## Foundational Supports for Children and Young People with Disability

Submission to the NSW Select Committee on Foundational and Disability Supports Available for Children and Young People in New South Wales



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### Introduction

#### **About Mental Health Carers NSW**

As the peak body for mental health carers in NSW, MHCN represents the interests of mental health carers to the NSW Ministry of Health, and provides information, capacity development and systemic advocacy on behalf of mental health carers. It regularly consults with carers across NSW to gain information on their opinions and experiences with the mental health system. MHCN uses the information gained in these consultations to provide feedback on policies and services on behalf of carers to NSW Health and to other health services and policy makers. With its core functions funded by the Mental Health Branch of NSW Health, MHCN developed the Mental Health Carer Advocacy Network (MHCAN) to broaden its engagement with mental health carers in its advocacy and to assist roll out of the NSW Lived Experience Framework.

By influencing changes in policy, legislation, and service provision, MHCN aims to make a positive difference to the mental health system for carers and through the MHCAN to empower carers to become champions for change, sharing their lived experience to evoke the solidarity of humanity to promote mental health reform.

In October 2022, MHCN was awarded the tender for Department of Communities and Justice Disability Advocacy Futures Program (DAFP) for psychosocial disability systemic advocacy. Over the next two years, MHCN will deliver systemic advocacy through this project that includes liaising with Individual Advocacy Providers, stakeholders, government, and non-government decision-makers, and DCJ to improve understanding of the unique issues faced by people with psychosocial disability.

### **Overview**

Mental Health Carers NSW welcomes the opportunity to contribute to the inquiry into foundational and disability supports available for children and young people in New South Wales. As the NSW peak body organisation for carers, families, and kin of people with mental illness and the systemic advocacy provider for people with psychosocial disability and carers, Mental Health Carers NSW has proven experience advocating for the inclusion, recognition, and support of people with lived experience in the care and services ecosystem.

Mental Health Carers NSW acknowledges the importance of early intervention and foundational supports for children and young people with disabilities, developmental concerns and/or mental health concerns. We emphasise the importance of supporting carers and families who are crucial to providing support, fostering wellbeing, advocating for inclusion, and providing long term stability in care. This submission highlights key areas where lived experience is relevant to the Committee's inquiry in terms of developing supports that address service gaps and opportunities for cross-sector collaboration with people with lived experience. It highlights the importance of including families and carers in the foundational supports framework to achieving a useful, accessible, and long-term sustainable system. Families and carers have lifetime roles in the lives of children and young people with disabilities, and for children and young people with disabilities who also experience mental health concerns. This includes providing care, advocacy, service navigation, support coordination, and safeguarding, which are often underacknowledged and under-supported in current disability services frameworks.

As Foundational Supports for psychosocial disabilities remain out of scope for the foreseeable future, Mental Health Carers NSW recommends that Foundational Supports for children and young people include mental health as part of the disability experience and ensure that supports are designed with individuals, families, and carers to meet the Committee's Terms of Reference that it covers "the role of foundational supports in a child's **overall** development, health, and wellbeing".

An individual's disability is impacted by their access to support networks and communities and how well they accommodate and respond to them as opposed to the condition itself.<sup>1</sup>

WHO, 2011. World Report on Disability

Psychosocial disability is seldom a single diagnosis but rather the effects that mental health conditions have on a person's everyday activities and experiences. It involves the limitations they may face socially, environmentally, academically, and emotionally and can present in many ways. Every child and young person's experience of psychosocial disability will be different, depending on several interrelated factors including the nature of the disability and the extent they can participate in activities and have access to supports that support their development. With the right supports, communities and governments can help children and young people with psychosocial disability and mental illness, their families, and carers. They can help by mitigating the social and environmental barriers and support them to manage mental health conditions as early as possible. This will give them the best chance to offset the systemic, environmental, and perceptional barriers of diagnoses, improve their mental health, and live confidently.

