding for individual advocacy under the view that the NDIS will be the 'fixer' for people with disabilities. There remains insufficient funding to continue supporting people with disabilities in the ACT for the advocate capacity that AFI currently has. It has been previously recommended that advocacy funding, both individual and systemic, be restored or increased to meet the need for continued advocacy.⁴

The new Strategy must also refrain from leaning heavily on the NDIS as a measure of oversight, monitoring, and delivery of 'engagement'. In our experience, we have supported people with disability who have been ineligible or continuously found unsuccessful in gaining the NDIS. People who do not have the NDIS face a higher difficulty in accessing supports and programs, as many support provisions have been registered to the NDIS and offer minimal support to people without NDIS funding. This is

² Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities (2019) in response to the List of issues prior to the submission of the combined second and third periodic reports of Australia [CRPD/C/AUS/QPR/2-3]. Compiled by the Australian Civil Society CRPD Shadow Report Working Group, July 2019

³ Previously echoed in Commonwealth of Australia (2017) *Senate Standing Committee on Community Affairs, Report: Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities*, but actively ignored in Commonwealth of Australia (2018) *Australian Government Response to the Senate Standing Committee on Community Affairs, Report: Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities*.

⁴ Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs, Study Report*, Canberra

where advocacy, to support all people with disabilities with or without the NDIS, is critical and it must be acknowledged within the Strategy to ensure that advocacy support continues to hold the Government, as well as providers, accountable.

Advocacy should not be an uncertain component of disability support. Accordingly, in outlining the target policy areas, the new Strategy must acknowledge and reflect on the necessity of individual and systemic advocacy. It should be included as an additional target policy role to reflect the role advocacy plays in improving policy gaps for people with disabilities, as well as providing feedback to both DSS and the ACT Government to improve best practice, legislation, and reform in all target areas outlined under the new Strategy.

Mental Health/Psychosocial Disability

The NDIS has overshadowed AFI's advocacy capacity in assisting people with a psychosocial disability access to mental health support. Since the introduction of providing funded NDIS-based advocacy on top of general advocacy provided, AFI has mapped a steady increase since the introduction of the NDIA in opening the NDIS to mental health. Ideologically, this is possible as AFI cannot effectively deny advocacy to a growing number of people with psychosocial disability and mental illness who are both NDIS participants and those found ineligible. The NDIA also appears to be working in isolation and not building on existing service delivery models, which in turn, falls back into the disability advocacy organisations where capacity is overflowing. The availability of individual advocacy is narrow and based on the severity of individual cases.⁵

States and Territories, including the ACT, are withdrawing their funding for several mental health support programs, and using this funding to offset part of their contribution to the NDIS. We direct the Strategy to acknowledge the UN Committee on the Rights of Persons with Disability feedback to the Australian Government to:

- (f) Ensure that all persons with disabilities have access to continuous, sustainable, and adequately resourced individual and independent advocacy programs, particularly outside the NDIS.⁶

At this stage, it is unclear what supports will be available for people with psychosocial disability and mental illness who do not meet the NDIS eligibility criteria. AFI has had clients identify that community service organisations that are ineligible for NDIS are not taking on clients who were applying for the NDIS, leaving them with no support or transition to alternative programs.

There is now a psychosocial measure and continuity of support being put in place to ensure people with psychosocial disability and mental illness, regardless of being on the NDIS or not, have time to transition.⁷ This has represented a gap in services that this cohort has experienced where additional support has not been provided post in June 2019.⁸ In our experience, with the associated risk that people with severe and persistent mental illness and complex needs will fall through system gaps once again as they are not eligible for the NDIS, for whom support ceased in June 2019.

There is an additional concern that regional and rural Australians with disability have been left out of the current Strategy. Regional and rural advocacy needs to be added to the Strategy, particularly capturing issues faced by people with disabilities and psychosocial disability/mental health outside the metropolitan areas. The current Strategy does not accommodate to the urgency and importance of regional and remote mental health and suicide nor a focus on services and advocacy in regional areas.

