Foundational Supports

Department of Social Services

A joint submission from Disability Representative Organisations

12 December 2024

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Acknowledgements and style note

The organisations contributing to this submission acknowledge all the individuals who lent their time and expertise to its development. This submission would not have been possible without these efforts.

This submission is written in person first language (i.e., person/people with disability) to match the language commonly used by the Australian Government.
The submission was prepared with the assistance of the Coordinator, National Coordination Function (NCF) for DANA.

The authors, organisations and individuals supporting this submission acknowledge the Traditional Owners of the lands on which this submission was developed.

Signatories to this submission

The following Disability Representative Organisations (DROs) endorse this submission:

- Australian Autism Alliance
- Children and Young People with Disability Australia
- Community Mental Health Australia
- Disability Advocacy Network Australia
- Down Syndrome Australia
- First Peoples Disability Network Australia
- Inclusion Australia
- National Ethnic Disability Alliance
- People with Disability Australia
- Physical Disability Australia
- Women With Disabilities Australia

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Disability Advocacy Network Australia (as NCF for the DRO Program)

Introduction

The Disability Representative Organisations (DROs) that are signatories on this submission welcome the opportunity to participate in consultation regarding general foundational supports. This comes at an opportune time, during a period of significant reform that will undoubtedly have far-reaching impacts on people with disability and the disability community.

Foundational supports have the potential to address critical gaps in support that exist for people with disability, both outside and with access to the NDIS. Prior the NDIS review, Professor Bruce Bonyhady described the NDIS as "an oasis in the desert", where people are left without access to crucially needed supports outside of NDIS individualised budgets. Foundational supports are envisaged to address this issue, replacing previous Tier 2 initiatives, including the NDIS/DSS Information, Linkages and Capacity Building program (ILC).

Currently, Foundational supports are still in the consultation phase as of December 2024, with an expected staged implementation from July 2025. While we highly value meaningful consultation, there is uncertainty and instability in the sector that centres on a lack of clarity on current funding arrangements. Specifically, there are concerns around how these will change service provision for DROs and other organisations that provide supports, particularly those that rely on ILC funding and Tier 2 funding.

We anticipate that more time will be needed to roll out foundational supports. We also understand that most of the current ILC grants have no funding allocation post June 30, 2025. As will be discussed in this submission, measures are needed to ensure that (1) funding streams are made available post June 30, 2025, and (2) interim funding arrangements are established by Federal and state and territory governments to ensure continuity of supports for people with disability.

We have seen many crucially needed supports fold due to discontinued funding. Many projects and programs funded by ILC grants have significant overlap with the proposed foundational supports, such as information services and peer support groups and networks. Despite this, many organisations lost funding this year and ceased providing these activities, with some forced to shut their doors. As a result, significant injections of funding are needed to rebuild, replace lost staff, plan new activities and revive support offerings.

There are also concerns about the availability of quality and independent foundational supports. We take a strong stance against disability service providers being able to provide foundational supports as there are issues with conflict of interest, and poor outcomes for people with disability when they have been excluded, or partially included, in decision-making. For this reason, people with disability and their representative organisations, including DROs, must take on central roles in leading and decision-making at all stages in the development of foundational supports - through design, implementation, and delivery.

This strong partnership between the disability community and governments is crucial in leveraging and representing the unique perspectives and diverse expertise of people with disability in this component of reform. Principles of inclusion, accessibility and affordability should be incorporated into any foundational supports structure, including:

- inclusion requirements to ensure that people with disability and lived experience have meaningful governance and employment opportunities;
- availability at no cost to people with disability to mitigate barriers to access;
- accessible information and supports with diverse service options, including place-

based supports and expertise accessible across all communities.

Our recommendations are based on addressing these priorities and principles and were developed through strong collaboration between DROs. They bring together the experiences and expertise of their organisations and members across the disability community. The submission was prepared by the National Coordination Function (NCF).

