

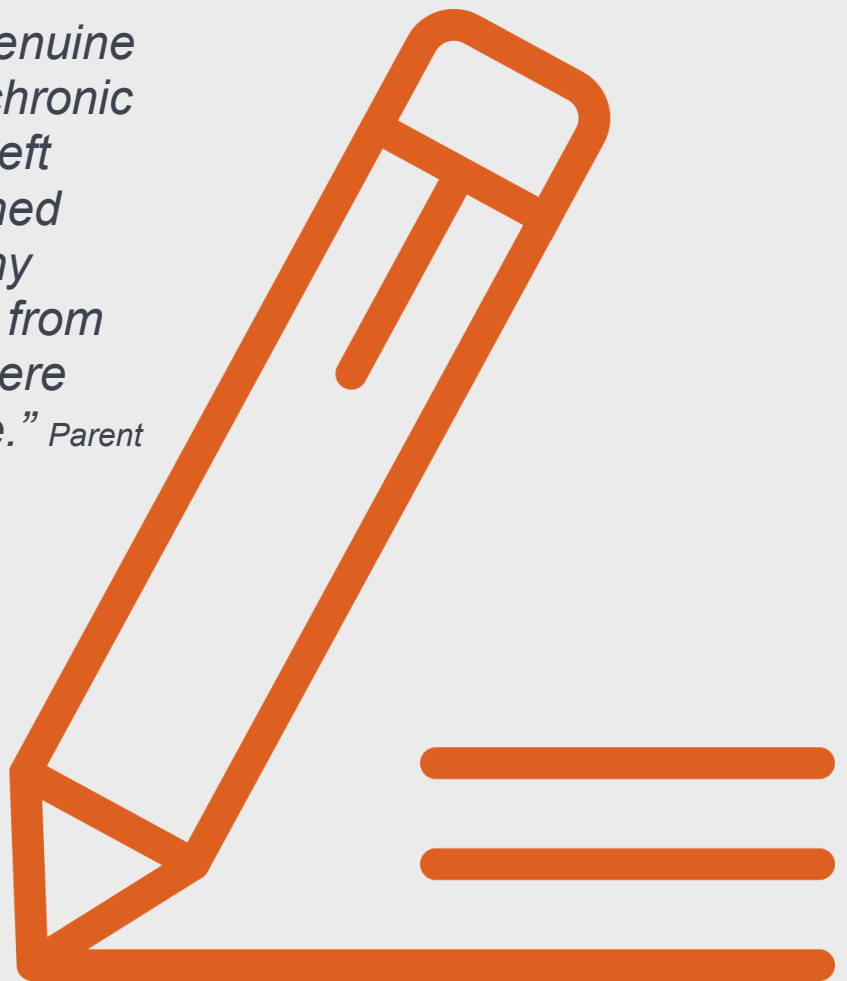
Foundational Supports

CYDA's response to DSS consultation papers:

1. Supports for children with developmental disability, and
2. General supports

“This is going to take genuine commitment to fix the chronic underfunding that has left people feeling abandoned and what drove so many people to seek support from the NDIS -- because there has been nowhere else.” Parent of young person with disability

December 2024



Children and Young People
with Disability Australia



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A note on terminology:

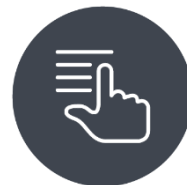
The disability community has largely recognised and used inclusive language and terminology for decades. In this submission, Children and Young People with Disability Australia (CYDA) uses person-first language, e.g., person with disability. However, CYDA recognises many people with disability choose to use identity-first language, e.g., disabled person.



Content note: Discussion of systemic neglect, discrimination and mistrust.

Acknowledgements:

Children and Young People with Disability Australia 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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Summary of recommendations

As the representative organisation for children and young people with disability across Australia, CYDA welcomes the opportunity to make a submission to the consultation on Foundational Supports. Children and young people under 25 make up a significant 61% of all NDIS participants, forming the majority of those supported by the Scheme¹. Yet they continue to face significant marginalisation due to age-related factors, legal constraints and limited agency. Insights from the CYDA community highlight the urgency for the provision of quality Foundational Supports that are specifically aligned to their needs.

We strongly urge the Government to adopt the **six recommendations** outlined in this submission.

Key Recommendation 1: Redesign the approach to policy and program reform for Foundational Supports.

- 1.1 Reframe approaches to target systemic barriers, not just people with disability.
- 1.2 Foreground lived expertise, create co-design communities of practice.
- 1.3 Implement a Youth-directed Interactive Digital Storytelling Platform

Key Recommendation 2: Work with Disability Representative Organisations to co-design short, medium and long-term funding solutions for Foundational Supports.

- 2.1 Commence transition from the current federally funded Information Linkages and Capacity (ILC) program to Foundational Supports within the next three months.
- 2.2 Fund a discovery mapping project that identifies existing services and supports that could be categorised as Foundational Supports.
- 2.3 Innovate by establishing a Grassroots Connection Model (See Appendix 1).

Recommendation 3: Guarantee children with disability remain in the National Disability Insurance Scheme until viable and effective early childhood approaches are available for all.

Quality Early Childhood Foundational Supports must be at the core of this commitment. CYDA therefore calls on the government to:

- 3.1 Build an inclusive, universal, and high-quality Early Childhood Education and Care (ECEC) system that sits alongside NDIS's Early Childhood Intervention

¹ NDIS Quarterly 2024-25 Q1_ Supplement Report Table E.24 Participant profile per quarter by age group – National. Available at: <https://www.ndis.gov.au/about-us/publications/quarterly-reports>.

program to cater to children with disability in partnership with the disability sector.

- 3.2 Coordinate the commissioning of inclusion support in ECEC and Foundational Supports to streamline responsibilities and funding, improving outcomes for children.
- 3.3 Strengthen partnerships and information sharing between the NDIS and the ECEC sector to provide consistent and clear support within local communities.
- 3.4 Develop clear pathways to services and processes to ensure no child falls through the cracks (Refer Recommendation 4 for suggested ways to achieve this).

Recommendation 4: Provide Foundational Supports that leverage existing success and address service gaps.

The mapping exercise proposed in Recommendation 2 will identify successful programs, supports, and services requiring additional resources to meet community demand.

Key gaps include:

- Peer group and decision-making supports for people with intellectual disability.
- Support and service delivery in regional and remote areas, including access to periodic and intensive services. To better support children and families in rural and remote communities, existing mobile children's services should be strengthened and expanded under Foundational Supports².
- There have been minimal supports for children and young people with disability who are dually engaged in state-based systems, including child protection. The design of Foundational Supports must take into account the complexity of these intersecting systems.

Recommendation 5: Implement a joined-up evidence-based youth practice framework to support young people aged 9-25.

The Framework should:

- be co-designed in a community of practice that centres the lived experience of young people aged 9-25.
- be delivered through a joined-up youth specific framework that ensures service improvement and consistency across gender, geography and other intersecting demographics.
- encompass workforce training and clear accountabilities to enable continuity of support across systems such as education, health and child protection.

² Examples of existing mobile children's services include [Uniting Care Queensland Programs for Outback Communities](#), [Puggles Children's Services Van](#), [Remote and Isolated Children's Exercise](#) and [Isolated Childrens Parents' Association](#).

- be informed by evidence-based practice, intersecting with the Australian Government's Youth Strategy and developed with DROs to ensure its suitability.

Recommendation 6: Provide funding for co-designed intersectional youth programs for young people aged 9-25.