This is now an empty void where services are not readily available to assist in urgent situations where

⁵ Productivity Commission (2017), *National Disability Insurance Scheme (NDIS) Costs, Position Paper*, Canberra, p. 34

⁶ Committee on the Rights of Persons with Disabilities, Concluding observations on the combined second and third reports of Australia: CRPD/C/AUS/CP/2-3, June 2019, p.10

⁷ Federal Government has announced \$121.29 million for 12 months extra to ensure transition. See: House of Representatives Senate Estimates Hansards, 5th April 2019, p.30

⁸ Michael, L. (2019) 'People with severe mental illness left behind in NDIS transition', *Probono News*, 16th April 2019: <https://probonoaustralia.com.au/news/2019/04/people-with-severe-mental-illness-left-behind-in-ndis-transition/>

mental health is prevalent and places additional strain on disability advocacy organisations which are more in numbers than mental health advocacy supports and services. It is essential to be included where the Strategy focuses overall on closing interface gaps in health, housing, education and justice, include disability funded advocacy organisations to assist in closing the gaps where advocacy is needed in regional and remote areas and how best, to assist in crisis intervention where needed.

It is expected that the Federal Government and State and Territory Governments will work constructively under the Strategy to ensure greater regional control and responsibility for mental health funding in regional and remote areas to close gaps. Canberra is a regional city, and AFI has been experiencing a surge of enquiries to accommodate people with disabilities and mental health in outer-Canberra regional NSW townships where Canberra is considered the nearest 'city' service for healthcare other than Sydney. There is currently no active individual advocacy support⁹ adequately available in regional NSW near Canberra¹⁰ that allows for travel between regional towns and cities.

There is concern that regional and remote areas that require much attention will continue to miss out, due to the lack of advocacy availability or assistance organisations placed in regional areas. This is considering gaps in the availability and funding of adequate and accessible clinical services and effective mental health, suicide prevention and intervention programs, to meet local level demand. It will be the responsibility of each State and Territory to include regional areas in their funding allocation but there needs to be a specific and separate model included in this Strategy to ensure regional areas remain a priority for people with disability and psychosocial disability/mental health, particularly where organisations like AFI cannot actively assist.

Improving Community Attitudes across Outcome Areas

AFI supports and welcomes the proposal of the new Strategy to have a stronger emphasis on changing community attitudes across all outcome areas. We also support the principles that guide government and civil society policy and program design that support and uplift the rights of people with disabilities in changing community attitudes. AFI provides strong expertise in training, resources, and self-advocacy development in the ACT. Our work also is trusted, and we are approached by the ACT Government to provide expertise and project development in a broad range of areas, particularly in supported decision-making training and Easy-English translation. In our work, we do not just view people with disabilities as the target audience but take a whole-of-society approach where inclusive practice benefits all.

Since the implementation of the current plan, AFI can attest to the attitudinal and cultural understanding of disability has progressed. We also recognise value, where supported decision-making and disability awareness training is led by people with lived experience of disability and government consultations and roundtables, involve advocates who work closely with people on the frontline. In our experience, the rights, and attitudes of people with disability have been largely defined by the ability to participate in the community actively. The higher the 'social competence', the greater the social inclusion as an individual; however, the environmental and social barriers of how a person with a disability can interact vastly changes this experience if an individual is unable to participate fully.

Where lack of awareness, negative community attitudes, and stigmatising beliefs prevail, attempts at greater community integration through policy had previously been met with resistance in the ACT. It has only been recently that the ACT Government has been extending funding to support great inclusion and disability liaison support to tackle cultural and social change in the ACT through the Disability Justice Strategy¹¹, paving improvements through service delivery and supports. We have found that growing the understanding of public responses to disability has had important implications for the likely success of inclusion policies.

⁹ It has been our understanding and observation from enquiries that an individual advocacy organisation in Queanbeyan do not have advocacy capacity outside of Queanbeyan, NSW.

¹⁰ Rural Disability Advocacy Service (RDAS) is the closest and based in Wagga Wagga and extends to Albury-Wodonga. NSW townships such as Goulburn, Cooma, Yass and Shoalhaven have limited to none.

¹¹ ACT Disability Justice Strategy 2019-2029, https://www.communityservices.act.gov.au/__data/assets/pdf_file/0007/1626631/Disability-Justice-Strategy-Annual-Progress-Report-2019-2020.pdf

Combinations of cultural and attitudinal barriers have led to people with disabilities being effectively excluded from participating equitably in the ACT community, particularly in guardianship and parenting decisions. As a result of discrimination and social exclusion, the invisibility of persons with disabilities at all levels of society and the lack of positive responses becomes a driving factor as to why people with disabilities cannot actively participate on an equal basis in areas of social and economic life if they are perceived that they 'cannot'. The rights of people with disabilities make their own decisions and are part of any process where our institutional structure determines their 'capacity' is fundamentally ignored. Training and education around supported decision-making have proven that cultural and attitudinal changes can be made, but unfortunately, the lack of long-term, sustainable funding removes the priority.