Recommendations

Recommendation 1: Genuine co-governance, co-design and shared decision-making with people with disability and their representative organisations, including DROs, must be embedded in every stage of foundational supports through initiatives set out in the NFP Blueprint. This must include representation on all decision-making bodies that establish, review and award tenders/contracts, as well as representation on evaluation and monitoring of program success.

Recommendation 2: Work with DROs to establish a commissioning framework that would allow disability led peak bodies and grassroots groups to partner together and seek funding for the vital local solutions to advocacy, peer support and capacity building already existing or vitally needed.

Recommendation 3: DROs must be appropriately resourced to perform any roles throughout the stages of design, implementation and delivery for foundational supports. This resourcing must enable a sufficient increase in their capacity to perform these roles, as well as demonstrate the value of their time, expertise and engagement.

Recommendation 4: Put in place an **18-month interim funding agreement with peak organisations to support the transition from ILC grants** to foundational support models. This will provide continuity of service and develop the capacity of other grassroots groups and peak organisations to transition into a model of service delivery in the new system of foundational supports.

Recommendation 5: Inclusion requirements on boards and governance structures for organisations delivering programs to ensure people with disability play a role in decision-making.

Recommendation 6: Government **set employment of people with disability requirements** that will mean funded organisations are required to create real employment opportunities in their program for people with disability to address the systemic issues of unemployment and underemployment across the community of people with disability.

Recommendation 7: Government work with employers to **ensure inclusion and accessibility measures** are put in place to support workers with a disability to thrive in the workplace.

Recommendation 8: Government work with employers to **ensure intersectional and culturally competent supports** are put into place to support people with disability, especially those from First Nations, CALD communities and other marginalised groups, in both workplace settings and transitions into work, such as internship settings and higher education settings.

Recommendation 9: Government must invest in a **self-determined, disability rights informed and culturally safe First Nations disability workforce** to fill significant workforce capacity gaps across the disability support sector.

Recommendation 10: Programs need to be provided at no cost to the participant in recognition of significant economic barriers people with disability face.

Recommendation 11: Incorporate best practice for accessible information and supports guided by the national plan to promote accessible information and communications currently in development in the foundational supports framework.

Recommendation 12: Mitigate barriers to access by **improving diversity of service options**, including both place-based programs in person and online information in accessible formats.

Genuine partnership with the disability community to design and implement foundational supports

The "nothing about us without us" principle is at the heart of the disability rights movement. Enhanced representation and inclusion of lived experience expertise leads to better, more responsive, effective and fit for purpose programs and systems.[1] There is abundant evidence that the leadership and active presence of people with disability are central to achieving the transformative systemic and cultural change needed.[2] Both government and not-for-profit policies and programs have been designed and implemented largely by people without disability, leading to poor and sometimes disastrous outcomes and trauma for people with disability.

People with disability and their representative organisations must be actively involved in deciding how resources intended to serve their interests are prioritised, applied and structured. Effective governance of foundational supports must start with rebuilding trust between government and people with disability, demonstrating how evidence provided by people with disability and their families and carers is factored into decision-making, and ensuring that any reforms affecting their lives are codesigned, transparent, evidence-based, adaptable to a range of needs, and appropriately resourced.

Formal partnership in decision-making with people with disability and their representative organisations

The UN Convention on the Right of Persons with Disabilities (CRPD), which Australia agreed to in 2008, includes a requirement of "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."[3] Too often we see lip service to this principle, without dedicated funding to facilitate the inclusion and meaningful participation of people with disability, especially those with intellectual disability, acquired brain injury or other cognitive impairment.

Feedback from our communities, received in targeted consultations and surveys by DROs, have demonstrated the structural barriers embedded in the current consultation on general foundational supports. The common themes in speaking with members has been confusion caused by lack of context, ineffective discussion questions, and opaque definitions of what foundational supports means. This has meant many people have felt ill equipped to

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[1] Jennifer Smith-Merry (2020) Evidence-based policy, knowledge from experience and validity., *Evidence & Policy*, vol 16, no 2, 305–316; Laufey Love, Rannveig Traustadottir, Gerard Quinn and James Rice (2017) 'The Inclusion of the Lived Experience of Disability in Policymaking', *Laws:* 6 (33). Patsie Frawley & Christina Bigby (2011) 'Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia', in *Journal of Intellectual and Developmental Disability*, 36:1, 27-38.