Foundational Supports can address critical gaps in support for people with disability both inside and outside the NDIS. Unfortunately, there is confusion around which jurisdictions will be responsible for said supports and cost sharing, which/if they will replace aspects of NDIS packages, the role of DROs, the future of ILC funding, and why the public cannot expect access to any psychosocial disability supports within the next 2 years.<sup>2</sup> Disability supports scoped by the select committee must include psychosocial, community, and mental health supports for children and young people. Mental health services in the community are often the first supports to fold due to discontinued funding thus investment is needed to rebuild these services and ensure their availability. Protecting and leveraging NSW's mental health supports can mitigate the risk of increasing the severity and prevalence of mental health concerns and psychosocial disability among children and young people and ensure that they have access to the community and family supports that may be a long time coming for adults in NSW. DROs, people with lived experience, and families and carers must be included in the development of these supports to ensure accessibility, equity, and prevent conflicts of interest.

<sup>&</sup>lt;sup>2</sup> DSC, What's Happening with Foundational Supports? 12 February, 2025. https://teamdsc.com.au/resources/whats-happening-with-foundational-supports

### **Summary of Recommendations**

1	No changes to or cancellations of NDIS Plans while Foundational Supports are
	being developed
2	Foundational Supports are designed and implemented in genuine partnership with
	the disability community
3	Free and accessible information and communications for children and young
	people
4	Information, peer support, education, and capacity building for families and carers
	are embedded in Foundational Supports
5	Long-term sustainable funding for advocacy services, DROs, and community
	support programs

# Mental Health, Psychosocial Disability in Children and Young People

While rates of psychosocial disability generally increase with age, children and young people remain vulnerable to escalating mental health issues. Approximately 1 in 7 Australian children aged 4-17 years will experience a mental health problem. Adolescence is the peak time for the emergence of mental health problems and around 50% of diagnosable adult mental health problems onset before the age of 14 years.<sup>3</sup>

The ABS reports that 3.4% of boys aged 0-14 years and 1.9% of girls had psychosocial disability. The higher prevalence among boys was due to higher rates of autism diagnosis for boys.<sup>4</sup> Gendered issues in diagnoses between sexes, however, contribute to lower numbers in girls as their autism generally presents differently or 'masks' the expected standard or stereotypical autistic behaviors and are therefore more difficult to assess.<sup>5</sup> Girls are more likely to experience higher rates of anxiety and affective disorders than boys, with much higher presentations of non-suicidal self-injury and hospitalisations.<sup>6</sup> Suicide is a leading cause of death for young people with adolescents at high risk, particularly males and LGBTIQA+ youth, while intervention for ideation and self-injury for girls and young

<sup>&</sup>lt;sup>3</sup> ADGP, 2018.

<sup>&</sup>lt;sup>4</sup> ABS 2018.

<sup>&</sup>lt;sup>5</sup> Furthermore, additional data collection is needed to identify the prevalence of neurodivergence among non-binary children and young people.

<sup>&</sup>lt;sup>6</sup> AIHW, 2020.

ABS data shows that patterns of psychosocial disability gradually increase with age. Of the 1.1 million Australians with psychosocial disability:

- 58% had nervous or emotional condition
- 41.1% had social or behavioural problems, and;
- 40.2% had mental illness, such as schizophrenia

Most Australians with psychosocial disability have one or more psychosocial impairments and 85.5% have a coexisting disability including physical, intellectual, and sensory. Individuals with psychosocial disability or mental health issues are more likely to experience comorbidities and engage in high-risk and/or addictive behaviours. This includes drug, tobacco and vaping, and alcohol abuse as forms of self-medication or learned adaptive and coping mechanism behaviours. Individuals with schizophrenia, bipolar illness, depression, and schizoaffective disorder are four times as likely to engage in at-risk gambling behaviours than the general population. Young Australians aged 14-24 with self-reported mental health issues were more likely to have engaged in drug taking, with increasing percentages dependent on the severity of their psychological distress. Relationships between mental illness and substance abuse intersect with demography, race, gender, and family history however, there are clear links between psychosocial disability and mental health issues and the development of comorbidities.

As aforementioned, Foundational Supports for people with psychosocial disability in NSW have not been identified as a target group for the first phase of development. However, emotional well-being and mental health should not be overlooked as these are crucial factors in a person's quality of life. As such, MHCN advocates that it is essential that Foundational Supports for children and young people, their families and carers include services and supports that can educate, intervene, and mitigate the intersectional factors that can escalate a young person's mental health. There are opportunities for early intervention to mitigate mental ill health becoming a factor in self-medication, addiction and social disengagement. Instead, by helping children and young people, their families, and caregivers, NSW Foundational Supports can better facilitate and encourage their

<sup>&</sup>lt;sup>7</sup> ABS, 2020; LGBTIQA+ Health Australia, 2021.

<sup>8</sup> ABS, 2020.

<sup>9</sup> National Drug Strategy Household Survey (NDSHS) 2023; AIHW, 2024

<sup>&</sup>lt;sup>10</sup> Bergamini, A., et al. 'At Risk Gambling in Patients with Severe Mental Illness: Prevalence and Associated Features', *Journal of Behavioural Addictions* 7(2): 348-354.

<sup>&</sup>lt;sup>11</sup> AIHW, 2019.

inclusion and participation in the community as young adults.

Recommendation 1: No changes to or cancellations of NDIS plans while Foundational Supports are being developed

A comprehensive alignment of state and federal funding with Foundational Supports is required for an equitable system. Inconsistencies and unknowns around jurisdictional oversight and responsibility result in significant gaps in service provision and access. Aligning state and federal funding and ensuring that organisations, providers, and users have access to clear information around program oversight will streamline delivery and improve service access for all children and young people regardless of socioeconomic status or geographical location.

MHCN has been advised by stakeholders that reductions of NDIS packages are occurring despite no change in their circumstances and without adequate foundational supports in place. Families are carers are concerned about what the future of supports will look like. Family Advocacy reported in their 2024 submission on Foundational Supports that 'the NDIA confirmed that they have increased their staff team to focus on completing over 1200 "eligibility reassessments" each week. Of these, 48% are having their NDIS access revoked i.e., approximately 600 participants each week. 80% of those receiving reassessment letters are the early childhood group, children aged 5-9'. It is therefore essential that the NSW Government take steps to improve trust in the system's ability to meet peoples' needs.

In a statement about recent changes to the NDIS Act, it was stated that 'the recent 'getting the NDIS back on track' changes to the NDIS do not change a child's participant status or remove their access to the NDIS'. This does not necessarily reflect community experiences and does not recognise the number of changes happening within the system and their impacts on children and young people, and families and carers.

<sup>&</sup>lt;sup>12</sup> 'Children Targeted in NDIS Crackdown', *The Saturday Paper*, January 11, 2025.

Children and Young People with Disability Australia has previously advocated that the NDIS is not fit for purpose for older children and young people who are experiencing a range of 'complex biological, psychological, and social changes during their first 25 years'.<sup>13</sup> The NDIS model is more geared towards the needs of adults with disability, who may be clearer about what their needs are, which is not suitable for children and young people who are less likely to be clear on what supports and services are needed or how to choose a suitable service providers.<sup>14</sup> As such, CYDA reported in their 2024 survey that participants were concerned that Foundational Supports would not adequately address diverse needs and would replace NDIS supports or justify cuts to them.<sup>15</sup>

People with psychosocial disability comprise the highest rate of NDIS rejections across the board and face recurrent 'reproving' criteria for their disability, having their disability challenged, or being removed from the NDIS or denied altogether, which causes distress for the individual, their families, and caregivers.

The DSS's consultation phase on Foundational Supports concluded mid-December 2024. As there is not yet an appropriate system for General Supports, there can be no justification for removing any child or young person from the NDIS or reducing their packages. The NSW Government can advise the NDIA to cease any future changes to NDIS packages while Foundational Supports are being developed. Nobody should have to deal with the additional stress of the removal of their supports and the uncertainty of the future. MHCN encourages the Department of Social Services to be transparent with the disability community and regain trust by ensuring no further changes are made to plans to ensure continuity and minimise the impact to children, young people, families and carers, and service providers.

A reactive and rushed design of Foundational Supports risks developing inadequate systems, misallocating resources, and excluding vulnerable children and young people from services they need. Children and young people with disabilities and mental health issues require these services to support their daily lives and there must be no further

<sup>&</sup>lt;sup>13</sup> CYDA, 2023. Reimagining a Better NDIS for Children and Young People.

<sup>&</sup>lt;sup>14</sup> PRECI, 2024. Discussion Paper on Foundational Supports for Young Children with Developmental Concerns, Delays, or Disability, and their Families: 8.

<sup>&</sup>lt;sup>15</sup> CYDA, 2024. Young people, Parents, and Caregivers on General Foundational Supports: Summary of Survey Responses Collected October 2024.

changes or cuts to packages until services have been designed carefully and implemented properly.

# Recommendation 2: Foundational Supports are designed and implemented in genuine partnership with the disability community

The 'nothing about us without us' principle is at the forefront of the disability rights movement and inclusion of lived experience and representation results in more effective and fit-for-purpose programs and services.<sup>16</sup>

Children and young people with disabilities require a diverse range of supports dependent on their individual needs, ages and life stages, and backgrounds. It is essential that the design of childhood and youth-specific support includes the lived experience of supportusers, families, and caregivers that considers the range of developments and life changes that occur between infancy, childhood, adolescence, and young adulthood. Foundational Supports must be inclusive of people with lived experience because they know what supports they need to facilitate their social and emotional wellbeing and reach their goals. They also know what is currently missing and what is in-demand but under-resourced. MHCN recommends that the state government explore the Australian Government's Engage! Youth Strategy to inform this process.<sup>17</sup>

The framework must be trauma-informed, neuro-affirming, and culturally sensitive. Australia agreed to the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2008, which requires the 'equalization of opportunities for Persons with Disability in influencing the promotion, formulation and evalution of policies, plans, programs and action at national and international levels to further equalize opportunities for Persons with Disability'. However, representative and advocacy organisations are rarely funded adequately to facilitate this inclusion and create meaningful engagement. DROs, advocacy organisations, and peak bodies must be resourced to participate in decision-making and co-design phases, implementation, and delivery as they have access to

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<sup>&</sup>lt;sup>16</sup> Smith-Merry, J. 2020. 'Evidence-based Policy, Knowledge from Experience, and Validity', *Evidence and Policy* 16(2): 305-316.

<sup>&</sup>lt;sup>17</sup> Australian Government, 2024. Engage! A Strategy to Include Young People in the Decisions We Make.

<sup>&</sup>lt;sup>18</sup> UNHCR Convention on the Rights of Persons with Disabilities, 2006.

stakeholders and lived experience who can provide important advice to service designers.

Further, MHCN recommends that psychosocial disability DROs and advocates are included in this process and funded to do so, particularly given the current absence of psychosocial Foundational Supports. This is because individuals, families, and caregivers are best placed to identify the systemic, social, and environmental factors that create additional barriers for children and young people with disability and mental health concerns, regardless of primary or secondary diagnosis. They know and experience the risk factors and, moreover, DROs can assist the design of supports for children and young people engaged in state systems, namely youth justice and child protection, which must be accounted for in Foundational Supports to ensure that vulnerable individuals are not further stigmatised or left out of programs altogether.