We will continue to support change across outcome areas to ensure these opportunities enable people with disabilities to access their basic human rights to be active and valued contributors to their community by addressing attitudes.

Government Responsibility to Assist People with Disability to Access Supports and Services

AFI strongly supports the proposal to include additional detail to clarify the roles and responsibilities of government in disability policy and service delivery. It is fundamental for our organisation that people with disabilities receive information from the government that easy to digest, clarify, and enable to supported decision-making. Information regarding supports should be available in multiple formats that are recent and easy to use.

AFI has a positive relationship with the ACT Government where our expertise is trusted and is made part of implementations, discussions, and requests for advice. However, we do strongly believe that the Strategy should represent and include the role of the advocacy sector rather than a mere stakeholder of the government to be consulted. The Strategy, as a whole, must acknowledge and reflect the varied range of community organisations working with people with disabilities by ensuring that funding and resourcing of organisations, like AFI, can improve outcomes for people with disability and assist in advancing best practice delivery.

The best work conducted between AFI and the ACT Government¹² has been a focus on co-design when funded and resourced appropriately. Where expertise, time, and capacity has been requested without funding, it has been difficult to weigh priorities. Under a co-design implementation, it is hoped that the Strategy can enable real value for money from the community sector, increase community well-being, and actively shift resources towards solution-focused measures. The areas of inclusion and best practice should be tenfold to ensure transparency, fairness, and involvement is central to the aims of the Strategy. We hope the Strategy can represent the role of the advocacy sector to improve outcomes for people with disability by implementing:

- A genuine show of co-production by services using real case examples and models of practice from advocacy organisations like AFI to demonstrate active client response. The Strategy needs to be explicitly clear in how input is being used by people who provide the input, particularly people with disability and mental illness. Information provided to the community, including to be promoted among organisations, needs to have an Easy English or Plain English component.
- The opportunity of key trusted organisations (in collaboration with smaller, less systemic-capacity organisations) to comment on materials in development by the government for the community sector in return for set funding provided to perform this work, as well as test, improve and provide expertise through training without expectation and 'unpaid' hours. Be equal in partnership, funding delivery needs to be longer-term in sustainable cycles – but should not be competitive against organisations or in forced collaboration to produce similar pieces of work for little outcome purposes. In turn, as a form of transparency, the government

¹² Namely ACT Office for Disability

needs to share their findings, and gap analysis with the community – co-design is treated as a shared approach to improve outcomes.

- Ensure that a range of views, including through focus groups and co-design groups within community organisations with a range of different focuses, are included in the guidance. For AFI, groups would be people with disabilities, their families, and support network. Leveraging better integration and coordination of support, and better outcomes.
- Co-design and inclusion should form a key part of the Strategy design where continual feedback from service users, individuals, and organisations to emphasise the importance of having conversations outside of the services themselves.
- Focus on outcomes, and evidence-based results from community grant funding need to ensure design, funding, delivery, and evaluation of service projects in the community sector meet population needs. Improved capacity to evaluate what works and change what does not, so that resources can be invested to maximise impact. Under tightened KPIs, the community sector needs agreed Terms of References if producing and providing resources for the ACT Government as part of co-design.

Real inclusion within the Strategy requires the aim of providing information and guidance within the community sector, for all people who use sector services, their families and carers, advocacy organisations, and government providers. Each organisation brings expertise. AFI is not a peak disability organisation and does not have membership organisations in which we represent; however, we do note the unfairness that evident in the community sector where key community groups that do not have the staff or systemic capacity, miss out on having a 'voice'.

We provide disability awareness and human rights training, creation of resources and materials, and support decision-making expertise for both individuals, community, and government organisations. Our systemic expertise encompasses all elements of this work. For the development of the Strategy, communication is key and needs to be reflected in an additional advocacy target area. Our training expertise in disability awareness, human rights, and supported decision-making have been recreated in several training packages as well as renowned resources – and it is frustrating to see government outsourcing similar, but low expertise training ('consultants') from interstate for the same information and expertise that can be invested in locally. In some instances, AFI has requested both Federal and the ACT Government to inspect presentations and training before delivery or requested to attend the training to provide insight or feedback without funding, payment, or full acknowledgment.

The Strategy should clearly outline government responsibility to assist organisations on the ground to improve outcomes. It should not be controlled by the government over the community organisations they consult and work with. This is currently a problem where control is influential in the types of projects and funding opportunities available. Collaboration between organisations on the ground to provide joint outcomes is necessary; however, forced collaboration to produce similar or joint pieces of work between organisations as a competitive means provide little outcomes and purpose and does not demonstrate meaningful co-production, rather a frustration. Current practice has demonstrated the opposite of collaboration in which, AFI hopes, the Strategy can improve and assure that measures are put in place to provide an equal platform of collaboration between both the government and community organisations.