[2] Jan Idle, Gianfranco Giuntoli, Karen Fisher, Sally Robinson, Christiane Purcal, Christy Newman, Kathleen Reedy (2022) *Research Report – Changing community attitudes to improve inclusion of people with disability.* Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, University of New South Wales, pp53-58.

[3] Preamble (f), UNHCR Convention on the Rights of Persons with Disabilities (2006) <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

contribute and meaningfully engage with the consultation process.

These experiences highlight the challenges often faced by people with disability when engaging with reform processes that are not led by people with disability. Further to this, there are a culturally diverse understandings of disability in First Nations communities that create additional barriers to engagement. We know that when there is active partnering with disability representative organisations in the process and investment in preparing communities to provide input on what is important to them, better quality feedback is collected to effectively guide reforms.

Incorporating DROs and other representatives of the disability community in decision-making at all levels of foundational support will ensure Australia meets its obligations and supports better program outcomes. People with disability can bring their invaluable lived experience and expertise to all aspects of the program, including designing, implementing, monitoring, and evaluating supports. There is a real opportunity to formalise the role of DROs and people with lived experience of disability across all levels of decision-making through the foundational supports framework.

Further to formal partnerships, shared decision-making with First Nations people is also required under the National Agreement on Closing the Gap (Closing the Gap). Including First Nations people with disability in decision-making around foundational supports is essential for governments to meet their obligations under Closing the Gap, but also to ensure the rights and needs of First Nations people with disability are reflected and addressed in foundational support structures.

The principles of co-governance, co-design and shared decision-making are reflected in the recent Not-for-profit Sector Development Blueprint (NFP Blueprint) that sets out sequencing for initiatives to embed these practices alongside a diverse suite of sector initiatives.[4] This includes a range of measures to actively support Aboriginal and Torres Strait Islander self-determination and community control and formalise accountabilities in line with Closing the Gap. The Blueprint should be carefully considered and incorporated into the various reform processes flowing from the NDIS Review, including foundational supports.

Recommendation 1: Genuine co-governance, co-design and shared decision-making with people with disability and their representative organisations, including DROs, must be embedded in every stage of foundational supports through initiatives set out in the NFP Blueprint. This must include representation on all decision-making bodies that establish, review and award tenders/contracts, as well as representation on evaluation and monitoring of program success.

DROs partner in designing, delivering and monitoring new model for Foundational Supports

DROs are uniquely positioned to play a significant role in both the direction of foundational supports and the provision of the programs. There is extensive collaboration and cooperation through the NCF that has been further developed and refined through major

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[4] See Initiatives under 'Pillar 2: A people-led and purpose-driven Not-for-profit sector'. The NFP Blueprint sets out a ten year vision, framework, core initiatives and implementation approach for a thriving NFP sector that supports Australia's people, communities and environment. Blueprint Expert Reference Group, *Not-for-Profit Sector Development Blueprint*, 27 November 2024 <Blueprint Expert Reference Group | Department of Social Services> accessed 12 December 2024.

reforms across the sector in recent years. DROs foster and connect networks of many organisations across the sector that successfully provide peer-led programs and are well placed to expand on the services they already provide. This includes strong formal and informal connections with state and territory DROs and disability advocacy organisations.

We recommend that the Federal Government partners with DROs to build a commissioning framework that preferences disability community-led programs, that are independent and bring lived experience and deep connection to their community in this work. The strength and expertise that DROs and their community networks contribute needs to be valued. Without the proper resourcing and time provided by the Federal Government, the capacity of disability leaders, and representative and advocacy organisations is severely overstretched by the pace of reform and overwhelmed by "consultation fatigue". Genuine partnership and resourcing by governments is crucial to support the leadership and inclusion of people with disability in co-design and decision making. Partnership extends to the design and implementation to the ongoing oversight, governance of how supports are delivered and, reporting and data collection mechanisms.