Committing to genuine partnership with lived experience for the long term will rebuild trust between government and people with disability to ensure that supports are designed with service users. Developing Foundational Supports by collaborating with stakeholders and engaging community to develop innovative delivery models will assist in tracking longer term goals and outcomes and avoid market gaps in service and support availability because they will focus on accessibility, workforce development, and sustainable funding.

# Recommendation 3: Free and accessible information and communications for children and young people

One in seven (13.9%) of Australian children and young people aged 4-17 years of age experience mental health problems, equivalent to approximately 560,000 people.<sup>19</sup> They are less likely to be engaged with therapies or supports and thus without intervention, leading to difficulties at home, school, and emotionally.<sup>20</sup> The DRC found that, despite international and domestic legal obligations, many Australians with disability cannot access information and communications 'on an equal basis with others, leading to poor health and education outcomes.<sup>21</sup> It also found that children and young people with

<sup>&</sup>lt;sup>19</sup> Sheehan, R. 2017. 'Mental Illness in Children: Childhood Illness and Supporting the Family', *Brain Science* 7(8): 97.

<sup>&</sup>lt;sup>20</sup>Australian Institute of Health and Welfare (AIHW). Child Health, Development and Well-being. 2014.

<sup>&</sup>lt;sup>21</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Final Report – Volume 6: Enabling Autonomy and Access: 62-64

disability experience inaccessible communication and information leading to social isolation, poorer performance at school, and increased vulnerability to abuse.<sup>22</sup>

In line with DRC recommendation 6.1, State and territory governments should develop a national plan to promote accessible information and communications, MHCN recommends that Foundational Supports include information and social supports that are free and easily accessible to recognize and address the significant socio-economic barriers that people with disability face, particularly people who are not eligible for the NDIS. Children and young people's access to finances will be determined by the family and/or guardian, or state service and therefore must be free to ensure equitable access for all. They also need access to support based on individual need and not determined by type or severity of disability as these cannot account for specific individual needs, which risks missing opportunities for early intervention. Broad-based information and advice are useful, but some individuals will need more personalised assistance such as in-person and one-on-one guidance and information for their support person or carer.

MHCN notes that psychosocial disability has the highest rejection rate of all disabilities in the NDIS and individuals face poorer economic outcomes as they must pay more out-of-pocket for therapy, counselling, assessments, and specialist services. This leads to higher disengagement from services, social disenfranchisement, and poorer mental health/disability. The NDIS Review found that supports outside the NDIS were unaffordable for many, which creates inequity of access between those who are and are not eligible for the NDIS.<sup>23</sup> Moreover, according to the Australian Human Rights Commission, '45% of people with disability live on or near the poverty line, 2.5% time the rate of poverty experienced by the general population'.<sup>24</sup> Rising costs of living disproportionately affects families and carers supporting children and young people with disability thus ensuring cost of access is not a barrier must be incorporated at every level of the Foundational Supports program.

To address funding shortfalls and reach as many children and young people disability as possible, MHCN recommends that there be accessible services that are at no cost to the

<sup>&</sup>lt;sup>22</sup> Koh, J., Kembhavi-Tam, G., Rose, V., Featherston, R., & Shlonksy, A., 2023. *Rapid Evidence Review: Violence, Abuse, Neglect, and Exploitation of People with Disability:* 17-18, 33.

<sup>&</sup>lt;sup>23</sup> Commonwealth of Australia, Department of the Prime Minister and Cabinet, *Working Together to Deliver the NDIS – Independent Review into the National Disability Insurance Scheme: Supporting analysis*, 2023: 57-58.

