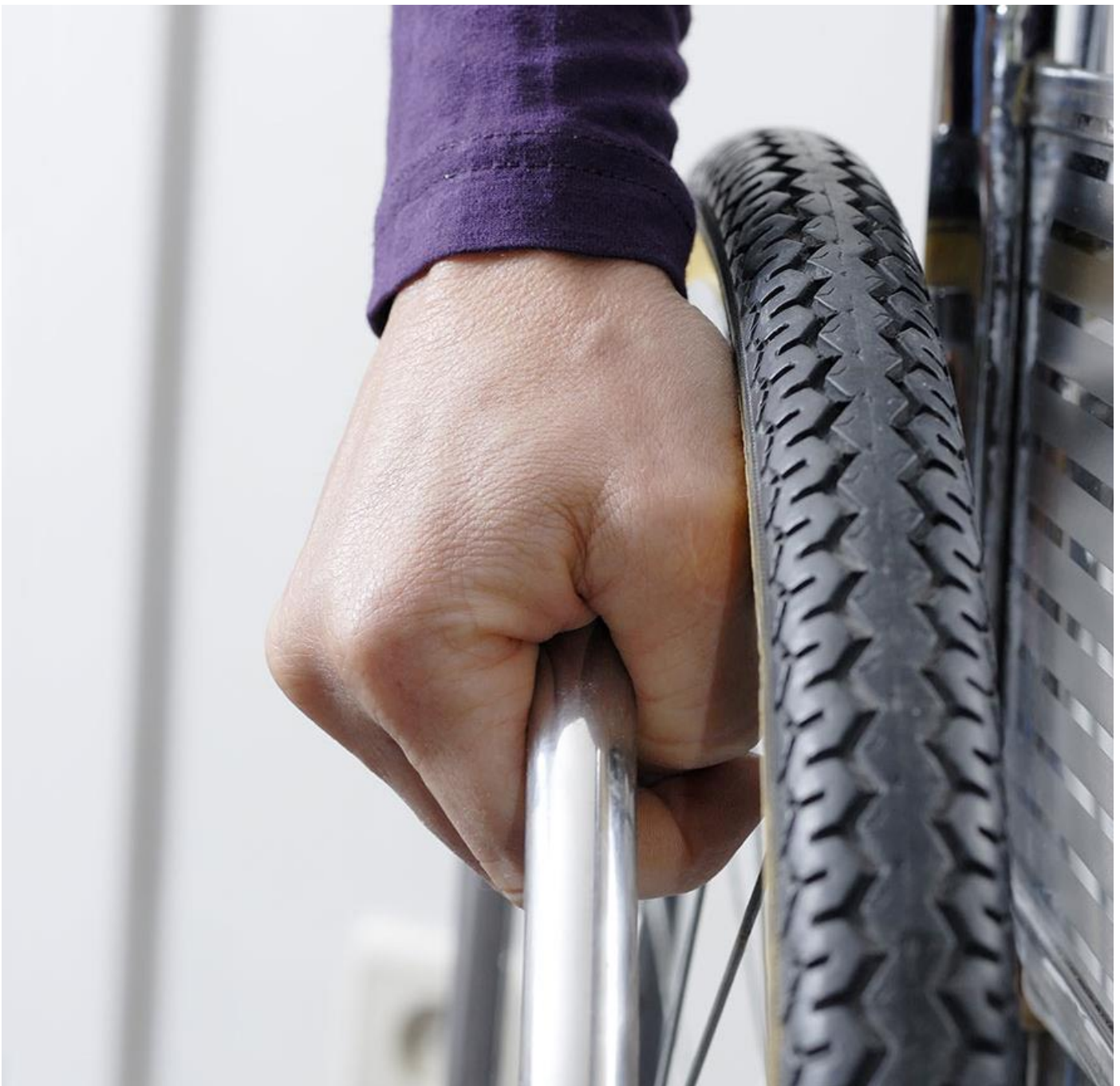


Submission
Review of the National Disability Advocacy Framework

Public Consultation 2022



Disability Advocacy Policy
GPO Box 9820
Department of Social Services
Canberra ACT 2601
Email: disabilityadvocacysecretariat@dss.gov.au