It is essential that DROs are adequately resourced to perform these roles. As set out in the joint submission by DROs on the Disability Royal Commission in January 2024, DROs should not only be leaders in reforms, but must be equipped with sufficient time, kept informed of government plans, and receive the required additional funding to engage and lead on reforms. These principles should be similarly applied for DROs roles in design, implementation and delivery for foundational supports.

Recommendation 2: Work with DROs to establish a commissioning framework that would allow disability led peak bodies and grassroots groups to partner together and seek funding for the vital local solutions to advocacy, peer support and capacity building already existing or vitally needed.

Recommendation 3: DROs must be appropriately resourced to perform any roles throughout the stages of design, implementation and delivery for foundational supports. This resourcing must enable a sufficient increase in their capacity to perform these roles, as well as demonstrate the value of their time, expertise and engagement.

Preventing gaps: Interim supports and programs

Service gaps between the NDIS, foundational supports and mainstream services pose significant risks, including unmet needs and increased hardship. Proactive measures are required to prevent these gaps and address the intersectional challenges of poverty, housing instability, and systemic barriers. First Nations people with disability also face additional intersectional disadvantage through systemic and sustained racism and discrimination. In the transition and building of a new system and funding structure, there are concerns of increased gaps, people being left behind and losing essential support. Programs must be allowed to take the required time to establish and scale, while also ensuring fairness in access across all communities.

DROs are well placed to work with the Department of Social Services (DSS) and other agencies to bridge that gap and work collaboratively to establish interim supports and programs that can easily adapt and grow as the programs and funding rolls out. The next 18 months are a critical transition period, and we recommend a period of transition funding be put in place to manage this stage and support relevant organisations to be ready to transition and build a workforce to support this change.

Recommendation 4: Put in place an **18-month interim funding agreement with peak organisations to support the transition from ILC grants** to foundational support models. This will provide continuity of service and develop the capacity of other grassroots groups and peak organisations to transition into a model of service delivery in the new system of foundational supports.

Commissioning framework: delivering a strong network of place-based expert programs

Delivery of foundational supports should be co-led by independent organisations that are informed by people with a disability. To ensure best outcomes for the people these services are designed for, it is critical to have representatives from DROs and people with lived experience at the core of decision making on funding programs, commissioning principles and oversight and long-term monitoring of program outcomes and delivery. We see DROs as having a key role in delivery and commissioning. DROs and their associated organisations are uniquely placed to expand on the place-based and expert-led specialised programs responsive to our constituencies. Our organisations already provide or have strong networks of organisation that deliver supports across the disability community, including:

- extensive advocacy support;
- peer-to-peer programs;
- capacity building programs;
- information and support programs.

Features of a foundational support's framework should include:

- building out and extending self-advocacy models;
- giving real preference to supporting the employment of people with disability and provides meaningful career opportunities;
- integrates longer term funding, including the application of appropriate indexation and minimum terms contracts and renewal periods, in line with initiatives under the NFP Blueprint.[5] We recommend a minimum five years, to support retention of staffing, allow for certainty in service provision and time for programs to develop and mature as the program develops, which in turn supports service users. This is particularly important for First Nations services.

Additionally, oversight and monitoring in place that includes DROs and people with disability, to ensure that the model is delivering the support that is intended.

Moving away from Local Area Coordinators (LACs) model

The current model of LACs failed to genuinely provide the information, linkages and community capacity building as intended. In remote communities this model was culturally

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[5] See Initiative 4b: Progress and monitor government actions to deliver full cost funding as sought by the NFP sector, including the application of appropriate indexation, and minimum term contract and renewal periods in all areas of service provision. Blueprint Expert Reference Group, Department of Social Services. *Not-for-Profit Sector Development Blueprint*, 27 November 2024 <Blueprint Expert Reference Group | Department of Social Services> accessed 12 December 2024.

unsafe for First Nations people and created more barriers to service access. There is an opportunity to reevaluate the tenders that favour large organisations, disconnected from the communities they serve, and instead consider which organisations are best placed to deliver the right services to the communities they support. Moreover, any tender process should be targeted and exclude providers who do not meet inclusion requirements or lack the requisite experience in disability services.