<sup>&</sup>lt;sup>24</sup> AHRC, 2022. Economic and Social Costs of Employment Discrimination Against Australians with Disability.

individual or family, digital and place-based, easy to navigate, inclusive of literacy and ESL, and require only necessary information from the individual. Additionally, there may be issues with accessibility for certain groups and variations in functional capacity, so it is important that information is available in a variety of formats (Easy Read, dyslexia-friendly, AUSLAN, Read Aloud, Braille). Services must be culturally competent, which requires developing culturally sensitive supports with peak body organisations and communities. To better reach and support children and young people, MHCN recommends that further investment is provided to Youth Community Living Support Services and 'Safeguards' Child and Adolescent Mental Health Response Teams to further implement their free community mental health services across NSW LHDs, particularly in regional and rural areas. These programs cater to individuals, families, and caregivers providing intervention, acute support, and postvention referrals. Offering children and young people diverse support options can prevent isolation.

The recent Online Safety Amendment (Social Media Minimum Age) Bill 2024 bans people under 16 years of age from using social media. This may be a deterrent for young people looking to access information about support and programs. MHCN recommends the development of alternative models for marketing and providing channels or forums for online peer support and information so that people under 16 with disability can access them safely, particularly people in rural and regional areas. MHCN recommends that scoping and development of alternative pathways to access such services could be part of the co-design process for Foundational Supports where people under 16 are engaged to map how they previously sought supports prior to the Bill and to identify alternative online, digital, and free options. Access to technology and internet connection must also be considered, as people with limited access to technology or digital literacy may face additional barriers to obtaining information and supports.

Recommendation 4: Information, peer support, education, and capacity building for families and carers are embedded in Foundational Supports

The NDIS Review found that families are more likely to experience stress and increased demands on their time that affect their wellbeing and causing exhaustion, anxiety,

isolation, and stress.<sup>25</sup> Both the NDIS Review and Disability Royal Commission emphasised the importance of informal supports. They found that families and carers have limited access to capacity building, peer support, or disability and/or neurodiversity organisations. Carers and families are lifelong supports for people with disability and are essential for long-term and sustainable care and safeguarding for people with disabilities. Implementing foundational supports for families and carers will align with the NDIS and DRC's goal of creating and maintaining strong informal support networks and systems.

Families and carers are usually the first to raise concerns about their loved one's development, and these must be taken seriously and deserve support. Families and carers are crucial to advocacy, supporting decision-making and service navigation, and providing care. They are uniquely positioned to provide positive outcomes and improve quality of life. They have the same needs as other families, however, carers and families face their own difficulties within services and within their relationships, such as limited capacity and/or financial support to provide care, lack of access to respite, difficulty accessing long-term in-home support workers, and poor mental health outcomes.

NSW Foundational Supports must provide peer-led capacity building and supports for carers and families to learn about disability rights, service and system navigation, family leadership and development, and supported decision making. These need to be free to access to address the 'two-tiered' system raised at the Disability Royal Commission where some families and carers have more resources to advocate whereas others may not. The importance of peer support models delivered by peaks and DROs was reenforced by the DSS and Social Deck in their *What We Have Heard* webinar in November 2024, where family capacity building through peer support groups has consistently been one of the most crucial supports across the disability community.<sup>26</sup>

Foundational Supports should include funding for peak body organisations and DROs to deliver peer facilitated networking programs, hubs, and/or playgroups for families and carers or auspice smaller grassroots groups to receive administrative and operate funds to engage with people with shared understanding, share stories and ideas, and build community. This will contribute to care and advocacy that is rights-based while also being

<sup>&</sup>lt;sup>25</sup> Commonwealth of Australia, Department of the Prime Minister and Cabinet, Working Together to Deliver the NDIS

<sup>-</sup> Independent Review into the National Disability Insurance Scheme: Final Report, 2023: 118.

<sup>&</sup>lt;sup>26</sup> DSS and Social Deck, What We Have Heard, 29 November, 2024.

supportive of carers' own experiences to provide their loved ones and themselves with positive outcomes and improved wellbeing. This support should be available without waitlists and not be conditional upon eligibility determination or designated diagnosis. These supports can include advocacy support, peer-to-peer programs, capacity building, and information and support programs.