Submission to Review the National Disability Advocacy Framework

Introduction

Thank you for the opportunity to provide feedback to this draft of the National Disability Advocacy Framework (NDAF) 2022-2025. As the original review predates the seismic changes that have occurred in the disability sector since the introduction of the National Disability Insurance Scheme (NDIS), Spinal Cord Injuries Australia (SCIA) welcomes the opportunity to contribute to a new, nationally consistent framework for advocacy with objectives, principles and outcomes aimed at achieving the best results for people with disability in a vastly different, and redefined disability landscape.

SCIA is grateful that the Department of Social Services (DSS) recognises the need to continue the recurrent 'block' funding for disability advocacy services. This continuity supports the good work of the many advocacy organisations that are funded through the National Disability Advocacy Program (NDAP) who support and represent the many people with disability who rely on the advocacy services we provide.

SCIA has been providing a dedicated advocacy service for many years with 14 staff members working within the SCIA Policy and Advocacy Department on both individual and systemic advocacy work which includes the staff in our Alstonville office (northern NSW) who work in individual advocacy. SCIA provides specialty knowledge in Spinal Cord Injury and similar neurological conditions and broader knowledge and experience across physical disability. It is important to highlight that SCIA has been in continuous operation since September 1967 and was started by people with an acquired spinal cord injury. SCIA continues to employ many people with spinal cord injury and similar physical disability. Not only does this create a vast knowledge base from which to draw from, but it also helps us to meet the individual needs of the people who use SCIA's services.

However, for advocacy services resources are always scarce, and this has never been more evident than in recent months. SCIA has been inundated with requests for individual advocacy support, particularly in the NDIS space. The option of referring clients to other advocacy services, an option that we have used in the past, has not been available to us because they, like us, are also at capacity. So, at the most fundamental level, the current objectives of the framework are not being met because of these limitations and people with disability needing advocacy are missing out.

As the complexity of the NDIS increases alongside the unprecedented growth in the number of disability service providers, it is vital that advocacy services like SCIA continue to be adequately funded. People with disability need to be appropriately supported and represented so they can actively participate in the decisions that affect their lives. This is the most effective way to ensure the rights of people with disability are maintained, promoted and valued.

Because of the amount of funding, regulation and resources that are applied to the NDIS, that is where the government directs most of its attention. But only a minority of people with disability (about 10%) are NDIS participants. Most people with disability are either not eligible for the NDIS – people over 65 with disability being one group – or without advocacy to help them with NDIS access, eligibility processes and planning decisions.

The Disability Royal Commission (DRC) interim report has acknowledged the vulnerability of people with disability who are not NDIS participants. The DRC interim report has also identified the lack of advocacy and representation for people with disability as one of the contributors to the incidents of violence, neglect, abuse and exploitation against people with disability.

Throughout this submission, SCIA makes references to these issues and the role that increased funding to advocacy groups like SCIA would make to ensuring the safety of all people with disability, especially the most vulnerable. It is after all, the activism and advocacy of the Disability Rights Movement that has led to substantial positive changes in Australian legislation, policy and practice. The sector is again at a crossroads as we await the DRC's recommendations. It is vital that advocacy services play a prominent role in addressing the systemic issues that are still leaving many people with disability more vulnerable than others, and less able to access the services that they need.

1. Do you believe the new NDAF encompasses your vision of advocacy? If not, what changes are required?

SCIA believes that the new Framework as it is written and expressed through its objective, principles and outcomes broadly meets our vision of advocacy. We also agree that aligning the Framework with an actionable and target driven workplan will bring a level of accountability to the Framework so Commonwealth, State and Territory Governments can measure progress towards the Framework's desired outcomes.

