Young people, parents and caregivers, on General Foundational Supports

Summary of survey responses collected October 2024

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## Background

The Australian Government is working to design and deliver additional supports in the community, referred to as Foundational Supports. These specific supports are additional to mainstream services and those services delivered via the National Disability Insurance Scheme (NDIS).

There are different types of Foundational Supports. The first of these for discussion are General Foundational Supports.

General Foundational Supports are supports available to help all people with disability, including those who are on the NDIS and those who are not. General supports will generally fall into three categories – information and advice, individual and family capacity building, and community capacity building.

On 20 September 2024, the Australian Government opened a consultation period to capture feedback about General Foundational Supports. This consultation period will close on 5 December 2024.

Children and Young People with Disability Australia (CYDA) are the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA values the lived experience of the community as a basis for driving systemic change and advocating for system reform that meets the needs of children and young people with disability.

## Introduction

On 9 October 2024, CYDA launched a survey to gather feedback from young people with disability, and their families and supporters, about Foundational Supports. Across three weeks, 258 responses were received from across Australia[[1]](#footnote-2). Seventy five per cent of respondents were NDIS participants, or a family member of an NDIS participant. More than one in five respondents were adults with disability with many identifying that they were also parents of a child or young person with disability.

The highest representation of disability types was Autism (64%), ADHD (47%), intellectual disability (34%) and psychosocial disability (31%)[[2]](#footnote-3). One in five respondents reported a neurological disability, including acquired brain injury, cerebral palsy, or epilepsy.

Survey questions were designed to measure the community’s understanding and response to Foundational Supports, as well as gain insight into potential challenges or things to consider. Respondents were also invited to offer suggestions for how Foundational Supports could be designed.

This survey did not include questions related specifically to the Foundational Supports for children with developmental concern, delay and/or disability and their families, carers and kin, as this was introduced to the Government’s consultation after the survey was released.

This survey is part of CYDA’s ongoing commitment to understand how children and young people with disability, and their families and caregivers experience reform in the sector.

## Key Issues

### Young people, parents and caregivers do not believe they have enough information about Foundational Supports

Almost all survey respondents (93%) reported that they did not have enough information about Foundational Supports to understand how they would impact their lives. Of the survey responses, 100% of young people under 25 years stated that they did not currently have enough information about Foundational Supports.

There doesn't seem to be much information about what the purpose of the supports will be, and how they will help people with disability and their families. This is more important for people who aren't eligible for NDIS. (Parent of a child or young person with disability)

Combined with continual changes and reform across the sector, there was a strong sense of uncertainty and distrust. Parents reported that changes that had occured recently had been poorly communicated and implemented.

The current government and NDIS in general has given [people with disability] and their parents/carers absolutely no reason to trust them. (Parent of a child or young person with disability)

Respondents noted that even where they had actively sought information about Foundational Supports, the information did not provide any clarification. Fifty-six per cent of respondents reported that they were confused, with many noting that this was causing fear, worry, or uncertainty about the supports that would be available.

We have insufficient information as how they'll work and who they're for. People are scared about losing access to supports they presently receive (if they are removed from NDIS onto foundational supports). (Parent of a child or young person with disability)

Overall, survey responses noted the importance of clear information provided to the community in a way that is timely and accessible for all those who may be impacted.

I think every participant and caregiver could benefit from more information about Foundational Supports. (Young person with disability)

Despite the concern about limited information, 73% of respondents stated that they did intend to engage in the government consultations. Most respondents preferred to receive information via email (69.5%), webinar (49%) or via a website (42%).

### Young people, parents and caregivers are concerned about Foundational Supports replacing NDIS supports

Amongst survey respondents, there was significant worry and confusion about Foundational Supports. Almost 1 in 2 respondents stated they were feeling worried about Foundational Supports; this was much higher for young people under 25 years (80%).

While much of the concern appeared to be based on a lack of understanding, most responses expressed a fear of losing key NDIS supports with the implementation of Foundational Supports.

[I am concerned] because 'foundational supports' are being used as a reason why funding is being cut or certain supports are no longer NDIS supports, but it doesn't seem like foundational supports will replace these AT ALL. (Young person with disability)

Responses highlighted concerns children and young people would be removed from the NDIS, and forced to access Foundational Supports. With the lack of clarification about how Foundational Supports will be implemented, respondents were concerned that they may not meet their needs, but they would not have options.

They don't exist, I'm worried they won't meet [our] needs. I'm concerned my granddaughters will get kicked off the NDIS and foundational supports won't meet their needs (Caregiver of children with disability)

Generally, young people with disability appeared to be willing to better understand Foundational Supports and how they could provide support. One in four young people expressed that they were interested in the new system and what it could mean for them and the community[[3]](#footnote-4). They noted Foundational Supports had the ‘potential to be useful’[[4]](#footnote-5) and that the new system could be a ‘great opportunity to create something great where ILC failed’[[5]](#footnote-6).