Peer support models

There is strong consensus that peer supports are crucially needed, and that that DROs can play an integral role in facilitating these. People with disability, their families and caregivers, not only develop expertise in their own disabilities and conditions over time, but they also become expert at navigating complex and bureaucratic service environments. This places them in a unique position to support their peers. This was reenforced by DSS and the Social Deck in their "What we have heard" webinar on the 29th of November. In particular, it was noted that family capacity building through peer support groups has continuously been one of most crucial supports across the disability community.[6]

DROs are best placed to build a model of peer support, that is led by, and for, the disability community and is already occurring in many of the member organisations represented by DROs nationally. DROs can play an integral role in facilitating these, including partnering with disability led peak bodies and grassroots groups.

Hosting or auspicing models

An example of how DROs can play a leading role in commissioning can be seen in a recent proposal by Children and Young people with Disabilities (CYDA). This proposal puts forward an innovative model of peak organisations hosting or auspicing smaller grassroots groups to receive operational funds and administrative support to enhance their existing capacity building, peer-to-peer or advocacy models. This may include funding for:

- Facilitators and coordinators of grassroots groups;
- Operational needs;
- Practical materials and equipment.

The hosting or auspicing organisations could provide:

- support with reporting of program outcomes and acquitting of funds;
- ensuring auspice organisations are meeting funding requirements;
- relevant insurances and support to meet program regulations;
- ensuring relevant training and guidance for group coordinators, so they remain current and avoid misinformation;
- support for new groups wishing to establish a program and fill a need;
- hosting of service directories and providing referrals to relevant local groups;
- providing networking opportunities across auspice organisations; and
- Seeding of services into local areas where gaps exist

The model allows smaller organisations to focus on the provision of core services, while peak organisations build economies of scale for the support elements such as administrative

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[6] DSS and social Deck "what we have heard" webinar on the 29th of November 2024

tools, insurances and financial reporting requirements.

International examples of fiscal hosting organisations:

- UK- https://thesocialchangenest.org/; https://thesocialchangeagency.org/
- Europe- https://www.oceurope.org/why-oce
- Aotearoa (New Zealand) - https://teahuahu.nz/open-collective-nz/

Principles for a human rights-based commissioning framework

Inclusion requirements

There is an opportunity for government to set some significant inclusion requirements for foundational supports. This could include:

- requiring boards and management of organisation to have people with disability and lived experience as part of their governance and decision-making;

- requirements to create employment and employment pathways for people with disability and lived experience, considering and implementing accessibility and inclusion requirements and accommodations needed to sustain their employment;

- inclusion requirements must include the provision of culturally safe and appropriate services including for First Nations communities, culturally and linguistically diverse (CALD) communities, and other marginalised groups.

First Peoples Disability Network (FPDN) shared in the NCF consultation, that it is critical for First Nations communities to have self-determination in decisions impacting their own communities. Cultural connection, social, and kinship care are critical in culturally responsive models of support and should be prioritise in any future program. It is vital to consider how funding models are framed, so they are inclusive of ways of working in First Nations communities. Those approaches should include long term trust and relationship building, tailored and locally based solutions, and recognition of the unique barriers that First Nations people face in engaging with complex bureaucratic systems and supports. Any reforms must address factors such as the cultural understanding of disability and inclusion, lower rates of disability diagnosis, and the fear and trauma associated with government intervention in the lives of First Nations people.

Additionally, the foundational supports workforce must be equipped with the skills necessary to understand complexities and connections of cultural protocols and other systems, such as housing, health, immigration, and education. Existing skill sets within the disability advocacy sector should be leveraged to avoid duplicating efforts and ensure a seamless integration of services.

Recommendation 5: Inclusion requirements on boards and governance structures for organisations delivering programs to ensure people with disability play a role in decision-making.