However, the NDIS is now a fully-implemented national program – widely regarded as the largest social policy reform since the introduction of Medicare. As of March 30, 2022, there were more than 518,688 active NDIS participants receiving support from approximately 27,700 service providers. The number of NDIS participants is likely to top 600,000 by 2024. And the NDIS only represents about 10% of all people with disability in Australia.

The NDIS was only beginning to roll-out nationally when submissions were requested for a National Advocacy Framework Review in 2015. At about the same time as advocacy groups were preparing their submissions to the Framework Review, the Victorian Ombudsman published its report: *Reporting and Investigation of Allegations of Abuse in the Disability Sector: Phase 1 – the Effectiveness of Statutory Oversight, June 2015*. On the role of advocacy groups, the Ombudsman said: *“there is a critical role for advocates to assist people with disability; however, there is limited appreciation of the importance of this role, manifest in its modest funding.”*

In the current environment, the role of advocacy groups is even more important than it was in 2015. SCIA, and other advocacy services that perform a similar role, are experiencing unprecedented demand for support. There are more than four million people with disability who look to SCIA and other advocacy services for support, but the funding we receive is not proportional to demand. And while much of our individual advocacy work is focused on advocating for the rights and interests of NDIS participants, we are an advocacy service for all people with disability, within and outside of the NDIS.

As the number of NDIS participants and providers have increased exponentially, funding for our services has remained static. In most cases people with spinal cord injury or a similar disability have more complex and high support needs and as such, often require more advocacy support to get the plans, funding and services they require to live as active citizens with as much independence and participation in society as they choose or can achieve. So, when considering the current demand for our services, and the inevitability that demand will only increase in the coming months and years, it is difficult to see how we can confidently say that the Framework encompasses our vision of advocacy without an urgent increase in funding for advocacy support.

However, while SCIA believes that increased funding for advocacy services is integral to the success of the revised Framework, we also believe that there are many structural issues that beset the disability sector that have never been adequately resolved. Unfortunately, many of these issues have compounded through the transition to a new market-based service model. Given the opportunity and with adequate funding, advocacy - including education resources to encourage self-advocacy and peer advocacy services - could play a much larger role in the correction of these issues. The DSS' own NDIS Quality and Safeguarding Framework, 2016 stated that *"participants need to understand and assess available information, and use decision-making and self-advocacy skills."*

For example, the processes undertaken and the subsequent results of individual advocacy work, especially in the NDIS space, could be shared between advocacy groups, and where appropriate with participants, through an online portal. This would avoid the costly duplication of resources that have already been spent in reaching a prior decision.

And there are cost benefits associated with increasing the role of advocacy in the disability sector. We note that so far in this, the 2021 – 2022 financial year, the NDIA has spent more than \$41.4 million on legal costs relating to NDIS access and funding disputes at the Administrative Appeals Tribunal (AAT).

It is something of an anomaly that advocacy groups are not more actively involved in the design of NDIS participant's plans given our experience and regular involvement in the review and appeals process. We believe that more participation by advocacy groups could: streamline and avoid problems in the planning process; reduce the number of NDIS participant funding reviews, appeals and AAT proceedings which are timely and costly; and assist Local Area Coordinators (LAC) with knowledge gaps – a problem often raised by NDIS participants.

In summary, our vision is to receive funding commensurate with the increased demand for advocacy by people with disability. We also believe that the Framework should explicitly reference peer advocacy which is support provided by advocates who have either shared or had similar experiences to the person they are supporting. Peer advocates who are trained and have achieved the relevant qualifications are an invaluable resource and support for people with disability to build their confidence and develop their own skills and knowledge.

2. Are the principles of the NDAF appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?

SCIA believes the principles of the Framework are appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS. However, SCIA also believes that the disability sector has changed in ways that could never have been anticipated prior to the roll-out and implementation of the NDIS. SCIA believes that the NDAF could acknowledge, either as new principles or as an extension to the definitions in the existing principles, some of these changes and the impact that they are having on the role of advocacy in the disability sector.