On the flip side, the ACT Government does excel well in gathering voices and holding consultations to gain views of community members; however, they are not widely advertised or promoted to be widely inclusive and reliant on advocacy organisations. This is two-fold:

1. It is difficult to engage people with disabilities in the ACT due to population numbers, enthusiasm to be involved without 'recycling' topics that are refreshing to comment on and be involved in. This was evident in consultation for this Strategy consultation – people simply did not engage with the purpose of the Strategy and the significant difference it could make to their lives in comparison to what they are already experiencing. The Strategy was more relevant for conversation between government and community organisations.
2. The reliance and expectation on community organisations to run consultations without resourcing, time, and capacity to gather 'voices' of people with disabilities.

There are different examples of co-design and delivery in which will need to be agreed upon by both the government and the community sector to ensure the Strategy achieves its purpose. Community organisations, in turn, need to be transparent and honest of their limitations to participate, deliver and implement outcomes.

Availability and Frequency of Public Information on the Strategy's Progress

We support the proposed outcomes framework as a mechanism to hold government and registered disability service providers to account for being achieved by programs and services that are delivered to people with disabilities in the ACT. We fundamentally believe that frameworks that evaluate and monitor outcomes need to be periodically reviewed in stages throughout the Strategy implementation, rather than one lump evaluation at the beginning and the end.

AFI supports the annual reporting of progress against each target area. We are conscious of too many reporting channels that may be complicated and hinder transparency of reporting and who will be responsible for the monitoring, oversight, and reporting at jurisdictional government level to be fed back to DSS to report against progress, and ideally would like to be reassured how this will operate.

The UN Committee has suggested in their feedback to the Australian Government to:

- (c) Establish a formal monitoring mechanism under the NDS, including the Office of Disability Strategy as recommended by the Senate Standing Committee on Community Affairs in 2017, ensuring effective coordination between the federal and State level.¹³

AFI fully supports this recommendation made to ensure that it is accompanied by ongoing key outcomes of each target area, particularly the status of engagement and policy development measures. This can be headed by DSS as a separate government entity but also to better inform and engage in policy development across jurisdictions to track progress in states and territories in areas under each target outcome. It is crucial that the Targeted Action Plans contain measurable goals and robust monitoring, formalised performance reporting framework, evaluation, governance, and accountability requirements.

With the proposed Targeted Action Plans to track and monitor outcomes throughout the Strategy, it is also expected that stakeholder engagement methods will be raised to ensure the improvement of target outcomes where the advocacy sector is involved. The Targeted Action Plans need to also involve a wide range of diverse stakeholders including Aboriginal Torres Strait Islander, CALD, psychosocial disability/mental health, and young/older people representatives and organisations.

¹³ UN Concluding Observations, National Implementation and Monitoring, art.33, p.13

Delivering and Monitoring under the Engagement Plan

AFI is pleased that the Strategy will be improving the active participation of people disabilities through an Engagement Plan ('the Plan'). The Plan will need to be communicated to the disability community of its difference from the NDIS. We have found that consultations for people with disabilities regarding the Strategy in the past have been difficult to explain and break down as the confusion of the NDIS intertwines with the change in which the Strategy implements in each jurisdiction. The delivery and monitoring of outcomes ultimately falls to policy development understood by government and community organisations and is, in reality, unrelatable to people with disabilities who do not follow the progress of the Strategy as it is removed from their direct everyday experiences.

Article 31 of the CRPD – statistics and data collection – requires that *"States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention"*.¹⁴ Statistics and data collection should be used to identify and address the barriers experienced by people with disabilities in exercising their human rights, and data should be disseminated to people with disabilities within the criminal justice system.

Stronger data collection of the experiences by people with disabilities, whether they engage in advocacy, is necessary to gain an accurate picture of the delivery and monitoring of the Plan and overall Strategy. We acknowledge that DSS will engage in a national data collection approach.

Conclusion

We look forward to the outcomes of the Stage 2 Consultations and the development of the Strategy. We believe that an understanding of people with disabilities, their families, and support networks using local community services are the experts of their own lives and are essential in the development and design of future engagement and services under the Strategy.

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¹⁴ UN Human Rights, UN Convention on the Rights of Persons with Disability (CRPD), *Article 31: Statistics and Data Collection*
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-31-statistics-and-data-collection.html>