In addition to ensuring that all new Foundational Supports for the 9-25 cohort are co-designed, intersectional and embedded, CYDA calls on the government to specifically fund:

- 6.1** A co-designed *Creating Access for Young People with Disability Under 16 project* that examines how young people with disability under 16 will be able to access information about supports and build their sense of community in the absence of social media and provides specific channels of support for this cohort.
- 6.2** A *Young People with Disability Under 16 Online Hub*, a streamlined one-stop-shop website, digital platform or app that provides access information on specific supports, peer groups and resources that are tailored to young people under 16.



Introduction and key recommendations

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has extensive national networks of young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability in Australia will fully exercise their rights, realise their aspirations and thrive in all communities. We do this by:

- Raising community attitudes and expectations
- Championing initiatives that promote the best start in the early years for children with disability, and their families and caregivers
- Leading social change to transform education systems to be inclusive at all points across life stages
- Advocating for systems that facilitate successful life transitions to adulthood
- Leading innovative initiatives to ensure the sustainability and impact of the organisation and the broader sector.

CYDA welcomes the opportunity to address both consultation papers from the Department of Social Services (DSS) Foundational Supports consultation.

This submission uses data from the following sources:

1. CYDA's Foundational Supports Survey from 9 to 31 October 2024, with 258 people responding to questions about Foundational Supports. See **Appendix 3** for a full report on survey findings. In this submission, quotes from this source will be referred to as *Survey*.
2. CYDA and The Social Deck's Consultation on Foundation Supports held on Tuesday 26 November 2024, with 6 young people with disability under 25 years of age attending and providing their views on Foundational Supports. In this submission, data from this source will be referred to as *FS Consultation*.
3. Data collected in 2023 as part of a series of *Reimagining NDIS* consultations, which informed the NDIS Review Final Report, *Working together to deliver the NDIS Independent Review into the National Disability Insurance Scheme* (used with permission)³. Although this data was collected prior to the current discussion about Foundational Supports, many topics discussed are relevant. In this submission, quotes from this source will be referred to as *Consultation*.

³ <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis>

Direct quotes drawn from the data collected are indented from main text, italicised and in inverted commas, anonymised (or pseudonyms used) to protect privacy and minimally modified for brevity and/or clarity.

Submission structure

Due to overlap in questions across consultation papers and given the community we represent includes children and young people up to the age of 25 with disability and their parents/caregivers, we have chosen to structure our response as follows.

We first provide two key recommendations that apply to both consultation papers. We then move to address the consultation papers separately in two Parts.

Part 1 will address the consultation on children with developmental delay and we will refer to children (aged 0-9) and their families, parents and caregivers.

For context, there are currently⁴ 159,326 children under 9 years old with an NDIS plan. Additionally, 80% of the 1200 eligibility reassessments NDIS are currently undertaking each week are focused on 5-9 year old children. This has resulted in 48% of those reassessed being removed from the scheme (equating to 600 people per week), the vast majority of whom are under 9 years old^{5 6}.

Part 2 will address the consultation on general supports and we will refer predominantly to young people aged 9-25, and their families, parents and caregivers.

Before moving to discuss the two consultation papers, we provide two key recommendations that frame both discussions.

Key Recommendation 1: Redesign the approach to policy and program reform for Foundational Supports.

CYDA calls on the government to redesign the approach to policy and program reform for Foundational Supports.

Respondents to CYDA's Foundational Support Survey were overwhelmingly worried and confused about the introduction of Foundational Supports and believe they will be worse off in the short to medium term. Survey respondents also echoed a general lack of trust in government processes, voiced in several recent consultations across the disability community and sector, regarding recent changes to the NDIS and disability related programs and legislation⁷.

⁴ As of 30 September 2024. See link to NDIS Quarterly Report for more information: <https://www.ndis.gov.au/about-us/publications/quarterly-reports>.

⁵ 2024-25 Supplementary budget estimates, 6th November 2024, Social Services Portfolio Hansard. Available at: https://www.aph.gov.au/Parliamentary_Business/Senate_estimates/ca/2024-25_Supplementary_budget_estimates.

⁶ <https://teamdsc.com.au/resources/ndis-act-explained:-eligibility-reassessments>

⁷ Consultations where participants from the disability community and sector expressed lack of trust in government processes related to the NDIS include: DSS and Social Deck Consultation "What we heard about Foundational Supports", 29 November 2024; consultations for the Final Report of the Independent Review of the NDIS 2023; and consultations for CYDA's Reimagining a Better NDIS For Children and Young People Report 2023.

“I don't trust gov to actually listen and do what pwd and families say is really useful. I don't trust organisations paid to provide foundational supports to actually employ decent ppl or treat and train their staff properly and pwd will suffer.” (Parent/caregiver of a child or young person with disability, Survey).

“I'm scared that the NDIS is going to kick myself and my child off the scheme for "not being disabled enough", even though sometimes we struggle with the most basic things, and they are going to ask us to seek out these mysterious foundational supports which will just be pretty websites and fact sheets and not actual help.” (Has disability and is parent/caregiver of a child with disability, Survey).

“I feel I am being blindsided by Government after so many negative changes to the NDIS recently.” (Parent/caregiver of a child or young person with disability, Survey).

In order to re-build this trust, government needs to:

1.1 Reframe approaches to target systemic barriers, not just people with disability.

Both Foundational Supports consultation papers emphasise upskilling people with disability, who are often already highly skilled at navigating an ableist world. To better enable inclusion, more focus should be placed on upskilling the community around children and young people with disability. Confronting and removing the social, cultural and systemic barriers that people with disability face each day is required to achieve the goals stated in the consultation papers. Young people in CYDA and The Social Deck's FS Consultation highlighted the importance of government funding to ensure capacity building for businesses and services through disability training and awareness, as well as quality and safety assurance through developing a Disability Tick (similar to Rainbow Tick). An example of best practice in this submission is Scenario 2 of our Grassroots Connection Model, where young people with lived experience are training employers to be more inclusive (see **Appendix 2**).

1.2 Foreground lived expertise, create co-design communities of practice.

CYDA urges the government to avoid standard policy making processes and communication. Evidence demonstrates that children and young people and their families are feeling let down by the recent NDIS consultation process, and CYDA is concerned that it may impact the current consultations on Foundational Supports^{8 9}. In

⁸ DROs (2024) Joint Submission on the Consultation on Draft Lists of NDIS Supports. Available at: <https://cyda.org.au/joint-submission-on-the-consultation-on-draft-lists-of-ndis-supports/>.

⁹ CYDA (2024) Submission to Draft Lists of NDIS Supports. Available at: <https://cyda.org.au/cydas-submission-to-the-draft-lists-of-ndis-supports/>.

keeping with our obligations as signatories to the UN Convention on the Rights of Persons with Disabilities and in particular Article F¹⁰, impacted communities need to be at the centre of policy processes, and decision making needs to be collaborative and shared.

Children and young people with disability and their families want to design solutions to policy problems, and are already taking actions that solve policy problems. Examples include:

- The Australian Government's Office for Youth's Employment Youth Advisory Group¹¹ which includes disability representation; and
- CYDA's *LivedX Policy Papers*¹², a series of policy papers and recommendations that emerged from co-designed sessions where young people with disability shared their priorities.

Young people in CYDA and The Social Deck's Foundational Supports Consultation emphasised the vital importance of co-design in the development of policies, programs, information and resources, particularly to ensure that they are accessible, inclusive and age appropriate.

