Family
Advocacy

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

April 2025

"Children that learn together, learn to live together"

***Jody Carr, Former Minister for Education, New Brunswick, Canada,
speaking at Family Advocacy's National Symposium on Inclusive Education 2017***

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Acknowledgement:

Family Advocacy would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was and always will be Aboriginal land.

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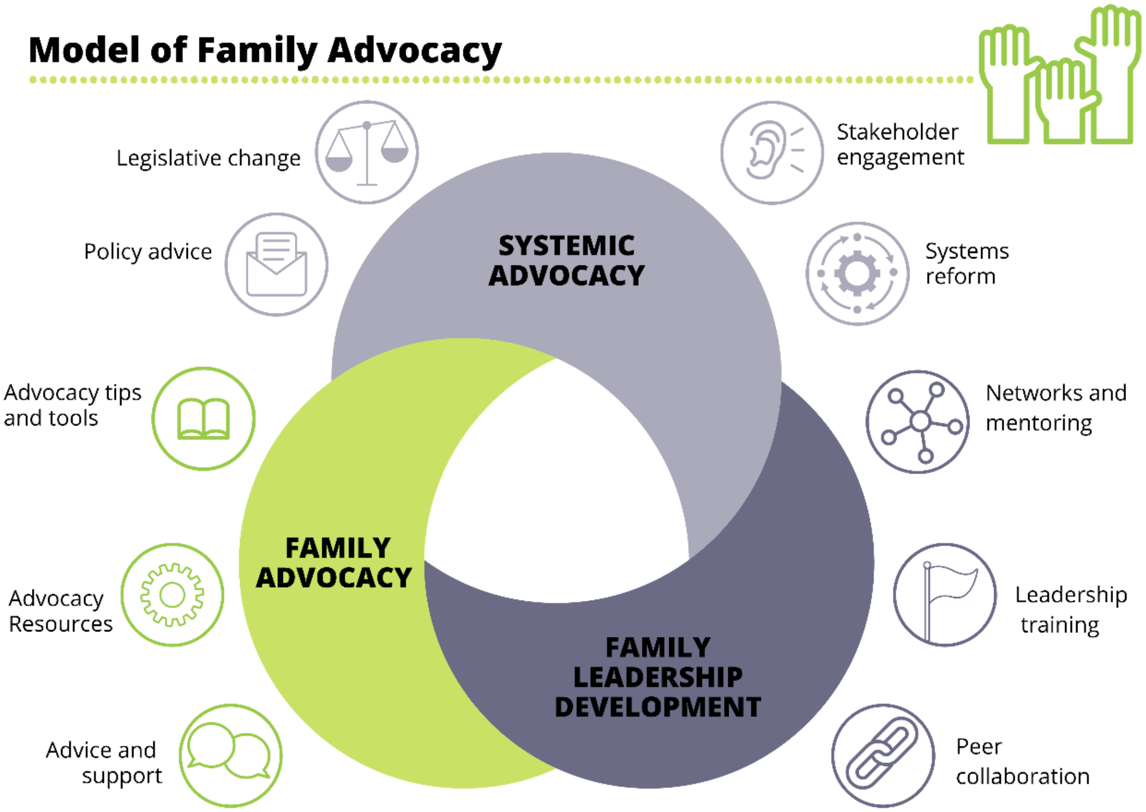
Introduction

Family Advocacy is a community based, state-wide disability advocacy agency, funded by state and federal funding programs to promote the rights and interests of people with developmental disability across NSW. The main objective of Family Advocacy over the last 34 years is to support families to advocate with, or at times, on behalf of the person with disability, with the goal to support people with disability to realise their goals, hold valued roles and lead lives embedded in the community to experience the same things that most Australians take for granted: an education alongside their same aged peer, a job and a home of their own. We continue to be governed and staffed by people with disability and families and provide services in the following ways:

- Advocacy advice and advocacy information to individuals
- Advocacy development for family members of a person with disability - Advocacy is often undertaken by families and can be required over the lifetime of their family member. Strengthening the advocacy capacity of families is essential to this.
- Systemic Advocacy

We provide a visual illustration of the Model of Family Advocacy below, but for more information, it is discussed in much more detail in UNSW, Social Policy Research Centre’s (SPRC) report, Family Advocacy Model Research.



Family Advocacy also has an initiative, Resourcing Inclusive Communities, also working across NSW, and holds the philosophy that people with disability thrive in the heart of the community, sharing the same everyday experiences as their fellow Australians. It provides information and resources to assist people with disability to live meaningful lives, as valued members of their communities. We share our vision of social inclusion with the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Resourcing Inclusive Communities works with many allies in the community to support this vision. Of note, is the National Alliance of Capacity Building Organisations (NACBO) and this model is discussed in detail under “Capacity Building Supports”.

In considering our advocacy efforts and capacity building efforts, both of which have a clear focus on the investment of families, we feel we are not only well positioned but also play a vital role in any work directed at supporting and building the capacities of these young families across NSW.

Family Advocacy appreciates the opportunity to provide a submission to the Select Committee on Foundational and Disability Supports Available for Children and Young People in New South Wales (hereinafter, the Select Committee). We will address the Terms of Reference that relate to the current lived experience and direct feedback we hear from families who have a loved one with disability and as an organisation who observes what provides genuine inclusive outcomes for people with disability.

We strongly encourage the Select Committee to adopt the Recommendations suggested in this submission. We look forward to the Recommendations of this Parliamentary Inquiry and to be meaningfully involved in the process of creating a society where children and young people are included in *all* systems, not just disability systems.

Executive Summary

As you no doubt aware, at this particular point in time, the disability policy landscape is in a state of flux, with a swathe of reforms stemming from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (hereinafter, Disability Royal Commission) Final Report providing 222 recommendations in September, 2023 and the NDIS Review final report “Working together to deliver the NDIS” proposing 26 recommendations and 139 actions in December, 2023. Foundational Supports are due to commence being phased in July 2025.

Despite not yet receiving an official response from the NDIS review, we are deeply concerned to hear at a Senate Community Affairs Legislation Committee Hearing recently, 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 eligibility reassessment letters, are the early childhood group, children aged 5-9. The remaining 20% are from other groups of participants, across a range of disabilities[1]. We are also hearing from other families that their loved one’s NDIS plan have been significantly reduced when there has been no change of circumstances.

Whilst we appreciate, the NDIS is just one part of the picture, funding approximately 10% of people with disability in Australia, these actions have undermined trust and people with disability and their families are feeling extremely uncertain about the future, the NDIS, and what foundational supports will actually look like. There are grave concerns their loved one will no longer have the supports they need to be able to participate meaningfully in and contribute towards their community, particularly where we see this dangerous gap where NDIS supports are significantly reduced or revoked prior to the commencement of Foundational supports. Good faith is not unlimited in the absence of delivery. Whilst any reform occurs, it is important for the Australian and NSW government to take steps to foster trust in the system’s ability to meet people needs effectively.

Family Advocacy strongly encourage the Select Committee, to consider in its findings, the current and potential impact of reform and its timing, to be front of mind to safeguard against further deterioration of trust between people with disability, their families and the Government. The timing aspect of change can

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[1] https://everyaustraliancounts.com.au/growing-concern-regarding-increased-rate-of-eligibility-reassessment/

not be understated as this is often not well thought through with government reform agenda's and often creating more damage than the change originally sought to address.

An essential aspect to any reform will need to involve a strong communication strategy to people with disability and their families. This should consider clarity around the guidelines for eligibility to Foundational Supports, ensure meaningful involvement of people with disabilities, their families and relevant stakeholders in this communication strategy. In our view, Foundational Supports should be available for anyone that needs support, regardless of diagnosis, to ensure no one slips through the cracks. In addition, we recommend designing and implementing capacity building programs to better meet the needs and preferences of people with disabilities and their families. This will improve the cost effectiveness and sustainability of the supports.

Lastly, but not least, careful reflection is needed by NSW Government on what the 'end goal' is in relation to this current reform agenda. In alignment with the National Disability Strategy's broader plan to create a society where people with disability are included in *all* systems – not just disability systems - we would assume the NSW government would agree that this would be people with disability living, working and contributing to their communities, in whatever version was possible. This end goal can be achieved and practices that are current barriers can be reformed, however, serious change efforts will need to work towards this. The bar in this regard needs to be set high and some current practices will need to be examined closely and adjusted so this end goal can be realised. We are at an important place in time around meaningful change for people with disability and the Select Committee has the opportunity to set the scene through strong recommendations to NSW Government.

This submission presents evidence of persistent gaps in key foundational supports and services across NSW. Our current system lacks foresight in relation to the end goal of people with disability learning, living and contributing to their communities. The lack of accessible early childhood opportunities, lack of typical pathways, specialised early intervention services to navigate to these settings and opportunities, lack of diagnostic services aimed at this outcome, and lack of cross-sectoral coordination, is causing real harm to children and their families. Thus, limiting potential and opportunities to experience the fullness of life that is afforded to children without disability.

Case Study from Parent from the Inner West, Sydney – **It became obvious through his behaviour that my preschool child had a good day whilst he was in an inclusive learning space in a regular day care (where he was treated like a child first before a label) but not in the Early Intervention Centre (EIC), which was therapy based. I wanted him to be in a regular class at his local school but was pressured by the school that he would be better off in the support unit.**

In term 1 of Kindergarten in a support unit (SU), he received an award for being the most inclusive child in the school playground where all children, including from the mainstream, played together. In term 2, they decided to restrict all the SU kids to a sandpit with a locked pool fence euphemistically named "the sensory garden". This is a form of social and environmental restrictive practice. He could not read or write by the end of the year. He regressed socially and academically. He displayed similar behaviour to when he attended the EIC. His speech went backwards, he would only grunt like when he was 3 years old. He refused to enter the classroom. He could not read or write.

During this period, I started to learn about my child's rights and the legal obligation of the school. I decided to move him to a regular class in a mainstream school. By the end of Year 2, he could read and write at peer level and when he is sick, his friends run up and tell him they missed him.

The difference? The attitude of the Principal and teacher treating him like one of the kids and providing support where needed in a regular setting. See him as a person first and label after that. Staff have a collaborative working relationship with me with the focus on what was best for the child.

It’s important to note that when we talk about early intervention, it is directed at children in typical settings such as regular preschools and not specialist disability groups, if the aim of foundational supports fostering genuine participation is to be realised. The solution is not just “more professionals” – it is a better model of practice. Quality support is not just about credentials – it’s about connection, context and culture.

We urge the NSW Government to establish a system of inclusive, accessible, and community-based foundational supports—delivered early and equitably to all children, regardless of diagnosis or location. Further to this, thoughtful consideration is required to ensure any supports and services that are set up hold clear objectives and strategies that enable participation for these children in community spaces that are typical for children in the same age group.

We would also recommend that any reform needs to have a strong focus on the capacity development of families that link with the objectives of Government, genuine participation in community. Families are the best ally and asset to the young person and when armed with good knowledge, high expectations, supported to build confidence they are usually well placed to push back against systems such as mainstream services, allied health services, and NDIS, that create barriers for their child. Family Advocacy, holding 34 years’ experience around family leadership are well positioned to assist with this work and welcome the opportunity to work with government in this regard.