Person-centred approach (choice and control)

SCIA believes that for advocacy support to be fully effective it needs to be able to respond adequately to the inherent issues of an expanding NDIS and to the needs of people with disability who are not NDIS participants. For that reason, there is both a need and expectation for disability advocates to be fully informed on NDIS policy.

With additional funding, advocacy could play a much larger role in making improvements to the disability workforce. Skilled support worker shortages have been a perennial problem for the disability sector, even prior to the implementation of the NDIS. The growth of the NDIS means that the skilled support workers capable of supporting people with spinal cord injury and similar disability are now spread far more thinly across the sector.

SCIA is concerned that these staff and skill shortages are having an even greater impact on people with disability who are either not eligible for the NDIS or are unable to access the NDIS. Unskilled workers who are supporting people on the unregulated side of the disability and aged-care sectors may represent a serious risk for people with disability and are arguably perpetuating a two-tier system of support. People with disability over the age of 65 are particularly vulnerable to these types of arrangements.

In an interview on Sky News preceding the 2022 Federal Election, Tony Burke, who has since been appointed Federal Minister for Employment and Workplace Relations conceded that large parts of the NDIS and the care-economy are being delivered by contract workers from the gig-economy where minimum standards and minimum wages do not apply. The combination of people with disability who do not have adequate funding for the supports that they need, and workers who are able to provide supports that they are not trained to provide, at potentially discounted prices, could be a recipe for disaster that needs to be vigilantly monitored. Having said that, people with disability have the right to choice and control and this arrangement can work in the interests of the worker and participants in the right circumstances to empower both.

With appropriate funding, advocacy groups like SCIA, with our broad knowledge and experience, including lived experience, would be ideally positioned to play a larger role in any initiatives to improve the knowledge and understanding of the disability workforce on the fundamental human rights principles and the importance of protecting those rights for people with disability.

Access to supports

The growth of the NDIS has made it increasingly difficult for many people with disability to navigate without advocacy. This is especially true for people with high and or complex support needs. From SCIA's observation, those with the greatest need wait longer and are most affected by the scheme's complexity.

The assessment processes for eligibility to some funding types are onerous, expensive, and undertaken at the participant's expense without any guarantee of success. This is especially true in the eligibility process for Supported Disability Accommodation (SDA) and Supported Independent Living (SIL) services. Many people with disability in the community have been impacted by these processes. And rather than allocating accommodation vacancies to those who are most in need, people with disability who have the means to pay for their assessments are advantaged because they do not have to join the queue for community health funded assessments. Additionally, if participants are in hospital waiting to be discharged, between homes or are without suitable housing during their assessments for eligibility to SDA, there is limited funding for short and medium-term accommodation.

People with disability who are not eligible for the NDIS or unable to access the NDIS are particularly vulnerable in the housing market. Many people with disability live in sub-standard accommodation that is manifestly unsuitable to their needs, yet they are bound to their circumstances for the lack of an appropriate alternative. This includes people with disability living in boarding house style accommodation and young people with disability languishing in aged-care facilities.

The lack of available, accessible accommodation and the duration and complexity associated with the eligibility process places enormous pressure on advocacy groups and the NDIS. SCIA and other advocacy services already contribute significant resources in supporting people with physical disability through the SDA eligibility process. However, this is a structural problem that precedes the NDIS, and it is an issue that will continue to compound as the demand for all types of accommodation grows. The scope for advocacy in this area could be expanded to include advocacy groups working with housing providers and service providers on solutions that meet the individual needs of the people they support.

Justice

It is essential that advocacy services are suitably funded to ensure that vulnerable people in group homes and other forms of private disability accommodation are protected. The need for this advocacy is supported by the substantial evidence that has been provided to the DRC by advocacy services and by residents of group homes and other forms of supported accommodation who have been subjected to violence, neglect, abuse and exploitation.

The incidents that have come to the attention of the DRC are but a small proportion of a much bigger problem. People with disability deemed to be at risk should be assigned an advocate so their short- and long-term safety and security is assured in more suitable accommodation with appropriate supports and services.