CYDA recommends the government employ people with disability, including young people, to shape and review all communications regarding program and policy design to prevent the perpetuation of ableist messaging. Below CYDA recommends one such approach for communication updates about Foundational Supports:

1.3 Implement a Youth-directed Interactive Digital Storytelling Platform.

Create an immersive, accessible digital platform where children and young people with disability can explore NDIS and other service/support system updates through relatable, real-life scenarios. Using co-designed narratives, users may navigate interactive case studies addressing common concerns, such as funding school support, accessing therapy or employment supports. Features like Easy Read, Auslan videos, audio narration, multilingual support and provider assessment decision trees, would support decision-making and enhance inclusion and engagement.

We recommend this be federally funded by the Department of Social Services and NDIS administrative budgets and that the platform would undergo piloting with user feedback mechanisms to refine its accessibility and relevance. Ongoing monitoring through analytics, feedback surveys and third-party reviews from people with disability would ensure the platform remains effective and impactful, fostering deeper understanding and inclusive communication of NDIS changes.

¹⁰ UNHCR Convention on the Rights of Persons with Disabilities. Available at:

<https://www.refworld.org/legal/resolution/unga/2007/en/49751>, Article F: "Equalisation of opportunities for Persons with Disability in influencing the promotion, formulation and evaluation of policies, plans, programs and action at national and international levels to further equalise opportunities for persons with disability."

¹¹ Information on the Youth Advisory Group is available at: <https://www.youth.gov.au/youth-advisory-groups/employment-youth-advisory-group>.

¹² CYDA's LivedX Papers are available at: <https://cyda.org.au/advocacy/youth-led-advocacy/livedx/>.

In the following Recommendation 2, CYDA presents short and medium-term funding solutions for achieving a quality Foundational Supports program that addresses systemic barriers and creates opportunities for government to effectively engage and partner with the disability sector.

Key Recommendation 2: Work with Disability Representative Organisations to co-design short, medium and long-term funding solutions for Foundational Supports.

CYDA calls on the government to work with Disability Representative Organisations to co-design short, medium and long-term funding solutions for Foundational Supports.

As argued in CYDA's 2023 submission to the NDIS Independent Review¹³, the delivery of Tier 2 supports through federally funded Information, Linkages, and Capacity Building (ILC) grants has been hindered by insufficient investment and a poorly implemented Local Area Coordinator function that deviates from its original intent. Despite Tier 2 being designed to support approximately 4 million people, funding for these supports represents less than 1% of the total NDIS investment¹⁴. We therefore make the following recommendations to support the transition from ILC grants to Foundational Supports.

While CYDA fully supports the recommendation in the Disability Representative Organisation (DRO) Joint Submission on Foundational Supports for an 18-month interim funding agreement with peak organisations, we also propose an additional approach:

2.1 Support the transition from the current federally funded ILC program to Foundational Supports within the next three months by:

2.1a. Opening a funding round to ensure Foundational Supports programs and projects are operational within 12 months.

2.1b. Establishing the new funding guidelines in partnership with the DRO community, co-designed with people with disability.

2.1c. Restricting the Foundational Supports funding program to the not-for-profit sector and for-profit industry with a social purpose¹⁵, prioritising disability organisations that employ people with disability.

2.1d. Allowing for the roll-over of existing ILC funded (2024–27) projects, provided they meet the new guidelines and performance outcomes.

2.1e. Extending the ILC funding model from time-limited to long term to ensure systemic and sustainable change.

¹³ <https://cyda.org.au/cyda-submission-to-the-independent-review-of-the-ndis/>

¹⁴ D’Rosario, M (2023) Not a one-stop shop: the NDIS in Australia’s social infrastructure, National Disability Services, Per Capita, Australia, 14 November.

¹⁵ Chan, C (2023) The Rise of Purpose Driven Organisations. Available at: <https://managersandleaders.com.au/the-rise-of-purpose-driven-organisations/>.

2.2 Fund a discovery mapping project that identifies existing services and supports that could be categorised as Foundational Supports.

There are many supports and services that are filling gaps left by governments but are limited in what they can achieve due to lack of funding. Use the funding model outlined in Recommendation 2.3 to ensure these activities are better resourced and provide funding opportunities for new supports and services that target underserved communities, such as peer and decision-making support for people with intellectual disability and additional services for people in rural and remote communities.

2.3 Innovate by establishing a Grassroots Connection Model (Appendix 1).

CYDA recommends the government establish a **Grassroots Connection Model** to support new and existing community groups to connect with children and young people and their families and caregivers. Having effectively been designed by the communities who need them, these groups play a vital role in the provision of informal 'foundational supports' by sharing trusted information about services and best practices, yet they remain unfunded and at risk of sustainability challenges. The proposed Model has been endorsed in the DRO Joint Submission on Foundational Supports.

Justification and Alignment with Foundational Supports

The proposed Grassroots Connection Model aligns with the NDIS Review Final Report and the proposed Foundational Supports Strategy, particularly Action 1.2, which highlights the need for funding to enable multiple programs and initiatives¹⁶. This Model would ensure community groups can integrate their efforts with mainstream services such as education and employment, fostering comprehensive support for children and young people.

The recent discussion as part of the DSS and Social Deck Foundational Supports consultation process and as outlined in the DRO Joint Submission has highlighted the urgency for a Peer Networks Fund. Such a fund presents an opportunity to leverage this funding source to underpin the proposed Grassroots Connection Model. This approach would capitalise on the growing recognition of community-led initiatives, reinforcing the need for targeted investment to sustain and expand these critical grassroots efforts. Such funding would ensure these groups remain viable, effective, and embedded within the broader ecosystem of disability support services.

¹⁶ Australian Government (2023) Working Together to Deliver the NDIS Final Report. Available at: <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis>.

Grassroots Connection Model overview

This section provides an overview of the Model. More detail can be found at Appendix 1 and 2, including specific examples of scenarios where the Model could be applied in practice.

The Model would use a **fiscal partnership approach**, where a trusted third-party organisation (such as a disability not-for-profit advocacy organisation) manages financial administration and governance. This ensures funding is delivered efficiently without imposing bureaucratic burdens or compromising community group independence. Fiscal partnership approaches are increasingly common both nationally and internationally, regarded as innovative best practice and crucial for building civil society infrastructure¹⁷. Examples of fiscal partnership approaches that could be considered include:

- **Fiscal sponsorship:** Originating in the United States in the 1950s and gaining traction over the past 20 years, fiscal sponsorship involves a contractual agreement where non-profit organisations offer their charitable legal and tax status as well as administrative and other resourcing to local community groups to sponsor projects. There is a US Fiscal Sponsor Directory with 376 organisations listed, and the approach has been adopted by some organisations in Australia¹⁸.
- **Fiscal hosting:** Drawing from the fiscal sponsorship approach, non profit or civil society organisations establish contractual agreements to act as financial and administrative hosts for smaller grassroots groups. This approach is implemented by organisations in the United Kingdom, Europe, and Aotearoa New Zealand¹⁹.
- **Auspicing arrangements:** Auspicing is the most common approach to fiscal partnership in Australia. Community groups or individuals can approach auspitors to provide legal, tax, administrative and governance support through a contractual arrangement. Any legally constituted body can act as an auspitor, and examples include state and local government, schools, non-profits, and neighbourhood houses²⁰.

Through the fiscal partnership approach, **flexible microgrants** (\$5,000–\$10,000 annually) would allow community groups to fund multimode activities such as online platform hosting, accessibility improvements and face to face community-building

¹⁷ Foreman, E (2024) Fiscal Hosting is a Critical Part of Civil Society. Available at:

<https://www.alliancemagazine.org/blog/fiscal-hosting-is-a-critical-part-of-civil-society/>.

¹⁸ For US Fiscal Directory see [Fiscal Sponsor Directory | Connection, resource and news about fiscal sponsorship](#). For Australian examples see [Documentary Australia](#) and [Creative Australia](#).

¹⁹ For international examples see: [The Social Change Nest](#) (UK), [Open Collective Europe](#) (Europe), and [Open Collective NZ](#) (Aotearoa New Zealand).

²⁰ For an overview of auspicing, see: [Auspice Agreements - Arts Law Centre of Australia](#). Examples of auspitors in Australia include State Government: [Creative Victoria](#), [WA Road Safety Commission](#), [Victorian Government](#), Local government: [Wagga Wagga City Council](#), [City of Unley](#), Non-profits: [Social Ventures Australia](#), and Neighbourhood Houses: [Winchelsea Community House](#), [Maldon Neighbourhood Centre](#).

events. Community groups would set their own priorities based on identified local need and report on outcomes aligned with their existing successes, rather than conforming to rigid funding requirements.

To build capacity, the Model would include **LivedX Connection Coaches** (people with lived expertise) to provide tailored support on governance, financial management and funding processes, alongside workshops and peer learning opportunities.

This recommendation offers an innovative approach which ensures community groups remain sustainable and effective while respecting their autonomy and reducing administrative inequality, enabling them to continue their critical role in the community.

Part 1: Foundational Supports for children under 9 years with developmental concern, delay and/or disability

Recommendations 3 and 4

Children under 9 and their families, parents and caregivers require evidence-based supports and programs that are tailored to their specific life stages as they transition between early childhood settings and milestones. These supports and programs should centre the lived experience of children and be co-designed by existing communities of practice. They should also ensure a support environment that is consistent and continuous by providing a joined-up framework supported by evidence-based practice. CYDA proposes two recommendations to address these requirements.

Recommendation 3: Guarantee children with disability remain in the National Disability Insurance Scheme until viable and effective early childhood approaches are available for all.

Quality Early Childhood Foundational Supports must be at the core of this commitment. CYDA therefore calls on the government to:

- 3.1 Build an inclusive, universal, evidence-based and high-quality Early Childhood Education and Care (ECEC) system** that sits alongside NDIS's Early Childhood Intervention program to cater to children with developmental concern, delay and/or disability in partnership with the disability sector.
- 3.2 Coordinate the commissioning of inclusion support in ECEC and Foundational Supports** to streamline responsibilities and funding, improving outcomes for children.

Currently, inclusion support in ECEC is fragmented:

- At a national level, the government funds Inclusion Agencies through the ECEC Inclusion Support Program, the ILC program and NDIS funded supports
- At state level, government funded programs include Education Standards Authority (NSW), Preschool Boost (SA) and School Readiness Funding (VIC).

With a new commissioning process for Foundational Supports expected, clear leadership is essential. Coordination would streamline responsibilities, while joint commissioning could create a more effective system.

3.3 Strengthen partnerships and information sharing between the NDIS and the ECEC sector to provide consistent and clear support within local communities.

3.4 Develop clear pathways to services and processes to ensure no child falls through the cracks (Refer to Recommendation 4 for suggested ways to achieve this).

Recommendation 4: Provide Foundational Supports that leverage existing success and address service gaps.

The mapping exercise proposed in Recommendation 2.2 will identify successful programs, supports, and services requiring additional resources to meet community demand. The government must also address remaining service gaps to ensure no child or young person is left unsupported based on their eligibility for the NDIS or not. **No child should be removed from the scheme without appropriate supports in place.**

Recent reviews, including the 2023 NDIS Review, the Inclusion Support Program Review, and the Productivity Commission Report, highlight significant gaps in supports for young children and emphasise the urgent need for integrated services in ECEC.

Key gaps include:

- Peer group and decision-making supports for people with intellectual disability.
- Support and service delivery in regional and remote areas, including access to periodic and intensive services. **To better support children and families in rural and remote communities, existing mobile children’s services should be strengthened and expanded under Foundational Supports²¹.**
- There have been minimal supports for children and young people with disability who are dually engaged in state-based systems, including child protection. **The design of Foundational Supports must take into account the complexity of these intersecting systems.**

General Foundational Supports for children, their parents/caregivers and families

This section brings together evidence from our community and outlines key support needs for children and their caregivers, highlighting the importance of the two previous recommendations, 3 and 4. In particular, the voices of children and young people and their caregivers demonstrate that there is not yet an adequate system of General Supports to justify the removal of any children from the NDIS. Additionally, the gaps in

²¹ Examples of existing mobile children’s services include [Uniting Care Queensland Programs for Outback Communities](#), [Puggles Children’s Services Van](#), [Remote and Isolated Children’s Exercise](#) and [Isolated Childrens Parents’ Association](#).

service outlined below create the impetus for Recommendation 4, building on existing successes and addressing gaps.

Parents and carers of children under 9 years old benefit from and trust support from peer networks with lived expertise. Many examples of peer-to-peer support underpin our recommendation for the government to leverage off existing successes when designing Foundational Supports. For instance, Alma, below, specifies the exact type of peer support she benefits from.

“So, it’s good to speak to others who are in a similar situation as you, but a little bit further ahead, as well as speaking to the therapists.” (Alma, parent/caregiver of child with disability aged 0-8. Consultation).

Our community have told us about many in-person support groups who offer information, advice, and social-emotional support for families and caregivers of children with specific disabilities like Down Syndrome, Autism, and some genetic conditions. These are more widespread in cities and large regional centres and are lacking in rural and remote areas.

“[T]he organisation for our condition [...] wasn’t really running very well when we were diagnosed that we’ve been – I’ve joined that as a volunteer and we’ve been working on building that up and getting more information out there and building up resources and partnerships and working really with other families and trying to train up professionals”. (Jenny, parent/caregiver of child with disability aged 9-14. Consultation).

“[W]e had a really close online group, and with that support, everyone would bounce ideas off each other and say, ‘Oh, my child tried this out.’ But with Down Syndrome, because there aren’t that many people with Down Syndrome, it’s quite a small group. And everyone there is very supportive of each other and wanting the next child to do just as well as their child. So, just having somewhere like that to ask has really, really helped.” (Alma, parent/caregiver of child with disability aged 0-8. Consultation).

Funding grassroots online peer support groups that already contain high levels of trust and social capital is a straightforward way to enable Foundational Supports to reach the people who need them, at the time they need them.

Families of young children told us they received recommendations through their early childhood services and primary school and in instances like the family below, this is often the first step in generating a support system for a family.

“... but the school recommended that we see a paediatrician and then from there we went and just researched what sort of therapies they should be looking at.” (Chloe, parent/caregiver of child with disability aged 0-8. Consultation).

Increasing the capacity of existing support ecosystems like kindergartens, playgroups, primary schools, maternal child health visits, local hospitals and health services, is one way Foundational Supports, both General and Targeted, can reach the people who need them. As will be discussed in the next section, families of children with disability already access and rely on these supports but with variable success. Ensuring the right level of resourcing to include these services in the Foundational Supports system would ensure these services are more successful for families.

Targeted foundational supports for children, parents/caregivers and their families

CYDA calls for transparency in how governments agree on and define who is eligible for support from NDIS and who is eligible for Targeted Foundational Supports to prevent children falling through the cracks. In particular, we seek absolute clarity around terms like “permanent”, “substantially reduced functional capacity”, and “extended period of time”. We also request a policy for how these decisions will be made where there is disagreement that includes guarantees of support and services during the review period. There should also be a clear and fair plan for children when they turn nine years old.

Parents and caregivers of children are currently accessing a patchwork range of formal and informal “targeted supports” such as allied health services, mental health services, informal online support groups, peer support groups, school services, and maternal child health services.

Cost of living pressures are a reality for many families of children with disability. It is important that Targeted Foundational Supports build in specific and ongoing funding to ensure that allied health services and other existing supports are able to be provided free or at very low cost for children who are not eligible for the NDIS. This is critical because lack of access to required supports when a child is very young can have significant long term consequences for the child and their family.

“Allied health services to include those for young children with deficits in single domain, less severe deficits and those who are not eligible for services through NDIS also including children with ADHD.” (Parent of child with disability. Survey).

One parent we spoke to described the targeted and context specific support offered by their child’s psychologist to themselves as well as other people in their family who act as carers for their child with disability.

“[H]e also works with our inner circle. So, it’s our parents, our siblings. And he’s got homework for them to do, because she seems them on a regular basis, she sees them weekly. So, he’ll write up some notes for them to work with her, when we do drop her off to our mums’ houses.” (Celeste, parent/caregiver of child with disability aged 0-8. Consultation).

Supports that build the capacity of the community around the child better enable inclusive environments.

Some families like Mandy’s in the quote below have been able to access what we might now see as Targeted Foundational Supports through their local school.

“Most of the support has been recommended from school. I was very lucky; their school actually offers an early intervention program for speech and OT.” (Mandy, parent/caregiver of child with disability aged 0-8. Consultation).

However, until Mandy’s child began the early intervention program at school the family “struggled” with very little support. The services they attempted to access through a local hospital did not meet the child’s needs.

“[W]e’d use non-NDIS funded services like speech, audiology and OT from our local hospital [who said], ‘We’ll make you a program, we’ll call you in six months,’ and then that’s it, they discharge you. You don’t get the continuous support.” (Mandy, parent/caregiver of child with disability aged 0-8. Consultation).

Another parent explained how they accessed private therapists through a funding stream designed for children with disability prior to NDIS coming online.

“I engaged Better Start and I was able to access private therapists through Better Start funding, those therapists had a little bit more of a grasp on NDIS and how it was being rolled out in [our regional town], and were able to also assist me there and I felt that they gave some very good advice and were quite trusted as therapists” (Annie, parent/caregiver of child with disability aged 0-8. Consultation).

Two contrasting experiences with maternal health nurses further demonstrates the potential for this role to be expanded to open up pathways to both NDIS and Foundational Supports.

“Okay, when [my child] was 18 months old, we actually moved in from [a very remote] to [a slightly less remote town]. [...] It was hard to find any

support at all. We had a child health nurse appointment that left me in tears and no advice about local mothers' groups, nothing about playgroups, nothing about doctors or paths or anything. All I was told was to check a Facebook page". (Mandy, parent/caregiver of child with disability aged 0-8. Consultation).

"[W]e were offered the enhanced maternal health nurse so they came to our home and initially, she actually helped me to get onto the NDIS or she lodged my application for me because I didn't know what to do so she just rang me, asked me like, 'When you see the doctor next, get this report.'" (Kylie, parent/caregiver of child with disability aged 0-8. Consultation).

People in regional and remote communities are particularly concerned about how Foundational Supports will meet their needs.

"How they will be delivered. We live rurally and have limited therapy options. I'm concerned that foundational supports will only be large companies which will mean I can no longer use any local providers." (Parent of a child with disability. Survey).

"Information & advocacy navigating the NDIS itself. Obtaining supports in a regional area is REALLY challenging, so what is government planning to overcome this? We need something like a case manager to be reintroduced". (Parent of a child or young person with disability. Survey).

For children under nine years old, these communities need careful consideration as the heavy reliance on online and telehealth style supports is not suitable or sufficient to meet their needs.



Part 2: General Foundational Supports, Young people aged 9 to 25

Recommendations 5 and 6

Young people aged 9-25 require supports and programs that are tailored to their specific life stages as they transition to independence. These supports and programs should centre the lived experience of young people themselves and be co-designed by existing communities of practice. They should also ensure that support is consistent and continuous by providing a joined-up framework supported by evidence-based practice.

CYDA proposes two recommendations to address the gaps evidenced by our work with young people aged 9-25 and their parents/caregivers, outlined in the remainder of Part 2.

Recommendation 5: Implement a joined-up evidence-based youth practice framework to support young people aged 9-25.

As young people aged 9-25 transition out of the more intensive family care of childhood and into more independent lives, they need supports (both information, advice and referrals as well as capacity building) that suit each life stage.

These supports should be co-designed in a community of practice that centres the lived experience of young people aged 9-25. They should be delivered through a joined-up youth specific framework that ensures service improvement and consistency across gender, geography and other intersecting demographics. The framework should encompass workforce training and clear accountabilities to enable continuity of support across systems such as education, health and child protection. The framework needs to be informed by evidence-based practice, intersecting with the Australian Government's Youth Strategy²² and developed with DROs to ensure its suitability.

Recommendation 6: Provide funding for co-designed intersectional youth programs for young people aged 9-25.

The Foundational Supports ecosystem must be led by people with lived expertise. Programs designed to support young people should be co-designed by them to account for their specific social-emotional wellbeing as well as their intersectional needs. Genuine co-design will help to dismantle some of the problematic power dynamics and mistrust that has plagued NDIS design and delivery.

²² Australian Government (2024) Engage! A Strategy to Include Young People in the Decisions We Make. Available at: <https://www.youth.gov.au/engage/resources/engage-our-new-strategy-include-young-people-decisions-we-make>.

Further, there have been minimal supports for children and young people with disability who are dually engaged in state-based systems, including child protection and youth justice. The design of Foundational Supports must take into account the complexity of these intersecting systems.

Funding services and programs that are already embedded in the lives of people who require Foundational Supports will also address the criticism that NDIS decision-makers lack understanding of the disability sector. See **Appendix 2** for examples of existing groups who use their lived expertise to support their communities.

In addition to ensuring that funded programs are co-designed, intersectional and embedded, the government also needs to consider the impact of the legislation banning young people under 16 from accessing social media on their ability to access programs²³. This is particularly the case given young people themselves point to the importance of social media for facilitating access to information and peer networks.

In order to address the potential challenges that the social media ban may pose for young teenagers with disability seeking to access information about programs and build their sense of community, CYDA calls on the government to:

6.1 Fund a co-designed **Creating Access for Young People with Disability Under 16 project** that examines how young people with disability under 16 will be able to access information about supports and build their sense of identity and community in the absence of social media, and provides specific channels of support for this cohort. This project should be co-designed and draw on the lived experience of young people with disability under 16 to map the existing ways that they currently access support, including social media, and propose ways to mitigate the barriers to access that will arise after the social media ban.

6.2 Fund a **Young People with Disability Under 16 Online Hub**, a streamlined one-stop-shop website, digital platform or app that provides access information on specific supports, peer groups and resources that are tailored to young people under 16. Such a Hub would ensure that young people under 16 can continue to access supports and build a sense of community in the absence of social media.

Scope and outcomes

CYDA's previous work²⁴ has highlighted that the NDIS is not fit for purpose to meet the evolving and dynamic needs of older children and young people, who are required to navigate complex biological, psychological, and social changes during their first 25 years.

²³ [Online Safety Amendment \(Social Media Minimum Age\) Bill 2024](#)

²⁴ CYDA (2023) Reimagining a Better NDIS for Children and Young People. Available at: <https://cyda.org.au/cyda-submission-to-the-independent-review-of-the-ndis/>.

Similarly, a generic approach to Foundational Supports risks being incompatible with a neurodevelopmental theory²⁵ – changes in the brain and nervous system over the course of an individual's life. As children mature into adolescence and then young adulthood, they experience critical periods of growth and brain development as well as profound life transitions.

These transitions include the development of identity, autonomy, and the establishment of personal values. Neurodevelopmental theory underscores the importance of these transitions in shaping a young person's overall well-being and functioning and supports need to be tailored accordingly. This would entail providing intensive support during pivotal life transitions, such as when adolescents turn 18 and gain legal adulthood. As they are expected to demonstrate more autonomy in decision-making at this stage, there are few specialised supports for this circumstance. Yet young people encounter new systems as they mature, and their experience with these systems will have flow-on impacts on the trajectory of their lives and the opportunities they can access.

This need for youth and disability specific support at key transition stages was reflected in survey responses, such as this parent,

“Young people need to be recognised as needing youth-specific supports. It is SO HARD to find supports who are both youth-friendly AND disability inclusive. [...] They also need support at the big transition times of life, especially the transition from secondary school.” (Parent of young person with disability. Survey).

Young people from the FS Consultation similarly pointed to the need for age-appropriate supports, as well as supports that take into account identity and intersectional factors.

Young people in cohorts requiring Foundational Supports confront identity and intersectional challenges, including LGBTQIA+ and cultural experiences²⁶ alongside possible disability and diagnosis.

Finally, young people from CYDA's FS Survey and Consultation pointed to the need for accessible, interconnected and joined-up services, supports and data measures, especially between NDIS and Foundational Supports systems, to track outcomes and ensure no child or young person falls through the cracks.

²⁵ Spear LP (2013) Adolescent Neurodevelopment. *Journal of Adolescent Health* 52(2): S7-13. DOI: 10.1016/j.jadohealth.2012.05.006.

²⁶ Goff R et al. (2024) A Culturally Humble Approach to Designing a Sports-Based Youth Development Program with African-Australian Community. *Qualitative Health Research* 34(12): 1203-12-15. DOI: 10.1177/10497323241231856.

Information, advice, referrals

This section outlines some of CYDA's insights into the ways in which young people currently seek information, advice and referrals for the barriers they face in the community. It highlights the unique perspectives and needs of this cohort, demonstrating the vital need for these types of supports to be designed by and tailored to them as users.

Young people with disability, as well as other conditions, such as chronic illness, that communities are not designed to support, rely heavily on their peer communities (both virtual and physical) and internet searches for information, advice and referrals to support.

Young people in the FS consultation told CYDA that peer support was an important source of information and often occurred through social media.

They recommended the development of a streamlined service, platform or app where they could find age-appropriate and accessible information and supports.

In line with this suggestion, CYDA points to the need for a national individual advocacy service to support children and young people with disability and their families/caregivers. CYDA notes that although questions about appropriate channels to fund national advocacy remain unresolved in the disability sector²⁷, the need remains urgent, and governments must consider funding such an initiative as part of the broader ecosystem of supports available to children and young people with disability.

Foundational Supports should account for these existing methods that young people use to access information and supports. These methods are often digital or online based, as illustrated in the quotes below.

"I'm in a lot of different chronic illness Facebook groups." (Maysa, young person with disability aged 15-29. Consultation).

"I feel like the internet really helps. I will Google something or read on Reddit, lived experiences". (Miriam, young person with disability aged 15-29. Consultation).

Young people have access needs and communication preferences that are unique to their circumstances and development, and this should be carefully considered in a Foundational Supports environment. For instance, Margot's statement below highlights the additional mental load taken on by young people with disability who are required to provide their personal information to multiple service providers across many complex systems.

²⁷ Disability Advocacy Network Australia (2024) [Foundational Supports and Disability Advocacy Issues Paper](#).

“If only I could just CC all of this information to everyone at once, it would’ve been so much easier. But unfortunately the system is [...] unfair to people, especially those that, for example, are a little bit younger and have to deal with so much information at once”. (Margot, young person with disability aged 15-29. Consultation).

When written communication is necessary it should take into consideration accessibility needs and not be one-size fits all. This was an issue for Kai, a young person with disability, who found the way that the NDIS communicated regarding rejecting their claim was inaccessible:

“Basically what that six page document said was that apparently my issues are a medical issue and that the health system is meant to deal with them. Except they went in the most roundabout way of telling me that with six pages of words. It's not very accessible. It's not very easy to understand and if they can put it in plain English or simplified English, it would be a little bit easier.” (Kai, young person with disability aged 15-29. Consultation).

Communication should also consider intersectional needs, like language and culture of the young person. For example Alex, a young person with disability, noted that the NDIS system and language is not culturally accessible:

“[T]he NDIS is a very white system where they would, for example, provide information in a way that might not be the most culturally accessible, in simple like easy-to-understand language, especially when they’re debating words like what does “permanent” mean or what does “significant” mean.” (Alex, young person with disability aged 15-29. Consultation).

Capacity building

This section demonstrates the need to provide young people with capacity building supports that are designed by them with their life transitions and dynamic access needs in mind. It highlights the potential for Foundational Supports to leverage lived expertise and underscores the barriers created through a culture of low expectation and a one-size-fits-all approach.

Young people want the same opportunities as their peers but face barriers when navigating systems that discriminate against anyone who does not participate in a manner that follows the majority. The experience of Angela, a young person with disability, across her educational career demonstrates this ableist culture.

“I did do work experience at school, but again there was no real actual expectation for me to do it, and they didn’t really care whether I did it or not I guess.”

Then when she went to university,

“[M]y first year at uni when I approached the Accessibility Department [...] they said, ‘We didn’t think you were going to show up’ and there was just really low expectations.” (Angela, young person with disability aged 15-29. Consultation).

In order to meet the goal of young people having greater independence, autonomy and dignity, service and support communities must have a better understanding of young people’s needs. For instance, the following quote from a young person with disability, Maysa, demonstrates the need for service systems to understand the specific needs of this cohort. In the absence of knowledge of best practice, Maysa was forced to practice proactive self-advocacy to have a chance at these needs being met:

“[E]very service, whether it be a health service, a financial service, even an education institution, no one knows anything about my specific types of disabilities. And it means that the accommodations or the treatments that I’m offered are usually really limited and so I have to do my own research in order to be able to advocate for what should be best practice but just simply isn’t really known. Also I feel like I like to do my own research so I feel quite prepared when inevitably I am gaslighted by somebody.” (Maysa, young person with disability aged 15-29. Consultation).

Moreover, Foundational Supports should be based on young people’s goals and needs. This could include supports with personal development, counselling, and advocating for needed modifications, as the quote below demonstrates:

“Financial support (eg, for personal development, sensory items, counselling) for those that didn’t qualify for NDIS Help with advocacy and modifications in school.” (Young person with disability. Survey).

Being central to the design of supports intended for them will ensure young people have ‘access to services that are related to needs and goals’, as per the aims of the NDIS reform. One young person’s experience in the mental health space highlights the opportunity to improve the inadequacies of existing systems, including the lack of continuity of care and joined-up services:

“I waited for three months just to see a psychologist at Headspace, and in between that time I had no mental health support at all. They said [...] if I go to a walk-in clinic, it’s possible that I may not get the same person if I go in another time. So there was no point in me going there and then having to explain my entire life story to this person.” (Emma-Kate, young person with disability aged 15-29. Consultation).

Along with the expertise young people have needed to develop in the absence of support, numerous families have also described to us the expertise they have developed. This highlights an opportunity to leverage this expertise to ensure that young people and families are supported to be at the forefront of designing and delivering supports into their own communities:

“We actually did travel overseas to get information to find out what should we be doing. And then the next battle was getting people to do that. And I found that I really had to kind of – you find therapists [...] and having to train them.” (Jenny, parent/caregiver of child with disability aged 9-14. Consultation).



Appendices

This section contains three appendices that supplement CYDA's submission:

Appendix 1: Grassroots Connection Model Proposal

Appendix 2: Grassroots Connection Model in Practice: Three Scenarios

Appendix 3: CYDA's Foundational Supports Survey Report

Appendix 1 - Grassroots Connection Model Proposal

The Grassroots Connection Model is an innovative, proposed funding model designed to support disability and community-led support groups that already provide trusted spaces for young people and the parents/caregivers of younger children to connect, share information, and exchange best practices relating to Foundational Supports. The Model balances financial support with a commitment to safeguarding the independence and trust that grassroots groups have established within their communities. The funding process is tailored to minimise administrative burdens and promote equity, ensuring groups remain focused on their mission and autonomy. The Model has also been endorsed by the DRO Joint Submission on Foundational Supports.

Key Benefits

The Grassroots Connection Model will create a sustainable, trust-centred funding environment, empowering grassroots groups to continue their vital work connecting and supporting families of children with disability. It will do so by:

- Empowering grassroots groups: Providing resources without compromising trust, independence, or community values.
- Promoting equity: Avoiding reinforcement of inequality by simplifying eligibility and reporting requirements.
- Supporting sustainability: Building practical skills and financial stability through coaching and administrative support.
- Enabling efficiency and innovation: Funding multiple groups/programs provides cross pollination of ideas and innovation, enables funders to be more closely connected with the communities they serve and represent, offers an overall cost saving measure to the sector (shared costs such as tracking software, book-keeping, report generation), and generates networking opportunities.
- Focusing on community impact: Measuring success based on real-world outcomes, not externally imposed benchmarks.

Key Activity

As part of ensuring continued learning and networking opportunities, an Annual "Grassroots Forum" will be held to celebrate successes, foster collaboration, and share insights.

Model Overview

1. Funding Delivery via Fiscal Partnership Approach

A trusted third-party organisation (e.g., Disability Representative Organisation or a similar entity such as a philanthropic trust) serves as a fiscal host or auspitor, managing the financial and administrative responsibilities of the grant on behalf of the grassroots groups. The fiscal host/auspitor ensures funds are distributed efficiently, transparently and in compliance with grant requirements. Grassroots groups can then focus on their community work and delivering Foundational Supports without the need to establish complex financial or legal structures.

How it would work:

- a) The government allocates funding to the fiscal host/auspitor, which oversees financial management, reporting, and compliance.
- b) Grassroots groups apply for funding through a streamlined process. Once approved, the fiscal host/auspitor administers funds directly or reimburses groups for pre-approved eligible expenses.
- c) The fiscal host/auspitor provides optional administrative support, such as handling invoices or managing tax-related obligations, to reduce the burden on smaller groups.

2. Flexible Microgrants for Grassroots Groups

As part of the fiscal partnership approach, grassroots groups are awarded flexible microgrants by the fiscal host/auspitor amounting to \$5,000–\$10,000 per group annually.

Eligible Uses:

- Administrative costs, such as platform subscriptions, website hosting, or software tools.
- Accessibility improvements, including live captions, assistive technologies, or accessible event venues.
- Moderation training or resources for maintaining safe, inclusive online spaces.
- Community-building activities like local meetups, webinars, or resource-sharing initiatives.

Funding Guidelines:

- Groups define their own priorities for using funds, ensuring alignment with their unique mission and community needs.
 - Reporting is simple and narrative-focused, capturing stories of impact rather than enforcing rigid metrics.
3. Skills Development Support

Skills development for people with lived experience of disability and peer networks is built into the Model through:

LivedX Connection Coaches:

- LivedX Connection Coaches (people with lived experience of disability) will be employed to assist grassroots groups in navigating the shift to funded operations, offering tailored support in areas like financial management, governance, and compliance.
- Coaches will prioritise practical advice that aligns with each group's existing structures and culture, avoiding the imposition of rigid frameworks.
- Regular check-ins will be scheduled with Coaches to address emerging challenges and opportunities.

Workshops and Peer Learning Opportunities:

- In addition to the LivedX Coaches, there will be opportunities for peer learning through practical workshops on managing grants, fostering inclusivity, and using digital tools.
- Peer learning opportunities will also occur through connecting groups and sharing strategies for sustainability and community engagement.

4. Equitable and Trust-Centred Accountability

Accountability measures that are equitable and trust-centred are built into the Model through:

Outcome-Based Reporting:

- Funders assess success based on the group's existing activities and goals that are aligned to identified local need, rather than imposing external benchmarks.
- Groups provide simple reports, such as stories, testimonials, or community engagement statistics, to demonstrate impact.

Equitable Funding Criteria:

- Flexible eligibility criteria ensure smaller or less formalised groups are not excluded.

- Funding is accessible to all groups, regardless of prior grant experience, and groups that lack the time and expertise to apply will be supported to do so.

5. Governance and Independence

The independence and autonomy of grassroots groups participating in the Model is ensured through the following flexible governance measures:

Autonomy Safeguards:

- Groups retain full control over their operations, content and mission.
- The fiscal host/auspicator acts as a buffer, ensuring government involvement does not compromise trust or independence.

Simplified Rules and Regulations:

- Administrative requirements are minimal and designed to be inclusive of grassroots groups with varying capacities.
- Funds are accessible without forcing groups to adopt hierarchical or formalised governance structures.

6. Implementation and Allocation

It is proposed that the Model will be delivered through the following funding allocation:

- Flexible Microgrants: 60% of the funding pool.
- Skills Development and Coaching: 30%.
- Fiscal Host/Auspicator Administration: 10%.

Examples of Fiscal Partnership Approaches: International and Domestic

The Model will use a **fiscal partnership approach**, where a trusted third-party organisation (such as a disability not-for-profit advocacy organisation) manages financial administration and governance. This ensures funding is delivered efficiently without imposing bureaucratic burdens or compromising community group independence. Fiscal partnership approaches are increasingly common both nationally and internationally, regarded as innovative best practice and crucial for building civil society infrastructure. Examples of fiscal partnership approaches that could be considered include:

- **Fiscal sponsorship:** Originating in the United States in the 1950s and gaining traction over the past 20 years, fiscal sponsorship involves a contractual agreement where non-profit organisations offer their charitable legal and tax status as well as administrative and other resourcing to local community groups to sponsor projects. There is a US Fiscal Sponsor Directory with 376

organisations listed, and the approach has been adopted by some organisations in Australia²⁸.

- **Fiscal hosting:** Drawing from the fiscal sponsorship approach, non profit or civil society organisations establish contractual agreements to act as financial and administrative hosts for smaller grassroots groups. This approach is implemented by organisations in the United Kingdom, Europe, and Aotearoa New Zealand²⁹.
- **Auspicing arrangements:** Auspicing is the most common approach to fiscal partnership in Australia. Community groups or individuals can approach auspitors to provide legal, tax, administrative and governance support through a contractual arrangement. Any legally constituted body can act as an auspitor, and examples include state and local government, schools, non-profits, and neighbourhood houses³⁰.