(a) The Role of Services on Child Development, Health and Wellbeing

"With the right supports in mainstream settings, our son has gone from being non-verbal to now using sentences. Early intervention made all the difference. But we had to fight every step of the way to get there and keep him in regular settings." – *Parent from Western Sydney*

"It’s not just about therapy. Having someone who understands our child’s needs early on gives us hope, and that’s everything as a parent." – *Parent from Dubbo*

In answering the Terms of Reference, sections (a) - (i), we come from the angle of this very important premise. Through many years and experiences of families across NSW it has become a clear position that in order for their child with disability to get the good things of life - to have the opportunity to participate in, contribute towards, to be safe and included in their community (see diagram on page 15) – there are much broader factors beyond the current linear thinking of getting diagnosis, funding and therapy. Our families whose children have socially valued roles in life and are thriving, have often achieved this by having a loving family with a strong vision for inclusion for their child, that advocates and supports them towards this vision, have informal freely given relationships through friendships at school, work, and community groups (such as their local soccer team or art class), and therapies that are incorporated into daily life.

For example, trampolining at home for a young girl for 30 minutes in the morning before school to build strength, and regulate the nervous system, in order to help her cope with the school day. Without it, she would struggle with sitting still and concentrate. At the same time, it replaced the need to go to physiotherapy every week to build up her strength, thereby saving time and money for the parent. Another example of using speech therapy in typical settings is taking the child for a park play with siblings and neighbourhood kids to practice chatting with kids their own age and learning kid’s language which will be far more critical for inclusion than being in an office with an adult speech pathologist.

These examples show there are other ways of approaching developmental delays than just therapy. Allied health, GPs and early childhood professionals cannot work as isolated experts. Their value lies in building the capacity of families, educators and communities to support children in the real settings where they grow and learn. Our systems must evolve to reflect this.

Foundational supports play a critical role in shaping lifelong outcomes. When provided early, these services reduce developmental gaps, promote inclusion, strengthen family capacity and instruct learning for other young children who haven't got a disability about the diversity of their communities. However, they only create inclusion when clear objectives and strategies align directly with this outcome.

Further to this, and of interest to the Select Committee is the use of early intervention and how that can, if not considered carefully, be over medicalised verses being utilised within a child's natural environment. Early intervention is only as good as the environment and situation by which the intervention is attempting to support. Much attention over the years has been on overuse of therapies with little consideration to adapting this to the children's natural environment. There can be a tendency for the child to be left with lots of therapy and not much progression in how that can play out in real life settings. It cannot be overstated that environments where a child can play, learn and socialise alongside other children provides a strong opportunity for learning in this social context that specialised and congregated environments to children with disability will not provide to the same extent.

Services provided to children should be accessible and supported to build competencies to support all children including children with disability. We have an already established pathway for young children in our communities, such as playgroups, occasional care, family day care, child care centre or long day care, community pre-school, government pre-school, and this should be the focal point for all reform considerations. Thinking typically whilst adapting to support needs is these typical places is the key.

(b) Types of Services Available and Measures to Improve Access

"We were told to go private because the public waitlist was over a year. We couldn't afford $200 a session. So we waited. And he missed out on a year of support." – *Parent from the Northern Rivers*

This quote reflects a common experience of structural inequity—services may exist on paper but are not practically accessible to all families. Below is a mapping of typical early childhood services and supports: Preschool/Kindergartens, Playgroups, Family Day Care, Long Day Care Centres, Maternal and Child Health Services, Allied Health Services, Early Intervention Programs, Parenting Programs, Aboriginal Child and Family Centres, Supported Playgroups, Community Health Services. While a range of services technically exists, in practice, access is uneven and inconsistent—particularly for those in regional and remote areas or from marginalised backgrounds. Families in regional and remote areas, as well as those from culturally and linguistically diverse (CALD), Indigenous, and low-income backgrounds, face significant barriers in accessing timely and affordable support.

Some measures to improve access would be to support family advocacy and capacity building of families. As we have already expressed, families who have high expectations with a strong vision for their child to be included in society, tend to shift mindsets of all those around them, and push for systems to try harder to include the child. Other suggestions are to invest in mobile and outreach centres, to co-locate services (such as health, early education and family support/capacity building), incorporate digital and telehealth options.

(c) Diagnostic Services: Gaps and Barriers

"We had to get a diagnosis to get help, but getting the diagnosis was the hardest part. We were stuck in limbo." – *Parent from the Central Coast*

"We paid $1,800 for a private assessment because we couldn't wait 18 months. Most families in our town can't do that." – *Parent from Broken Hill*

"We waited over 14 months just to get an assessment. By the time my daughter got her autism diagnosis, she had already been expelled from two preschools." – *Parent from the Illawarra region*

The way the system is currently set up, diagnosis is often treated as a pre-condition for services. We do hear from families, the current system places an over-reliance on formal diagnosis as the gateway to support, creating a high-stakes, high-cost bottleneck that delays intervention, isolates families, and restricts inclusive opportunities. Children without formal diagnosis risk being excluded from early supports.

Despite widespread recognition of the importance of early identification and support for developmental delay or disability, access to diagnostic services—especially in regional and marginalised communities—remains deeply inequitable.

Another apprehension we have is allied health professionals operating in isolation. Many therapists work in clinical silos, disconnected from mainstream settings such as preschools, childcare settings and families lived realities. This limits the generalisation of skills to everyday environments where children live, learn and play.

Recommendations:

- Establish diagnostic hubs across NSW with multidisciplinary teams
- Subsidise private assessments where public services are unavailable
- Provide immediate post-assessment supports—whether NDIS-funded or not
- Ensure allied health professionals do not work in silos and collaborate with those in the child's natural environments such as home, preschool, playgroups etc.

(d) Gaps in Accessing Early Childhood Intervention (ECI) and Impacts

"Because my son didn't have a diagnosis, he wasn't 'eligible' for help. But that's exactly when he needed it most—before school started." – *Parent from South West Sydney*

"I had to quit my job to manage everything. The stress almost broke our family." – *Parent from Tamworth*

Access to Early Childhood Intervention (ECI) in Australia is marked by systemic inequity. The current system overwhelmingly depends on a family's ability to secure a diagnosis before getting any access to supports — yet many children with emerging developmental concerns, delays, or vulnerabilities are ineligible for support without a formal diagnosis. Many children will not receive a diagnosis until after the early years window has closed. This leaves a growing number of children without access to the help they need at the most critical developmental stage. These gaps have long-term impacts on children's development, family mental health, and school readiness. Delays in the early years lead to more expensive and intensive support needs later.

Families with or without NDIS plans are often left with no services at all, which creates parental stress and can have workforce impacts leading to financial strain and mental health challenges. The system relies too heavily on families' ability to advocate, fund, and coordinate complex supports. All children, whether they have NDIS or not, need access to supports so they can live, learn and play in typical settings. We recommend a shift to capacity building to support early childcare educators, health nurses, playgroup facilitators and general practitioners to offer early strategies, whether the child has a diagnosis or not. We would also encourage informal options like parenting groups, developmental play in typical settings, and peer support.

(e) Opportunities for Cross-Sector Collaboration

"We had five different people working with us, and none of them spoke to each other. I was the one holding it all together." – *Parent from the Blue Mountains*

Families often describe their experience navigating services as a “full-time job.” Collaboration between health, education, early childhood, and community services is rare and inconsistent. We would recommend a dedicated strategy geared towards bringing the key strategic players together with clear outcomes that work across those touch points, including advocacy organisations. Providing coordinated and local access points can help families navigate without being so overwhelmed. Resources developed to support this and utilized across the sectors. A clear objective of this strategy applying its efforts towards typical places across the community will be key to this.

(f) Best Practice Models Outside NSW

Families in NSW deserve a system that is proactive, not crisis-driven. Below are a few initiatives in other states. We place a caveat on these in not being involved in them directly to know how effective they are but encourage the Select Committee to explore their efficacy more deeply to see if they could be successful in NSW.

1. Victoria’s Integrated Early Childhood Hubs

Victoria is expanding its network of Integrated Early Childhood Hubs (IECHs) to provide holistic support for children and families, particularly in disadvantaged communities. These hubs combine early learning, health services, family support, and community engagement in a single location. The aim is to improve outcomes in early childhood development by offering accessible, wraparound services. Research by Social Ventures Australia has highlighted the importance of strategic placement and effective service delivery to maximize impact.

2. Tasmania’s Birth to Five Navigators

In Tasmania, the Birth to Five Navigators program supports families with children aged 0–5 by connecting them to appropriate services and resources. This initiative is part of a broader effort to enhance early childhood education and care, aiming to improve outcomes in areas such as curriculum, assessment, and pedagogy. The program includes training sessions for educators and support staff to strengthen their capacity in early years education.

3. Queensland’s Growing Early Minds Partnership with First Nations Communities

Queensland's Growing Early Minds initiative focuses on improving early childhood outcomes for First Nations children by partnering with local communities. The program emphasizes culturally appropriate early learning and development, aiming to close the educational gap between First Nations and non-Indigenous children. This approach is aligned with the broader strategy outlined in "Our Way," a generational plan developed in collaboration with Aboriginal and Torres Strait Islander communities to ensure children grow up safe and cared for in family, community, and culture.

(g) Workforce Issues

"Our OT left and there was no one else for 150 km. We still haven't found a replacement." – *Parent from the Riverina*

"I feel like we're being told to wait until there's a workforce—our kids don't have time to wait." – *Parent from Armidale*

The availability, sustainability, and appropriateness of the early childhood workforce—across education, health, and disability sectors—remain a fundamental barrier to equitable access and quality support. The system is under strain from high turnover, regional shortages, professional burnout, and a model of care that too often relies on siloed, medicalised interventions instead of holistic, family- and setting-centred approaches.

It needs to be acknowledged that sometimes, the early childhood educator, GP or allied health professional can actually be the barrier to a child's progression, with too much of a medicalised therapy approach and working in silos. It is vital that early childhood educators, GP's and allied health professionals (such as Speech Pathologists and Occupational Therapists) have the competency to know the early signs of developmental delay and strategies of support in typical settings.

(h) Implementation of the NDIS Review and Disability Royal Commission

We echo these recommendations below be implemented urgently:

NDIS Review Recommendations

Recommendation 1: Invest in Foundational Supports
Develop a unified system of support for people with disability, including early intervention supports for children and their families. NDIS Review+1NDIS Review+1
Recommendation 6: Create a Continuum of Support for Children Under the Age of 9
Establish a continuum of support for children under the age of 9 and their families, ensuring early intervention is available regardless of NDIS eligibility. NDIS Review
Recommendation 14: Improve Access to Supports for First Nations Participants
Improve access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements. disability.royalcommission.gov.au+3NDIS Review+3VicGov Connect+3
Recommendation 22: Embed a Highly Skilled, Person-Centred, Disability-Aware Culture Across All Disability Agencies and Governments
Embed a highly skilled, person-centred, disability-aware culture across all disability agencies and governments. NDIS Review

Disability Royal Commission Recommendations

Inclusive Education
Recommendation 7.1: Implement a national strategy to ensure that all children with disability have access to quality, inclusive education.
Recommendation 7.2: Establish clear accountability mechanisms to monitor and report on the inclusion of students with disability in mainstream education settings.
Recommendation 7.3: Provide targeted funding to schools to support the inclusion of students with disability, including professional development for educators.disability.royalcommission.gov.au

Early Intervention and Support
Recommendation 7.4: Develop a national framework for early intervention services that are accessible to all children with disability and their families.
Recommendation 7.5: Ensure that early childhood education and care services are equipped to support children with disability through training and resources.

Criminal Justice System
Recommendation 8.1: Implement strategies to prevent the over-representation of children and young people with disability in the criminal justice system.disability.royalcommission.gov.au
Recommendation 8.2: Provide training for police and justice personnel on the needs of young people with disability.
Recommendation 8.3: Develop diversion programs that are accessible to young people with disability.
These recommendations aim to create a more inclusive and supportive environment for children and young people with disability, ensuring they have equal opportunities to participate in education and community life.