For carer and family programs to be effective, they must be led by lived experience, independent of the direct support sector, and funded for the long term as opposed to short term grants. Organisations in the National Alliance of Capacity Building Organisations<sup>27</sup>, DROs, other and demonstrated programs such as the Belongside Families' peer groups, Amaze's 'The Autism and Family Supports Network', and Mental Health Carers NSW's 'Carer Connections' group and Service Directory, which provide peer-to-peer support, extend self-advocacy models and knowledge, and build confidence and social connection. These should be invested in for the long-term (e.g., a minimum of five years) with appropriate indexation in line with the NFP Blueprint.<sup>28</sup>

Children and young people have far less capacity to advocate for themselves therefore advocacy by families and carers is crucial to having their voices heard. Building family leadership, strong support networks, and improving wellbeing will assist families to develop their capacity to support and advocate for their loved ones and themselves, which will improve outcomes for all.

# Recommendation 5: Long-term sustainable funding for advocacy services, DROs, and community support programs

The introduction of the NDIS saw increased demand for advocacy services including systemic, representational, and individual advocacy, and MHCN anticipates that this will continue and likely increase with the roll out of Foundational Supports.<sup>29</sup> Advocacy

<sup>&</sup>lt;sup>27</sup> NABCO Evaluation Report, UNSW 2023

<sup>&</sup>lt;sup>28</sup> See Initiative 4b: Progress and monitor government actions to deliver full cost funding as sought by the NFP sector, including the application of appropriate indexation, and minimum term contract and renewal periods in all areas of service provision. Blueprint Expert Reference Group, Department of Social Services. *Not-for-Profit Sector Development Blueprint*, 27 November 2024.

<sup>&</sup>lt;sup>29</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Final Report – Volume 6: Enabling Autonomy and Access: 266.

organisations will be essential to identify systemic and individual issues that arise during the roll out especially around issues of clarity, queries around jurisdictional responsibilities, and service identification and referral. Advocacy funding needs to be separate from general foundational supports to avoid conflict of interest and ensure impartiality, which are key values for the disability advocacy sector. The Federal Government's response to the Disability Royal Commission in 2024 flagged a new advocacy program without details about how it would be funded, where funding would be allocated, which types of advocacies would be funded, or whether it was part of the Foundational Supports framework. MHCN recommends that this be clarified and communicated directly to DROs and advocacy providers to allow for comment and service preparedness.

There is uncertainty among disability and advocacy organisations around whether the development of Foundational Supports pre-empts the discontinuation of the ILC program and other NDIS services. Many organisations, Mental Health Carers NSW included, provide free training and support group opportunities for families and carers, once covered by the ILC program. The instability of short-term funding cycles disrupts service delivery, limits capacity to employ permanent skilled professionals, and risks provision of crucial supports to people who need them most. For MHCN, providing free services to carers and families is to support and educate them as carers and as individuals themselves so that their rights are upheld and they are protected in their duties. In line with the DRC recommendations 6.21b and c, Australian and state and territory governments should ensure long-term and stable funding for disability advocacy programs to meet demand, MHCN recommends that long term funding cycles are crucial to the longevity of Foundational Supports so that individuals, families, and carers receive continuity of support and organisations can deliver those services sustainably.

### **Conclusion**

Foundational Supports will fundamentally alter the landscape of disability supports and services in NSW. Development of these requires the leadership of people with disability, families and carers, and their representative organisations so that design and implementation leverages lived experience and community expertise. Foundational Supports must utilize and invest in the capacity for existing grassroots and non-profit services already in place, which have been designed to meet specific cohorts of people and have built trust and connection with people with disability, such as DROs, advocacy organisations, and smaller community groups and programs. MHCN understands that

designs for psychosocial disability supports are currently not in scope, however, it is essential that the mental health and wellbeing of children, young people, and their families and carers are considered in the general Foundational Supports design because they are and will always be part of disability experiences.