Additionally, residents in group home accommodation are reluctant to complain about the quality of the services they receive for fear of losing their place and being unable to find an alternative. This is most prevalent where both SDA and SIL services are administered by the same service provider.

The discrimination and conflicts of interest that compromise the choice and control, independence and safety and security of people with disability is not limited to SDA, SIL and group homes. The government should also ensure that adequate funding is available for advocacy services to support people with disability if they experience barriers to not only the NDIS but mainstream services like public transport and infrastructure, medical and health services, Centrelink, educational institutions and any other service they require.

Where appropriate, funding for services specialising in self-advocacy training could provide people with disability with the skills to understand if their rights are being violated and subjected to discrimination or exploitation - and if so, what actions should be taken to address it. The DSS' own NDIS Quality and Safeguarding Framework, 2016 stated that *"participants need to understand and assess available information and use decision-making and self-advocacy skills."* It also stated: *"supporting participants to develop their self-advocacy and decision-making skills, and to understand their rights, is vital to ensuring they can use the information that is available to them to make informed choices."*

While self-advocacy may not be a substitute for advocacy services, in many cases it may be the catalyst to asking for support from an advocacy group.

Safeguards

There has been a significant change to the way that some people with disability engage their services. Since 2016, there has been a sharp increase in the number of 'gig-economy service-for-profit' online platform providers enter the NDIS marketplace. While participants and people with disability believe these providers may offer them more choice and control, and often a lower hourly pay rate compared with using a disability service provider, they also place the onus on people with disability to choose their own workers and manage their own bookings and accounts.

Many of these online platforms and marketplaces use contract support workers who operate outside the regulatory quality and safeguards provisions of the NDIS despite being able to be paid from NDIS funding for their services. In the context of the principles of justice and safeguards, it is important that people with disability are fully aware of their rights as consumers when engaging contract workers. The laws relating to the gig-economy and who is responsible in the event of an accident or incident - even non-payment or underpayment of wages and superannuation - are highly ambiguous. As the number of online platforms increase, there will be a greater role for advocacy services to advise people with disability about their rights when engaging workers and to provide advocacy if a problem arises.

Presumption of rights and capacity

There is an obligation under the United Nations Convention on the Rights of Persons with Disabilities to ensure that people with disability have equal access to policies and programs, assistance, support services and facilities to ensure the full realisation of their human rights and fundamental freedoms.

Yet many people with disability for reasons of intersectionality, remoteness, Aboriginal and Torres Strait Islander heritage, culture, incarceration, economic and or social disadvantage, age, gender and more, are unable to access the NDIS or other types of funding suitable to their needs that should and would be available to them with appropriate advocacy. Incidents of people with disability isolated in inappropriate housing and young people with disability in residential aged care facilities precede the NDIS and they have continued since the implementation of the NDIS. Without advocacy and the support of family and friends, they are vulnerable to violence, neglect, abuse and exploitation

Advocacy services could assist in building communication with other agencies including: the health department, educational institutions, justice, and aged care facilities so people with disability, currently in environments that are unsuitable to their needs, may be able to access support to assist them to live to their potential.

We also believe that funding for data development including disaggregated data, would be highly beneficial for the sharing of information across government agencies.

3. Are the outcomes of the NDAF clear and achievable? Should different ones be included? If so, what should be included?

SCIA believes the outcomes of the Framework are clear and achievable for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS.

However, SCIA would like additional outcomes to the Framework. We believe that these additional outcomes are highly achievable, and not only would they increase the independence, participation and opportunity for people with disability – particularly for people with disability who are currently unable to access funding and appropriate support and services - they would also add significant and much needed efficiencies to the disability sector.

The DRC will be releasing its final report in September 2023 which is expected to include a host of recommendations designed to protect people with disability from further violence, neglect, abuse and exploitation. The Framework must include outcomes relevant to the pending release of the DRC's report with suggestions that bolster the ability of advocacy services to respond appropriately and support the recommendations.