(i) Other Related Matters – Capacity Building for the Family, Capacity Building for the Community, and the Need for Disability Advocacy and Representative Organisations

We urge the Committee to ensure families' lived experiences are front and centre in decision-making. Systems reform must be family-centred, trauma-informed and rights-based.

Capacity Building for the Family

The current system places an onus on families to be fighters, fundraisers, and case managers just to access the basics for their child with disability. Every child deserves timely, inclusive, and accessible supports—without needing a diagnosis or a battle.

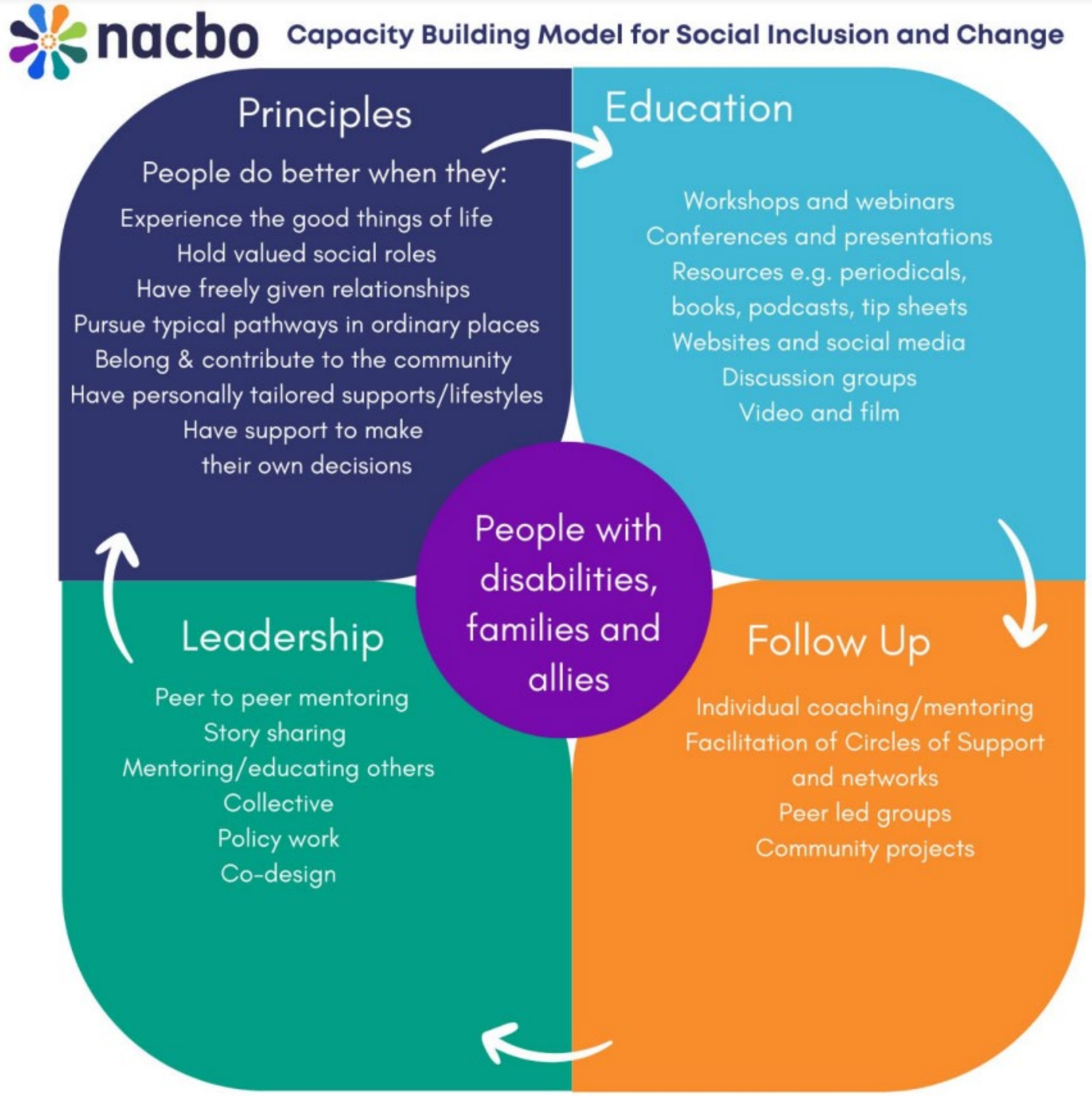
Our family has benefitted significantly from capacity building and leadership development - our child is on an inclusive life path (we have had to fight for it) but this is very much due to the capacity building in us as parents and our clear understanding of holding an inclusive life vision. It has helped us hold high expectations and resist wrong offerings that lead to segregation. Our child is connected and holds valued roles in their community, has a Microenterprise and we have benefitted from customised employment training. – *Parent from regional NSW*

For families, this might look like better information, peer support, parenting groups and workshops, education and training (i.e. online or in-person parenting courses). This would have a focus on:
- disability and rights awareness
- building skills in decision-support
- enabling independence and participation
- family leadership and development.

These supports would be focused on helping families, carers and kin of a person with disability to build their own knowledge and skills so they can support the person with disability to exercise choice and control and fully participate."

Family Advocacy, is a member of the National Alliance of Capacity Building Organisations (NACBO), an alliance of not-for profit, values-based, capacity building organisations that span across Australia with a combined experience of 85 years. We hold a shared vision and belief that all people with disability are valued citizens and should be supported to contribute to society through all facets of social and economic participation.

NACBO believes having access to the “Good things in life” must be a primary consideration of funded support and services for people with disability. These are the universal things that all humans value, enjoy, require and strive to achieve. These aspects of life give richness to who we are, who we are connected to and how we live our life. Below is an illustration of the NACBO Capacity Building Model for Social Inclusion and Change.



In our view, capacity building to be effective must be:

- Over the life course
- Mirrored on the typical experiences and roles that most Australians enjoy
- Rich in content, geared to high expectations
- Targeted at leadership development
- Led by lived experience
- Independent of the direct support sector

The critical aspect of person-centredness is where the person with disability, often with the supports of families and allies, drive the change required whereby supports are designed to suit the person rather than to suit the service or system. To achieve this, any capacity building needs to be content rich to inform decisions of what supports and services will add value to the person's life versus simply meeting a lower level need, for example, a roof over someone's head such as in the group home context.

There must also be an acknowledgement that many people with developmental disability, particularly people with complex disability, require extensive support from families and allies to see this through. Family, in whatever shape or form it may have, has a critical and vital role in the care and support of any individual. For many people with disability, this reality can be lifelong.

Over many years of undertaking this work, with many successful outcomes for people with disability, NACBO understands the approach needed to shift societal expectations, including the expectations of families. For example, families are often told by professionals, experts, the disability sector and others that their child would be better placed in a program and alongside others with disability. They are also often told that work, living in a home of their own, accessing typical places in community as others do is unrealistic for their loved one. Many messages are also reinforced around the safety of the person and others as justification for this attitude/belief. This leaves many families in a predicament that this is the best and often the only option afforded to their loved one with disability.

For many families that encounter our capacity building work, there is a need to address this sharply as a means to cut through the limitations of disability specific thinking. A potent means to achieve this has been to harness the 'lived experience' that highlights the way forward. Investment in family leaders therefore has been a primary strategy for NACBO organisations and for some for nearly 35 years. Families learn and respond to the experiences of other families and also provide a sense of confidence in taking the steps away from institutionalised practices. Also, for many families there is a stricken mistrust of the experts and services that they have been utilising.

It's important to mention that the 'lived experience' of families through the work of the NABCO organisations is very intentional. People with disability and their families that have secured good outcomes that highlight the aspects of the capacity building that we are attempting to instil and the necessary markers of the development and use of family leaders. In this respect, capacity building and peer support structures, needs to be rich in understanding around the content, successful theories of change and strategies that invite action into the lives of people with disability. In many respects, it constitutes a social change endeavour.

NACBO also recognise that there is no neat timeline or sequence of events and supports that equips people with disability and their families to shift their expectations. The complexities of the family unit, their values and the many barriers faced within mainstream and community spaces can inhibit this. We understand that there isn't a silver bullet or just one approach to shifting many years of institutionalised thinking that captures society's thinking and responses to people with disability.

To address this in any meaningful way, investment in capacity building needs to occur. Importantly, this focus must uphold the principles of the good life. People, their families and allies must have access to a suite of capacity building strategies to shift the reliance on historical thinking and challenge approaches, call out practices that lead to poor, and at times, dangerous outcomes and provide the platform for creating valued social roles that lead to deep connections within the community.

UNSW and Flinders University conducted an evaluation of NACBO projects, which drew conclusions about the impact of the NACBO values-based capacity building model and activities on enabling social and economic contribution and leadership of people with disability and their families. We invite the Select Committee to take a close look at the NACBO final evaluation report which outlines the principles of effective capacity building and describes how NACBO approaches this process. It covers the NACBO capacity building model, the outcomes and impact on people's lives and lessons for future capacity building initiatives, implementation and policies.

Additionally, it identifies key elements of effective capacity-building that should be considered for future government policy and organisational practices. These include:

1. **"Principles.** The principles and rights to authentic inclusion in the community are embedded in the processes and life outcomes of capacity-building.
2. **Person at the centre.** Capacity-building prioritises the person's motivations and preferences, understanding their changing situation, interests and goals.
3. **Across the life course.** Capacity-building is a lifelong process. It takes time to address new goals and overcome challenges that change over a lifetime. People choose from a range of capacity-building options according to what is most useful at the time.
4. **Holistic and interconnected.** Capacity-building involves the person and their networks of support (families, allies and friends) to lead change according to the person's preferences. Information and resources are linked to activity that builds high expectations, follow up, leadership opportunities and networks of peers.
5. **Leadership.** Investing in intentional leadership of people with disability and families can have an impact on personal and community development, as well as peer learning and sustainability. Effective leadership can also drive positive change in systems and policies.
6. **Long term outcomes.** Achieving success in capacity-building requires taking incremental steps towards long-term outcomes. Maintaining ongoing connections with capacity-building organisations and networks is important to meet high expectations" (p.V).

People keep people safe and personal relationships are key
"Governments, funding and services cannot keep people safe on their own, nor can they replace the richness of typical, freely given, relationships. People keep people safe and personal relationships are the key. I encourage families and support workers alike to continue finding ways to initiate, embed and sustain freely given relationships for people with disability – in family, with friends and neighbours, in the broader community and as individuals as these relationships sustain us all". –

Peer to peer supports
"Peer to peer supports from a family leader has benefited me personally many times in helping my loved one be better at decision making, being independent and participating in society. Recently connected with a group of parents about Microboards and had specific problem-solving conversations with other families further along the path than us. A Microboard will enshrine supported decision making in our child's life even if we suddenly weren't here. It also builds a team around a person."

"The evaluation found that the principled capacity-building processes used by NACBO, directly and indirectly, changed mindsets and outcomes for people with disability in regard to authentic inclusion. It also raised expectations and changed lives by empowering people with disability and families. People with disability experienced positive outcomes across a broad range of life domains. Outcomes in one area of life were often connected to outcomes in other areas, creating a more holistic impact and good life in the community" (p.IV)

The report also emphasised that uncertainty regarding funding and the reliance of short-term grants, hinders the impact of NACBO's capacity building efforts. This limitation affects NACBO's capacity to support individuals with a disability in influencing systems change. More importantly, it prevents NACBO from empowering people with disability to pursue meaningful roles and contribute to the social and economic fabric of their communities. Therefore, we recommend the investment in the NACBO model of capacity building with a long-term focus, such as 10 years, so families can have the skills, knowledge and confidence to support their family member with disability to access the good things of life (see diagram below).