²⁸ For US Fiscal Directory see [Fiscal Sponsor Directory | Connection, resource and news about fiscal sponsorship](#). For Australian examples see [Documentary Australia](#) and [Creative Australia](#).

²⁹ For international examples see: [The Social Change Nest](#) (UK), [Open Collective Europe](#) (Europe), and [Open Collective NZ](#) (Aotearoa New Zealand).

³⁰ For an overview of auspicing, see: [Auspice Agreements - Arts Law Centre of Australia](#). Examples of auspitors in Australia include State Government: [Creative Victoria](#), [WA Road Safety Commission](#), [Victorian Government](#), Local government: [Wagga Wagga City Council](#), [City of Unley](#), Non-profits: [Social Ventures Australia](#), and Neighbourhood Houses: [Winchelsea Community House](#), [Maldon Neighbourhood Centre](#).



Appendix 2 – Grassroots Connection Model in practice: Three scenarios

This section presents three Scenarios illustrating how the Grassroots Connection Model could be applied in practice. These are examples of youth-focused community groups that could benefit from funding and are aligned to the overall objectives of Foundational Supports.

Scenario 1 – Volunteer run peer support group for young gender diverse people (online and in-person)

Transfemme SA

This South Australian based group was founded, and is run by, young gender diverse people. The group began in 2021 and exists as both an online and in person community. Their two online spaces have 600 members with 30-50 people participating actively online each week. In person events are held fortnightly and operate out of a sexual health service who offer their space as in-kind support.

The group is entirely volunteer run and provides information, advice, referrals and emotional support to transfemme and gender diverse people, many of whom experience disability or conditions which impact how they access their community. For instance, gender diverse individuals experience higher rates of autism and other neurodevelopmental conditions and traits than cisgendered people³¹. Moreover, it is widely recognised that the gender diverse community, especially under 35 years old, experience significantly higher rates of serious mental health concerns, particularly suicidal thoughts, than their cisgender peers³².

In practice, the proposed grassroots connection model would enable...

- Onboarding, training and supporting more volunteers to support their peers, both online and though in person support groups.
- Embedding a lived experience governance framework³³ underpinned by a human rights approach.
- Allowing the group to continue the critically important work of supporting people through the many systemic barriers that stand in the way of meaningful participation in their communities.

³¹ Warrier V et al. (2020) Elevated Rates of Autism, Other Neurodevelopmental and Psychiatric diagnoses, and Autistic Traits in Transgender and Gender-diverse Individuals. *Nature Communications* 11(1). DOI: 10.1038/s41467-020-17794-1.

³² Australian Bureau of Statistics (2024) Mental Health Findings for LGBTQ+ Australians. Available at: <https://www.abs.gov.au/articles/mental-health-findings-lgbtq-australians#selected-measures-of-mental-health-for-lgbtq-populations>.

³³ Hodges E et al. (2023) The Lived Experience Governance Framework: Centring People, Identity and Human Rights for the Benefit of All. Available at: <https://nmhccf.org.au/our-work/discussion-papers/the-lived-experience-governance-framework-centring-people-identity-and-human-rights-for-the-benefit-of-all>.

Scenario 2 – Disability awareness training for employers led by young people with lived experience

Together Access and Inclusion Training, Youth Disability Advocacy Service

Together Training³⁴ is a tailored inclusion training initiative for small to medium employers, led by young people with lived experience of disability. The training was developed by the Youth Disability Advocacy Service and is run online or in person over four hours in two sessions with up to 30 participants, with follow up support and resources to implement learnings. Trainers with lived experience co-design and deliver the workshops focusing on practical skills, such as creating accessible workplaces, adapting hiring practices, and improving team culture. Interactive exercises encourage immediate application of concepts. The training covers assumptions and how to challenge them, disability models, disability terminology and language, intersectional disabled experiences, how to commit to access and inclusion, how to produce accessible work, and information on access keys and social scripts.

The training employs storytelling and interactive activities led by disabled young trainers to build employer capacity for inclusion. This empowers young people with disability as leaders and benefits small to medium employers by offering accessible, practical training and sustained guidance, driving long-term cultural change.

In 2022 and 2023, 40 free sessions were organised along with 75 fee-for-service sessions. In addition, from 2021 to 2023, 35,000+ people accessed Together's online resources about access and inclusion.

In practice, the proposed grassroots connection model would enable...

- The training program or alike disability awareness training to focus on core activities of employer capacity building, delivery and participant engagement, while the fiscal host/auspisor manages contracts, funding, and compliance.
- The development of updated content for training delivery.
- The production of training resources and delivery of post-training support.
- Monitoring and evaluation through the fiscal host to ensure the program's quality and impact.
- This approach highlights how fiscal partnerships can bridge Foundational Supports resourcing and capacity gaps while championing inclusive practices in the workplace.

³⁴ For information about Together Training see: <https://www.yacvic.org.au/ydas/resources-and-training/together-2/actions/together-workshops/>.

Scenario 3 – Volunteer run online peer support group for families and caregivers of children with school attendance difficulties

School Can't Australia

This group began as a Facebook community in 2014 to support families and caregivers of children who were unable to attend school (often referred to as school refusal). Many of the group's 14,800 members are parents of children with disability and many have NDIS funding. However, a large proportion do not have NDIS funding and both cohorts lack the support to enable their children to safely return to school.

The group has a wait list of 2300 and only has the capacity to admit 150-200 new members each week to maintain the balance of new members with informed and experienced members who will guide and support them. Additionally, moderators turn away more than 800 membership requests from professionals each year because they do not have the resources to provide the support and training they are seeking.

The 10 volunteer moderators, who are all parents and caregivers of young people who struggle to attend school, spend 86 hours per week screening new members, moderating the group to maintain a safe space, and hosting welcome webinars, as well as answering public and private requests for information, advice and referrals. An additional 80 hours per week are spent advocating, developing web content, and creating other resources (including zines & podcasts) to share their lived expertise. In more recent years the group's activities have expanded to giving presentations in local communities to share information about school-based trauma and support strategies.

This group undertakes an estimated \$1 million worth of voluntary activity each year³⁵. Despite the obvious and growing gap they are filling, they have no substantive or ongoing funding.

In practice, the proposed grassroots connection model would enable...

- Training programs for new moderators who could then provide additional guidance, support, and careful moderation for new members, allowing more people to join the group from the waitlist
- A new membership offering, including a training package, for professionals seeking advice and information about how to support children and young people experiencing 'school can't'.
- Improving website accessibility in line with digital accessibility guidelines.
- Undertaking more outreach to regional, rural and remote communities with the facilitation of in person peer support groups and training.
- This highlights how a fiscal partnership model could create ongoing sustainability and resourcing for a needed information, advice and referral community service.

³⁵ Westphal T, 26th November 2024. Personal Communication, Director of School Can't Australia, <https://www.schoolcantaustralia.com.au/>.

Appendix 3 – CYDA’s Foundational Supports Survey Report

On 9 October 2024, CYDA launched a survey to gather feedback from young people with disability, parents, and caregivers about the government’s proposed Foundational Supports.

These specific supports aim to address the gap between mainstream or community and NDIS supports.

Over three weeks, CYDA received 258 responses, many of which spoke of widespread anxiety and confusion about Foundational Supports.

Nearly all respondents (93%) said they did not have enough information to understand how they would be impacted, while nearly one in two were worried.

Many were also concerned that Foundational Supports:

- would replace NDIS supports.
- would not adequately address diverse needs.
- would not be practical or useful.

Click on the link to [CYDA’s Foundational Supports Survey Report](#)

Children and Young People with Disability Australia

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