The additional outcomes SCIA suggest include:

- An outcome specifically referencing an increase in the participation of people with disability in the NDIS and mainstream services should be included. The outcome should specifically identify participation by Aboriginal and Torres Strait Islander people with disability and people with disability from Culturally and Linguistically Diverse (CALD) backgrounds.
- An outcome that promotes the development of a data program including disaggregated data to be shared across government agencies to help with the identification of people with disability (people who are not protected by the quality and safeguards assurances of the NDIS) who may either be unidentified as having a disability or may benefit from more appropriate and targeted services or supports. These agencies may include but not be limited to federal and state departments of health; education; social services; corrective services; aged care; and disability including the NDIA.

- Now that the NDIS is fully implemented research and data should be more reflective of the lived experience of people with disability who are using the scheme.
- The Disability Discrimination Commissioner at the Australian Human Rights Commission (AHRC) should be given stronger powers to act against clear issues of discrimination. Where appropriate, advocates should be able to refer to the AHRC any government agency; or any corporation or organisation that discriminates against a person with disability. This added responsibility would negate the need for people with disability who have experienced discrimination to defend their own rights, often at great personal expense.
- SCIA would like to see a Federal Ageing and Disability Commissioner appointed with the power to investigate and address systemic issues occurring in the disability sector or in other circumstances, agencies or organisations that leave people with disability vulnerable to violence, neglect, abuse, and exploitation. We are aware that some states have appointed Commissioners with the power to act within their jurisdictions; we believe a Federal Commissioner is also required to ensure information and actions are uniform across the states.

4. Are the responsibilities, reform and policy directions of the NDAF relevant or should different ones be included?

SCIA believes that the responsibilities, reform and policy directions of the NDAF are relevant, however, we would like the Commonwealth, State and Territory Governments to make some additional commitments, so the Framework's responsibilities, reforms and policy directions have sufficient capacity to respond to future legislative changes and recommendations by the DRC when it presents its final report in September 2023.

Even though future changes to the sector may not be as seismic as the changes we have experienced during the term of the initial Framework, further reforms to the sector are forecast and we believe that the 2022-2025 Framework should reflect their arrival and impact.

For instance, we are likely to see an alignment of regulation across the care and support sectors relatively soon. Collaboration between advocacy services and other stakeholders including aged care and veteran care service providers will need to increase and people with disability will need to be fully informed on the impact that those reforms will have on their lives.

Additionally, now that the NDIS has been fully implemented, research and data should be more reflective of the lived experience of people with disability who are using the scheme. It is essential that reforms are made to address the systemic issues in the sector not entrench them. People with disability are best equipped to inform the sector on services that are failing NDIS participants and causing inefficiencies in the scheme, and advocacy groups are best placed to relay that information to government.

And while the Framework rightly endorses a person-centred approach and co-design principles, SCIA has seen reforms suggested prior to, and since, the roll-out of the NDIS that have caused people with disability considerable anxiety due to the lack of consultation and sufficient explanation from government to advocacy services. It is also obvious that reforms happen in the NDIS space and rarely address the needs of people with disability who are not eligible or are not able to access the scheme.

For instance, people with disability over the age of 65 are less able to access suitable services because aged care service providers and their workers may not have the appropriate skills to provide the necessary care to someone with disability.

Advocacy services facilitate information sharing and help people with disability to understand how changes to the sector and regulation may impact them. It is also possible that without assistance from advocates, people with disability may not understand or respond to their obligations to the reforms in a timely and informed way, which could cause an unnecessary disruption to their lives.

SCIA believes that additional funding should be provided to advocacy groups to support people with disability to deal with the practical and emotional upheaval that may accompany future sector reforms.

5. Does the NDAF identify what is needed in the current and future disability environment? If not, what changes are required?

Likely legislative changes at a state, territory and federal level will influence the way services will be provided to people with disability. It is important that the Framework makes provisions for people who are ineligible for NDIS funding. Advocacy will play an important role in ensuring that services are accessible and provided equitably.