As mentioned in the introduction, Family Advocacy has an initiative, Resourcing Inclusive Communities, which assists to access The Good Things of Life by providing:

- **Information:** Accessible and reliable information about the importance of holding a clear Vision for an inclusive life, thinking ordinary and typical, being included in mainstream, high expectations in the long term, good collaboration, the importance of having freely given supports as a safeguard, disability rights.

- **Peer Support Networks:** Peer support groups or online communities where families can share experiences, advice, and resources. These can also be a source of emotional support and solidarity. Resourcing Inclusive Communities, runs peer to peer networks which are very effective in providing information but also building the capacity of the family member. In addition, these networks also provide the opportunities for family leadership development. These are done through face to face and online formats.
- **Training and Education:** Offering workshops, courses, and training for families on the importance of having a Vision for their loved one with disability, how to access the good things of life (see diagram on page 15) through having socially valued roles, disability rights, supported decision making. These can help families build their own capacity to support their loved ones.
- **Family leadership development:** Our core focus is to empower families to take on leadership roles, and drive positive changes within their communities and the systems they interact with by analysing good inclusion and seeking to address barriers whilst educating others through their actions. In many cases, family leadership is undertaken when their family member with disability experiences limitations in cognitive understanding, has limited decision making competencies and may not be able to express their own interests, needs or rights in a multitude of situations. By fostering family leadership, our family members can better navigate complex systems, influence policies, and create more inclusive, supportive environments for people with disabilities.

Capacity Building for the Community

The aim of community capacity building is about building the capability of community and non-government organisations to be disability- inclusive. One of our concerns here is that Foundational Supports will fund segregated, congregated settings going back to the old days and thereby ‘othering’ people with disability. The Disability Royal Commission Final report made a clear connection with segregation and the violence, abuse, neglect and exploitation of people with disability. To ensure this does not happen and people with disability are genuinely part of their community, Foundational supports must be genuinely person-centred.

- **Starting with one person:** The principle of starting "one person at a time" acknowledges that lasting change often begins on a smaller scale. By focusing on individual needs, it is easier to build trust, tailor supports, and ensure that interventions are impactful. When one person is empowered to lead, advocate, or connect with others, they can act as a catalyst for further change. Empowering individuals to exercise their choice and control leads to a broader impact with a ripple effect. As people with disability and their family member gain confidence and skills, they can inspire others, spread knowledge, and influence community attitudes. This leads to a more inclusive society where others with disabilities can benefit from the same supports.
- **Building Family Leadership and Strong Family Support Networks:** By being person-centred, families develop greater capacity to support their loved ones effectively, leading to improved outcomes for the person with disability. In becoming advocates and family peer leaders, they ensure better community and service outcomes. By starting with families, we create a supportive environment that enables individuals with disability to thrive. Advocacy undertaken by families is the most significant and plentiful form of advocacy that exists, as families are advocating for their family member, in some form or another, sometimes from birth. Children cannot advocate for themselves and nor can many people with cognitive impairment without trusted support.
- **Building Social Networks:** Communities are strengthened when people with disabilities are supported to form relationships and connections. This can include connecting people with similar experiences or interests, as well as integrating individuals into broader social, educational, and recreational activities.
- **Disability Awareness and Inclusion Training:** Training programs for community leaders, employers, and the public to promote disability awareness, reduce stigma, and encourage inclusive attitudes. This could include workshops on inclusive hiring practices, disability etiquette, addressing unconscious bias/negative assumptions/ prejudice and creating welcoming environments.

- **Inclusive Recreation and Leisure Programs:** Communities should offer recreation and leisure options that cater to people with different disabilities, ensuring they are available in typical community sports, arts, and social activities.
- **Employment Opportunities:** A system focussed on increasing employment opportunities for people with disabilities, including through adopting the Customised Employment model.
- **Community-Based Mental Health Services:** Accessible mental health services that cater to the unique needs of people with disabilities, ensuring emotional and psychological well-being is integrated into the broader community.
- **Cultural and Religious Inclusion:** Services that ensure people with disabilities are able to participate in cultural, spiritual, and religious activities within their community, fostering a sense of belonging and acceptance.
- **Universal Design and Accessibility:** Investing in accessible infrastructure such as ramps, elevators, wide doorways, and accessible public spaces. This includes not just physical spaces but also websites and digital platforms that are accessible to people with sensory impairments for example, screen readers, captioning, etc.
  - By focusing on one person at a time and fostering community capacity building, foundational supports should ensure that individuals with disabilities are empowered to be active participants and included in their communities. They should not support and perpetuate segregation and congregation. This approach builds stronger families, more inclusive communities, and creates a ripple effect of positive change, ultimately leading to a society where everyone, regardless of ability, has the opportunity to thrive.

Specific outcomes for people with disability and their families, that ought to be measured to demonstrate accountability over time

- **Empowerment and Independence:** Measuring the degree to which people with disabilities can make independent choices about their lives for example, in education, employment, living arrangements.
- **Family Satisfaction and Support:** Tracking the satisfaction and well-being of families through surveys, support group participation, and outcomes of training or peer support.
- **Community Participation:** Measuring the level of community engagement by people with disabilities, such as participation in local events, volunteering, or employment. This can also include assessing the number of community programs that are truly inclusive of individuals with disabilities.
- **Educational Outcomes:** Tracking the educational achievements and opportunities available to people with disabilities, such as the inclusion of students with disabilities in mainstream schools, Year 12 completion, attendance rates, suspension rates and post-secondary education opportunities.
- **Employment Rates:** Tracking employment outcomes for people with disabilities in typical workplace settings, including the number of individuals employed in typical workplace settings, types of jobs held, and whether workplaces are inclusive and accessible.
- **Access to Services and Resources:** Measuring how effectively individuals with disabilities and their families are accessing available support services for example, mainstream education, early childhood centres, health care, mental health, legal aid, etc. and whether there are any barriers to service access.
- **Psychological and Emotional Well-being:** Assessing the mental health and emotional well-being of both individuals with disabilities and their families, which might include indicators like self-esteem, stress levels, or perceived quality of life.
- **Community inclusion:** Measure community inclusion for example, how accessible in physical/sensory/cognitive etc are community spaces like libraries, pools, shopping centres, beach, parks. This could be linked to the local Council's Disability Inclusion Action Plans.