Respondents who expressed some hope and optimism, did remain cautious about how any changes would impact individuals and that individuals may be removed from NDIS without an adequate alternative in place.

[I am] concerned it will take away current support from NDIS without providing the equivalent support... NDIS is not ideal, so maybe this would give equivalent or better support in more efficient and cost-effective ways. (Parent of a young person with disability)

However young people also noted that any new system has the potential to limit supports or could be ‘used to deny support to disabled people’[[6]](#footnote-7).

It could be beneficial or harmful depending on what it does and if it is a worse replacement for what already exists. (Young person with disability)

### Young people, parents, and caregivers are concerned Foundational Supports will not meet the needs of children and young people with disability

The consultation process undertaken by the Government did not provide clarity for many of the survey respondents. The discussion paper outlines Foundational Supports as including information and advice, individual and family capacity building, and community capacity building[[7]](#footnote-8).

I attended a webinar by the government and there are not going to be real supports. Just pie in the sky informational supports about being your own disability advocate. (Parent of a young person with disability)

Respondents noted concerns that Foundational Supports would, in practice, be ‘just pretty websites and fact sheets’[[8]](#footnote-9). This concern was reflected across the responses that the Supports would be informational supports and resources to build individual self-advocacy, rather than practical, useful supports to enable individuals to engage in their community.

You cannot expect people to be interested or have the personal resources to participate in a process of becoming informed about self advocacy for their own rights when their most basic needs for intervention and support as disabled people are not being met. (Parent or caregiver of a young person with disability)

There were also concerns Foundational Supports would not meet the specific needs of children and young people, particularly during middle childhood and transition into adulthood. Respondents reported a need for practical intervention and specific developmentally appropriate support that is individualised and responsive to changing life stages.

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 are either one or the other and my kids get caught in between. They don’t want to be treated like children but aren’t yet adults either. The under 18/over 18 thing just doesn’t work and they get infantilised. They also need support at the big transition times of life, especially the transition from secondary school. (Parent of young person with disability)

### Young people, parents and caregivers, are concerned Foundational Supports will not meet diversity of experiences

Respondents highlighted that accessing Foundational Supports may be difficult for CALD communities, parents with disability, parents in financial stress, parents with limited literacy and computer skills, and parents with low parental capacity. Responses also reflected concerns about how Foundational Supports would be relevant or accessible for those in the child protection system, or living in regional areas.

Concerns were raised that Foundational Supports would need to be disability-affirming, while also ensuring that they meet the diverse experiences across disability types.

Foundational supports need to be disability specific. Supports for a physical disability will not help my son with autism. There needs to be comprehensive understanding of what different disabilities look like, so that the supports will be appropriate. (Parent of a young person with disability)

A number of respondents noted that in regional areas, there were existing complexities accessing services and supports (both NDIS and non-NDIS), that were appropriate, evidence-based and affordable. Concerns were raised that this may not be considered in the design of Foundational Supports.

I live in [regional area] where we are behind best practice in education and health and lack funding and staffing in education and health. I don’t trust that there are resources for adequate supports. (Parent of young person with disability)

### Young people, parents and caregivers, are concerned about the government’s approach to consultation, and the design of Foundational Supports.

Survey responses clearly indicated a lack of understanding and confusion about Foundational Supports. With high numbers of respondents reporting that they had not heard of Foundational Supports, or they did not understand the information they were able to access. Communications relating to the consultation process, and about what has been proposed for Foundational Supports, was reportedly lacking, inaccessible, or not delivered to those who would be most impacted.

The consultation and information on foundational supports by the government has been totally inadequate. I don’t understand what they are at all. I don’t understand how they can be put in place by government or how they can be used. (Parent of a young person with disability)

Young people, parents and caregivers, also reported concerns about the way the funding would be structured. Some responses noted that they did not believe that state governments were on board, or they did not believe that state governments were well placed to design and deliver Foundational Supports.

Respondents felt sceptical about the government’s plans, and opinions were heavily impacted by the compounding of sector reforms in recent months. Changes within the NDIS and the broader disability sector, have eroded trust and confidence that governments are genuine in their consultation processes and commitment to co-designing with the community.

Overall responses reflect a strong concern that Foundational Supports have not been adequately considered to ensure they meet the needs of children and young people with disability.

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 no where else. And even that has come with it's challenges. If governments don't fund this problem it is just going to cost more money in the future and it's going to cost us and our families in terms of health and wellbeing. (Parent of young person with disability)

### Young people, parents and caregivers, have ideas about what is important to include in designing Foundational Supports.

Despite the concerns expressed throughout the survey responses, many respondents viewed the rollout of Foundational Supports as an opportunity to create a support system that would address the gaps left by the nature of NDIS.

For some respondents they noted that accessing the NDIS service system could be complex, and supports to do this – either via individual capacity building or advocacy – would enable more efficient and streamlined access.

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)

Some respondents identified the implementation of Foundational Supports as an opportunity to overcome barriers to inclusion across different aspects of the community. Individual advocacy was highlighted by multiple survey respondents as an aspect that could support inclusive community engagement of children and young people with disability.

I think a key role of foundational supports would be to help drive change in other settings, e.g. by providing workforce development and mentoring for teachers, coaches, employers and so on… We need increased Advocacy funding for Individual and group (social and systemic) advocacy to address issues and barriers to inclusion and participation. (Parent of a child or young person with disability)

Where family members were concerned about their child or young person being removed from NDIS, they regularly referred to the prohibitive costs of paying for therapy and services out of pocket. Some survey respondents identified the option of Foundational Supports providing services and supports at no cost, to mitigate the loss of an NDIS plan. It is noted, however that some of the suggestions such as allied health therapy and sensory equipment, may not meet the intended definition of General Foundational Supports and may be more suited to a future discussion about Targeted Foundational Supports.

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

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 responses highlighted design principles that were important to consider, including co-design, disability-affirming delivery, person-centred, and consistent. Responses noted service design should be flexible enough to meet individual differences and consider different disability types or a child/young person’s intersecting experiences. Foundational Supports should take into account the unique, and changing experiences of children and young people as they progress through middle childhood and into adulthood.

## Key messages

The following are key messages for consideration in the design and implementation of General Foundational Supports. These considerations are developed in direct response to the survey responses provided.

### Foundational Supports must be clearly defined and differentiated from existing supports (including NDIS supports)

Young people, families and caregivers are unable to meaningfully engage in co-design or consultation related to the design of Foundational Supports without clarification about the specific intent. Communications related to Foundational Supports have been limited, and not readily provided to NDIS particiants – or the broader community.

With recent changes to the NDIS, many young people, families and caregivers, are unclear about the differentiation between NDIS supports and Foundational Supports. This information has been inadequately communicated to date.

This survey has highlighted that young people, families and caregivers, are interested in seeing positive changes and a more equitable scheme. However with limited information about what these changes will be, there is still a high degree of scepticism, and hesitation to engage in the design process.

### The design of Foundational Supports must consider the varied experiences of children and young people with disability

Children and young people with disability live diverse lives. It is important that any service system created considers the different experiences of individuals across different identities, different life experiences, and different geographical locations.

For children and young people with disabilty living outside of metropolitan areas, there are limited services and supports available – within and outside of the NDIS. Many of the materials previously developed under ILC funding, did not address the specific challenges faced by this population.

CYDA regularly hears from the community about the importance of intersectional identities when children and young people are accessing services and supports. This includes consideration for cultural and linguistic diversity, First Nations, poverty, or gender diversity. These intersectionalities should not be considered separate to an individual’s disability, but are deeply embedded in who they are and how they engage with services.

There havee 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.

### Communication about the design and implementation of Foundational Supports must be clear, timely, and accessible

Providing widely-available clear information, in accessible formats, will build trust within the community, and support positive engagement. Young people, families and caregivers, have shown curiosity toward Foundational Supports. As part of the design and implementation, NDIS participants and the general community, should be well informed about how Foundational Supports will provide meaningful impact on the lives of children and young people with disability.

With ongoing reforms, it is important information is provided in accessible ways. This includes careful consideration of the communication channels, as well as the format of information. Scheme participants must receive information directly to ensure they are clearly and directly informed of changes that have a direct impact on their lives.

### The design of Foundational Supports should be underpinned by key best-practice principles.

The design and delivery of Foundational Supports should be heavily informed by best-practice in disability and rights-based approaches.

Children and young people with disability, and their families and caregivers, have high expectations of the support systems that are in place. They seek a support system that is neuro-affirming, culturally-appropriate, and trauma-informed.

Where Foundational Supports include the creation of resources, they should meet the highest standards of accessibility, as standard practice. Engagement or consultation must be offered in a way that is accessible and acknowledges disability discourse.

The design of any new service system must be developed via a genuine co-design process with the community. In order to do this, information must be clear and made accessible to a wide variety of stakeholders. The experiences of children and young people with disability in the current context, must be captured by engaging directly wherever possible.

## Conclusion

CYDA acknowledges the experiences of children, young people, and their families and appreciates their time to complete this survey. Their voices and perspectives play a key role, now and always, in designing CYDA’s advocacy and informing our messages to government.

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1. Survey was open from 9 October 2024 until 31 October 2024 [↑](#footnote-ref-2)
2. Many respondents reported multiple disability types. [↑](#footnote-ref-3)
3. 25% of young people expressed interest in learning more, compared with 28% overall [↑](#footnote-ref-4)
4. Young person with disability [↑](#footnote-ref-5)
5. Young person with disability [↑](#footnote-ref-6)
6. Young person with disability [↑](#footnote-ref-7)
7. Information accessed on the DSS Engage website (<https://engage.dss.gov.au>); 22 November 2024 [↑](#footnote-ref-8)
8. Parent or caregiver of child or young person with disability [↑](#footnote-ref-9)