Therefore, it will be crucial for the government to fund and maintain advocacy services to address issues across mainstream and community services.

We believe the Framework should include:

- Reform and policy provisions should be made to give due consideration to recommendations made by the Disability Royal Commission (DRC) when it presents its final report in September 2023. Based on the Commissioner's insights presented in the DRC's interim report, there is good reason to believe that legislation in the sector will be bolstered to mitigate the high number of incidents of violence, neglect, abuse, and exploitation experienced by people with disability both within and outside the quality and safeguards framework of the NDIS. In Question 3 of this submission, we have suggested some outcomes that we believe require funding prior to the release of the DRC's final report so people with disability have additional protections immediately.
- More input from advocacy services relative to funding, programs and services that are failing the NDIS and not serving participants. SCIA and similar advocacy groups would be constructive and valuable contributors to NDIS reforms especially given our depth of advocates with lived experience. SCIA's experience could have short, medium, and long-term cost benefits and other efficiencies that would improve outcomes for people with disability and the sector more broadly.
- SCIA believes an online portal is an essential resource for advocacy groups and people with disability. It is the ideal medium for keeping people with disability updated on changes to the sector; areas of concern; systemic advocacy work in progress; and the outcomes of individual decisions that may set precedents for other decisions.

6. Do you have any other comments, thoughts or ideas about the NDAF?

Despite the profound and largely positive impact of the NDIS on the lives of many people with disability, there are entrenched systemic failures of public safety, quality control and labour standards within the scheme that need to be addressed by increased government funding and greater input from advocacy services.

There are currently inordinately long waiting times for NDIA responses to applications for various specialised services and there is a significant backlog in NDIS plan reviews, resulting in default extensions of existing NDIS plans that inadequately provide for the changing needs of those requiring complex support.

Yet the true extent of the failures relates to the violence, neglect, abuse, and exploitation against people with disability and misbehaviour by service providers and other agencies that occurs outside the regulatory framework of the NDIS. People with disability who are found to be languishing in unsuitable accommodation or in the care of agencies or organisations that are not suitable to their needs and denying their human rights should then be provided immediate access to advocacy.

The DRC interim report states that the extent of the problem is still largely unknown because of data failures and the absence of quality and safeguard protections for people who are not eligible or do not have access to the NDIS. Therefore, funding for more sophisticated data development, including disaggregated data, as the basis for a working system of quality and safety assurance is essential.

There is still enormous inequity and fragmentation in the way funding and services are distributed to people with disability. For instance, people with disability over 65 years of age must rely on Home Care Packages that are currently capped at \$52,000 each year when the reasonable and necessary care funding for a 65+ year old person with quadriplegia costs more than \$200,000 a year. These oversights represent inherent injustices against vulnerable groups that requires concerted and collaborative advocacy to correct. The framework needs to recognise these inequities as systemic and represent a major fault line for further advocacy support.

People with disability who have access to advocacy are far more likely to achieve a better outcome for funding and services that meet their individual needs. Those without advocacy and the support of family or friends, are left alone to navigate an extremely complex system.

This 2022-2025 period should be a period of reform in the disability sector. It is SCIA's view that increased funding for advocacy would go a long way to ensuring a sustainable disability sector that achieves better outcomes for people with disability, their families and carers and acts in the interest of safety, quality and cost control and greater efficiency.

But there are systemic issues that exist within the NDIS and many that predate the NDIS. They include: Staff and skill shortages; violence, neglect, abuse and exploitation against people with disability; conflicts of interest by service providers; over prescribing of psychotropic medications to control challenging behaviours; problems with NDIS plans and plan reviews including when existing funding for supports are arbitrarily reduced or removed; and more.

Advocacy services often act as the intermediary between government and providers and can play a leading role in affecting systemic change to protect and prioritise the individual needs of people with disability. If we fail to address these issues, we will miss the opportunity to make effective change. Inaction will be felt by individuals and the structural issues will continue to act against their interests and destabilise the sector.