SYNAPSE

AUSTRALIA'S BRAIN INJURY ORGANISATION

Submission to the Review of the National Disability Advocacy Framework 2022-25

8 July 2022

About Synapse:

Synapse Australia is a national peak body providing a range of support services for people who have been impacted by brain injury and disability. Synapse promotes quality of life, self-determination and choice through information, specialist support and targeted research activities.

Synapse's mission is to ensure the rights of people impacted by brain injury, by connecting knowledge, policy, services and systems. We seek to focus both government and public support to realise funding for the development of specialist services nationally.

Our commitment to reduce the massive unmet need for services and support is unwavering. Our objective to seeing specialist and individualised services available to all in need is resolute. No matter where they live or which culture they belong to.

Objective and Principles:

Thank you for providing an opportunity to review the draft National Disability Advocacy Framework 2022-25. Synapse commend the development of a framework which supports people with disability by ensuring their rights are maintained, promoted, and respected. We value the shared commitment to disability advocacy between the Commonwealth, state and territory governments to ensure access to advocacy services for all people living with disability. We support this simple and succinct framework which is built on strong advocacy principles as its foundation. These principles outline the approaches required to work towards alignment of advocacy services and standards to improve outcomes and access for people with disability.

Synapse recommend the United Nations Declaration on the Rights of Indigenous Peoples, Article 22 be included as a foundational document under Principles to inform and support implementation of the Framework (p.3).

Additional considerations:

Synapse endorse the outcomes of the draft Framework going forward.

Synapse recommend additional consideration be given to include the role and function of supported decision making, a function many advocates facilitate for people with cognitive disability, particularly in the absence of family, networks of support or formal decision-makers.

Further, we recommend the inclusion of a systemic outcome related to the interaction between systems for those experiencing multiple disadvantages. At present there appears to be little overall systemic interaction throughout the process yet connecting individual advocacy to systemic advocacy is a vital piece work.

We support the 5th outcome (p.5) that 'people with disability, including those experiencing multiple disadvantage, are supported to have effective interaction and access to disability supports and services and/or mainstream services and facilities including supportive, flexible and timely access to justice and legal advocacy'. However, we note that for this outcome to be achieved, there must also be a dedicated channel for discussion between those systems to enable systemic changes.

To proactively deliver on these outcomes, it is imperative that work 'behind the scenes' occur across the intersecting systems. For many people experiencing multiple disadvantage, the often-hidden nature of disability does not allow many of the systems to even realise they interact, let alone how the various interactions occur. This is often the case for people with neurocognitive disability who frequently intersect with disability, family violence, health, justice, and housing systems. The absence of structured channels to explore these multiple-system disadvantages serves to magnify the vulnerability of the person with disability. Multiple disadvantage, with the additional layer of inadequate cultural safety, only heightens the risks for people with disability and hinders their access to appropriate advocacy and legal support.

There needs to be dedicated structures and frameworks that allow systems to interact and improve coordination and communication between disability services, the National Disability Insurance Agency, mainstream services, community-based services and governments, to develop the overall capacity of the sectors and to promote stronger linkages between individual and systemic advocacy.

A more proactive approach to systemic advocacy would enable learnings from individual advocacy to be strengthened and data captured across intersecting systems. In addition, providing impetus and recognition of the capacity building needed across other systems, not only in relation to representation at an individual level. Such capacity building and awareness serves to address discriminatory practices, however unintended, within these systems and prevent escalation in individual advocacy need as well as ensure that people with disability are not invisible, and unintended victims of these systems.

Synapse endorses the other outcomes of the draft Framework including but not limited to:

- People with disability are accorded the same rights and freedoms as all Australians.
- People with disability enjoy increased choice, control and wellbeing, exercise their right to make decisions, are involved in all decision-making processes that affect their lives, and receive the support they need to make those decisions.
- People with disability are able to participate in all aspects of the civil, political, economic, social and cultural life of our communities.
- Regardless of where they live, people with disability can access quality and independent advocacy support.
- People with disability, including those experiencing multiple disadvantage, are supported to have effective interactions and access to disability supports and services and/or mainstream services and facilities including supportive, flexible and timely access to justice and legal advocacy.
- Aboriginal and Torres Strait Islander peoples with disability will have a greater say in how advocacy is designed and delivered; have access to culturally and linguistically appropriate, and culturally safe, disability advocacy, including access to community controlled organisations delivering disability advocacy; and have access to, and the capability to use, locally-relevant data and information.
- Culturally and linguistically diverse communities, have access to culturally and linguistically appropriate, and culturally safe, disability advocacy that features the engagement and input of relevant local communities.
- People with disability have a range of ways to express their views and wishes about supports and services, play an active role in working out how things will improve, and can access a complaints mechanism and independent support and advice when providing feedback or making a complaint in relation to the supports and services they purchase or engage.
- The demographics of people with disability receiving individual advocacy reflects the diversity of the communities that the agencies are operating in.
- People with disability have the opportunity to be actively involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact them.
- There is increased community awareness of barriers to people with disability, the stigma associated with disability and the presence and value of advocacy supports.

Framing Advocacy from 2022-2025:

Synapse believes the future is less about 'new thinking' and more about 'grounded, evidence-informed and strategic thinking'.

It is vital to identify and distinguish between the specific roles of the Commonwealth, the NDIS and the State in relation to disability advocacy, in order to distinguish the paths to effective systemic responses**.** The Framework should cover the purpose, roles, principles, eligibility and assumptions of each party to create an equitable, responsive, accountable and high-quality disability advocacy system. The disability advocacy sector needs a far more coordinated approach to building capability and encouraging innovation whilst also providing value for people with disability and the broader community.

Advocacy must also be framed with recognition that specific cohorts of people with disability will need a more targeted approach. This is true for many people with neurocognitive disability who present with an invisible disability and frequently lack awareness of the difficulties they face to express these.

Information and referral is an important ancillary component of all advocacy work. Advocacy should assist people with a disability to navigate and access government services, departments and agencies; navigate and access commercial services like utilities, retail, and entertainment; navigate and access local councils and community services and facilities; and ensure lifestyle choices enhance their opportunities for genuine inclusion in the community and do not result in discrimination or have opportunities limited by discrimination to begin with.

Advocacy need:

The need for advocacy will only grow and whilst it is impossible to know the extent, there is evidence of current unmet demand as well as a broad consensus about a level of undeclared demand, which is both unacknowledged and unmet.

Add to this, the Australian population is ageing which implies a rising need for advocacy due to:

(1) the increased incidence of disability with increased age,

(2) the increased longevity of people with disability, and

(3) the ageing of family carers of people with disability and associated reduction in their informal caring role.

(4) the National Disability Insurance Scheme (NDIS)

As the NDIS is fully operational, there are implications for advocacy because the NDIS is linked with increased advocacy work at multiple points. Many people require advocacy as they learn about the NDIS, seek to access it, and when they create and implement their NDIS plans. They also tend to require advocacy when their NDIS plans are reviewed and if there is a need to appeal the reviewable decisions.

People with disability have broader awareness about services and rights. This includes many people who have either lived on the fringe (for example, in homelessness) and/or are not engaging effectively with the NDIS (such as people who have had a stroke, people with mild intellectual disability or acquired brain injury). Need for advocacy arises not only from heightened awareness about the NDIS and specialist disability services, but also from awareness of rights to access mainstream services, including education, transport, housing, health, and justice services. One must remember however, that only a proportion of people with disability qualify for NDIS support, and in many cases the absence of service availability (NDIS or other) amplifies disengagement. This disengagement frequently contributes to unmet need and greater incidence of people with disability surfacing in the justice system, out of home care, mental health services, homelessness and unemployment and other intersecting systems.

Government Agencies at all levels are seeking more access to representational bodies and systemic advocacy organisations.

The Disability Royal Commission creates a need for advocacy during the hearings, which is supported by the National Disability Advocacy Program . It is highly likely that system and service changes arising from the findings of the Royal Commission will create greater need for advocacy as well as the shortcomings of the current advocacy investment nationally.

As government and commercial activities move online, much information remains inaccessible to people with disability. This is related to both the format and channels of the information itself, as well as structural barriers faced by people with disability to digital inclusion. Recognising that people with disability have much lower levels of digital inclusion than other Australians means the role of appropriately funded in-person advocacy is critical.

Conclusion:

Synapse acknowledges the positive steps the Commonwealth has taken in reviewing the current National Disability Advocacy Framework and supports the principles and outcomes outlined.

Synapse recommend the Framework be strengthened by the inclusion of supported decision making and the provision of pathways to connect the intersecting systems with which people with disability will often come into contact during the life course. Particular attention must be paid to the systems that capture those experiencing disadvantage as too frequently the evidence demonstrates over representation of people with disability. This cannot be ignored or viewed as an issue to be identified and responded to within a silo or funding envelope external to a disability context.

Advocacy is vital to ensuring fundamental needs and rights are met and represented within services and the broader community to support full social and economic participation by people with disability as well as authentic choice and control regarding their services and supports.

Synapse believes the National Disability Advocacy Framework is more relevant and more necessary than ever. The broader context of the NDIS coupled with an ageing society implies the need for advocacy will only increase and the need for collaborative systemic responses will become greater. In addition, there are large numbers of people with disability who lack diagnosis and/or connection to the disability service system, but instead, continue to be forced into a repeated cycle of disadvantage, often intergenerationally, through their capture in systems (mental health, corrections, child protections, homelessness etc) ill-equipped to respond to their needs.

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