Specific Focus Areas for Families, Carers, and Kin:

- **Knowledge and Skills in Disability Awareness:** Measuring the extent to which families and carers feel informed and capable of supporting their loved one's needs for example, knowledge of the importance of having a strong Vision for an inclusive life, the importance of having socially valued roles to mitigate against devaluation, disability rights, and decision-making.
- **Family Leadership and Development:** Tracking family involvement in leadership roles or in advocating for change, as well as their capacity to support the individual with disabilities in exercising choice and control.
- **Access to Peer Support and Resources:** Measuring the availability and effectiveness of peer support networks and educational resources aimed at empowering families to provide better care and support for their loved ones.

By focusing on these outcomes and supports, communities, service providers, and governments can better design and implement programs that truly make a positive impact on the lives of people with disabilities and those who care for them.

The Need for Disability Advocacy and Representative Organisations

> "Mainstream Australia sees Inclusion as someone else's problem. (The NDIS is over there and will take care of it) Mainstream services, organisations from the top down (governance) and people at the participation level all need education and accountability to include people. Legislation to make sure there is a consequence if they don't. I have lived in a time when there was some funding for people with disability, providing them with some support and when lots of other people with milder disability had nothing. I fear we will return to those days, as people with mild ID generally aren't considered 'eligible' for anything. The usual IQ tests don't test for poor judgement, poor decision making, lack of friendships, lack of critical thinking, inability to think quickly on your feet, poor financial management and planning, poor understand of the importance of seeing a Dentist and Dr regularly etc. I am not confident that it is these things that will be available as part of Foundational Supports, but to me these things are the foundations of my son's life." – *Parent from Coffs Harbour*

Evidence from advocacy organisations show that demand for independent advocacy substantially increased with the introduction of the NDIS. People with disability needed assistance to access the Scheme, stay in the Scheme and appeal decisions made about their NDIS plans and individual funding. We foresee the same will be the case when Foundational Supports are rolled out, where advocacy will be required to rectify individual and systemic issues caused by unintended consequences or the lack of clarity around roles and responsibilities, as well as to understand the scheme and what it could do to bring about a good life.

Further to this, it is absolutely critical that advocacy be independent from general foundational supports. The NDIS Review proposed that individual advocacy could be a foundational support, potentially shifting how individual advocacy is funded. In January 2024, National Cabinet announced that $11.6 million has been invested into a Foundational Supports Strategy. This followed an agreement brokered in December 2023 that state and territory governments will fund foundational supports in a 50-50 split. In addition, the Federal Government's response to the Disability Royal Commission in July 2024 announced a new advocacy program, without detail, about how funding would be distributed, how it would relate to the Foundational Supports Strategy, or which kinds of advocacy would be included. Without any clarity around this, it is difficult to provide an informed opinion.

Broadly speaking, advocacy should be free, and impartial (free from conflict of interest), readily available and accessible to all people with disability. The need to advocate with impartiality, free of conflicts of interest, has been an important principle and value driving the work of the disability advocacy sector. Advocates need to be on the side of the person with disability only, so that the interests of governments, service providers or carers and family members do not take precedence or obscure the rights, preferences and wellbeing of the individual.

It is worth noting here, individual advocacy will always be needed and cannot be replaced by self-advocacy. Individual advocacy is not a replacement for building self-advocacy skills but rather a support that needs to exist alongside. One type of support does not replicate the other; both individual advocacy and self-advocacy programs can help a person with disability build the skills to self-advocate, however there are matters including NDIS appeals that require specialist knowledge of professional advocates and are rarely able to be effectively navigated by a person with disability on their own. As stated in the introduction, the Family Advocacy Model of Advocacy provides individual advocacy supports to families to help them advocate for the rights and interests of their loved ones with disabilities to navigate barriers/issues faced in areas such as NDIS, guardianship, education, or employment rights.

Conclusion

We are at a pivotal moment in disability policy reform—a moment that demands more than structural change; it calls for a recalibration of purpose. Families are navigating a system that too often delays support, over-medicalises childhood, and places undue burden on those with the least capacity to carry it. The stories shared throughout this submission illustrate a pattern of missed opportunities and avoidable harm, resulting not from lack of effort, but from a fragmented, diagnosis-driven, and inaccessible model of early intervention and foundational support.

As governments move forward with implementing the NDIS Review and the Disability Royal Commission's recommendations, the Select Committee has a critical role to play in shaping reform that is equitable, timely, and grounded in inclusion. It is essential that any new foundational support system prioritises connection, context, and culture—supporting children in their everyday environments, and investing in families and communities as key partners in the work of inclusion.

We urge the NSW Government to shift away from reactive, diagnosis-gated systems and toward proactive, universal approaches that support *all* children early, in typical settings, and with clarity of purpose. Foundational supports must be designed to unlock access—not gatekeep it—and ensure that no child is excluded based on postcode, diagnosis, or the capacity of their parents to advocate.

This reform must begin with trust. Trust that is built through transparency, communication, and visible action that centres the dignity, rights, and potential of every child. We encourage the Committee to keep this principle at the core of its recommendations—and to act boldly to ensure that no child is left behind.