Recommendation 6: Government **set employment of people with disability requirements** that will mean funded organisations are required to create real employment opportunities in their program for people with disability to address the systemic issues of unemployment and underemployment across the community of people with disability.

Recommendation 7: Government work with employers to **ensure inclusion and accessibility measures** are put in place to support workers with a disability to thrive in the workplace.

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Recommendation 9: Government must invest in a **self-determined, disability rights informed and culturally safe First Nations disability workforce** to fill significant workforce capacity gaps across the disability support sector.

Access and affordability

According to an Australian Human Rights Commission report, "45% of people with disability live on or near the poverty line, 2.5% times the rate of poverty experienced by the general population." [7] Disparity in the median gross personal income of people with disability was demonstrated in 2022 data, being only $575 per week for people with disability, compared with $1055 per week for people without disability.[8]

The rising cost of living disproportionately impacting people living with or caring for someone with a disability who are already significantly economically disadvantaged. Mechanisms to ensure cost of access is not a barrier to participation must be incorporated in any foundational supports program, namely though supports being provided at no cost.

Recommendation 10: Programs need to be provided at no cost to the participant in recognition of significant economic barriers people with disability face.

Accessible information and supports with diverse service options

All people should be able to access and understand information and make informed decisions about supports. We emphasise, that accessible information and communication is a fundamental human right enshrined in the UNCRPD. Information must be provided in accessible ways, to support people with physical, sensory, and other disabilities, as well as those with different language/communication needs.

Consistency in approaches to accessibility across jurisdictions will be improved through the

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[7] AHRC report, 7 Economic and social costs of employment discrimination against https://humanrights.gov.au/our-work/7-economic-and-social-costs-employment-discrimination-against-australians-disability

[8] Australian Bureau of Statistics (2022), Disability, Ageing and Carers, Australia: Summary of Findings, ABS Website, accessed 11 December 2024.

development of the national plan to promote accessible information and communications to be developed and agreed on by Australian Government and state and territory governments.[9] It is important that the plan is developed though genuine codesign with representative organisations of people with disability from diverse communities. This must be supported through the provision of highest standard accessible materials, including interpreters, translated materials and Easy Read information.

It is critical that government acknowledge and put in place funding measures to mitigate any potential access barriers that can be faced by people living with disability. This requires balancing digital solutions with local and place-based services hold valuable knowledge of their communities and services. Low literacy and speaking languages other than English (including First Nations languages) can be a barrier to using digital technology and services. Additionally, in parts of remote Australia, reliable internet connections are not available to people, further limiting people's ability to use online services.

To enhance access to supports, care and attention needs to be given to increasing choice and service options to give people choice in delivery mode to avoid further isolating program participants. Offering diverse choice of support options will prevent further social isolation and access limitations in program delivery of future foundational supports. It is vital that place-based supports:

- Ensure delivery is accessible including venues, information and communications provided, and other practical supports for face-to-face delivery;
- provide reliable and credible information, that is free of service provider conflict of interest and informed by lived experience and/or evidence based;
- equipped to link people with their local services and build networks within their local communities.

Recommendation 11: Incorporate best practice for accessible information and supports guided by the national plan to promote accessible information and communications currently in development in the foundational supports framework.

Recommendation 12: Mitigate barriers to access by **improving diversity of service options**, including both place-based programs in person and online information in accessible formats.

Conclusion

Foundational supports are a fundamental change to the landscape of disability supports, that require leadership and centring of people with disability and their representative organisations. We need to learn and apply the lessons of the past and ensure there is a significant role for DROs to leverage their expertise and networks across the community. A foundational supports framework needs to build and expand on the grassroots services already in place that are designed to meet the needs of specific cohorts of people.
We welcome the opportunity to partner with DSS and the government to create a system of supports that meet the needs of all people with disabilities that bridges the gaps between the NDIS and other supports across the country.

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[9] Royal Commission in Violence, Abuse, Neglect and Exploitation of People with Disability: Final Report, Volume 6: Enabling Autonomy and Access. 29 September 2023 < Final Report | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability>