

Disability Advocacy Network Australia

# PRIORITIES PROJECT REPORT



## INTRODUCTION

The NDIS Review and the Disability Royal Commission have delivered their final reports at the end of 2022 and 2023, laying out blueprints for reform that could profoundly change the lives of people with disability across Australia.

The Disability Royal Commission ran for four and a half years, and the NDIS Review for a year. During those years, people with disability, families, supporters, kin and our representative organisations told our stories of despair and hope, of frustration and innovation, of the past and the future.

The two final reports have a combined **248** recommendations and **139** supporting actions that cover everything from new governance models, to changes to schools, to fixing complaints, to removing barriers to work, to ending legal violence and much much more.

The complexity and breadth of these blueprints is hard to overestimate, and the timelines for reform are long – for some recommendations, out to beyond 2050.

We are impatient for change, after years of fighting, of telling our stories, of figuring out solutions and campaigning for an end to the abuse so many of us live with.

This priorities report sets out a clear set of key issues from both reports, as well as practical examples of where change can start, right now. These changes don't need another strategy, or more consultation, or more delay. They need to start now.

People with disability have been through some very hard years, living with the Disability Royal Commission, threats to the NDIS, the unfairness of the systems outside the NDIS and of course, COVID.

Our community needs a downpayment of trust, an investment in the positive future we have worked so hard to realise, so we can be assured these reforms are heading in the right direction.

These key priorities are practical, local, and can be up and running in the next year or two. In doing this work, we listened to our community. Together, we talked about the key issues and thought about pathways to change.

The wider blueprints from both reports will take years to fully implement. People with disability have waiting long enough for change, the time to act is now.

## **ACKNOWLEDGEMENTS**

## **Acknowledgement of Country**

The Priorities Project team worked across unceded Boon Wurrung, Kaurna, Wiradjuri, and Wurundjeri land while completing this work, and consulted with advocates and people with disability across many other lands. We pay our respects to Elders past and present and recognise the continuing connection of First Peoples to lands, skies, waterways, community and culture. Sovereignty was never ceded, and this always was and always will be Aboriginal land.

DANA uplifts the work of First Peoples Disability Network, the peak body for Aboriginal and Torres Strait Islander people with disability, and the National Disability Footprint.

Learn more about the Footprint at: <a href="https://fpdn.org.au/national\_disability\_footprint/">https://fpdn.org.au/national\_disability\_footprint/</a>

## Acknowledgements —

To complete the Priorities Project, we consulted extensively with people with disability, disability representative organisations and the independent disability advocacy sector, who are facing critical underfunding and service pressures nationwide. We thank all the advocates and people with disability who gave us their time to participate in the project - some of whom attended multiple consultations, had one-on-one conversations about specific locations and topics, wrote detailed survey responses from their lived experience, and sent through submissions, examples of services or supports, and ideas for reform. Independent disability advocates, many of whom are people with disability themselves, are a rich source of expertise on disability and mainstream-specific systems and processes, the critical intersections and safeguards, and most of all, what needs to change.

## **Glossary**

The disability sector uses many specific or unique terms and acronyms. In order to navigate complex systems and processes, people with disability and their families, friends, allies and decision supporters often need to learn what feels like a whole new language. Here, we share some of the most common phrases to support you in understanding our work.

**Australian Disability Enterprises (ADEs):** Segregated employment for people with disability (often with an intellectual disability). People working in ADEs are paid much less than the legal minimum wage for everyone else.

**Closed settings:** These are also called segregated environments and are environments that are not freely accessible by the public ('closed' to the public). This includes disability group homes, day services, special schools, and ADEs, but also includes non-disability focused environments like hospitals and prisons.

**Disability Royal Commission (DRC):** The Disability Royal Commission ran for over 4.5 years and heard from nearly 10,000 people with disability through hearings and submissions, producing a final report with 222 recommendations.

**Group homes:** Homes for people with disability, usually funded by the NDIS, where multiple people with disability live. These are sometimes called congregate settings or congregate living, or referred to as 'SIL homes'. Group homes can be small or large, with some having two people sharing a home, and others having up to 10 or even 20 people in the same house or site. People who live in group homes may not choose what time they wake up, what they eat at meals, and who their housemates are. The Disability Royal Commission has recommended the phase-out of group homes.

**Independent Living Options (ILO):** A newer and less clearly defined type of home and living support than Specialist Disability Accommodation or Supported Independent Living.

**National Disability Advocacy Program (NDAP):** The program that funds independent disability advocacy organisations at a national level.

**National Disability Insurance Scheme (NDIS):** The primary body providing disability support to Australians with disability under the age of 65.

**NDIS Review:** The independent review of the NDIS ran for 12 months and produced a final report with 26 recommendations and 139 supporting actions.

**Segregation:** The act, choice, or practice of keeping people with disability separate to the rest of the community. We also talk about desegregation: the process of removing segregated environments and including people with disability in the wider community.

**Specialist Disability Accommodation (SDA):** Physically accessible homes for people with disability. This support is funded for a very small amount of people with high-level home accessibility and support needs.

**Supported Decision Making (SDM):** A principle that focuses on making sure people with disability, especially people with an intellectual disability, have the support they need to make their own decisions about their lives instead of having decisions made for them by other people (which is called substitute decision making). People who support someone to make their own decisions can be called decision supporters.

**Supported Independent Living (SIL):** High-level disability support in the home, frequently provided 24 hours a day, 7 days a week. Frequently provided in group homes. People must apply and be assessed for SIL to receive SIL funding.

## A SNAPSHOT OF DISABILITY IN AUSTRALIA

To understand what needs to change, it is important to understand what it is like to be a person with disability in Australia in 2024.

## People with disability in Australia

- About one in five (19%) people in Australia are people with disability.
- Only around 12% of Australians with disability use the NDIS to get disability support, with many
  receiving no formal or community supports at all. The Scheme was not designed to support all people
  with disability from its inception and has always focused on supporting people with disability who have
  significant functional impact.
- People experience many different kinds of disability with different impacts. Most people with disability receive no funded disability support at all.

## **Accessing the NDIS** -

- To get onto the NDIS, people with disability need to satisfy NDIS access criteria. People with disability need to prove their disability is eligible for the NDIS, permanent, fully treated (in some cases), and results in significant functional impairment requiring ongoing support.
- Getting the evidence to get onto the NDIS can cost thousands of dollars and require visiting one
  or more specialists to gather specific evidence for Scheme entry. Bulk billing specialists are rare in
  Australia, so in order to be eligible for support, people with disability usually face significant cost
  beyond Medicare reimbursements.
- People who access the NDIS have an NDIS plan, which explains the supports they can receive and
  the budget they have for their supports. Plans can last from one year to longer plans of two or three
  years. Until a person's next plan is confirmed, they have no guarantee of NDIS support for the future and even then, the support they know they will get is limited to the plan duration.

## People with disability and poverty -

- People with disability are one in five Australians, but one in three people living in poverty. People with disability are significantly more likely to experience poverty than people without disability.
- Over 750,000 people with disability receive the Disability Support Pension. The maximum payment
  for a single person with disability people who are partnered receive lesser payments including
  additional payments is \$1,096.70 per fortnight. As of June 2023, the Henderson poverty line is at
  \$602.27 per week, or \$1214.54 per fortnight. A single person relying solely on the Disability Support
  Pension and unable to work will be living in poverty.

"Many people with disability do not want more bureaucratic processes and professional staff or services. Their main concerns are secure accommodation, employment opportunities and affordable food, petrol and household goods."

— Disability advocate

- Around 40% of people receiving Jobseeker and participating in jobactive employment programs (being required to look for work) have a disability. The Jobseeker payment is well below the Henderson poverty line at \$749.20 per fortnight maximum for a single person (under 55 years of age).
- Housing is a critical issue impacting all Australians, but the effects are more strongly felt by people
  with disability, who are more likely to earn less money and are overrepresented compared to
  mainstream populations across income support payments, including Jobseeker and the Disability
  Support Pension.<sup>1</sup>
- Having a disability results in significant extra financial cost. People with disability need at least 50% more income to have a similar standard of living to people without disability.<sup>2</sup>







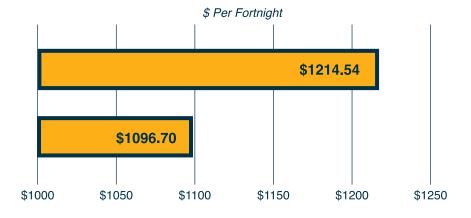




40% of people receiving Jobseeker and participating in jobactive employment programs have a disability

The maximum payment for a single person with disability including additional payments is \$1,096.70 per fortnight.

As of June 2023, the Henderson poverty line is at \$1214.54 per fortnight.



## **HOW DID WE IDENTIFY PRIORITIES?**



## The numbers











## • •) Who we spoke to -

- Disability Representative Organisations (disability peak bodies)
- DANA members
- · Independent disability advocates
- Other individual experts
- · Survey for people with disability, many of whom also attended consultations
- Our consultations included people from every state and territory in Australia, with representation
  of rural, remote and very remote areas and operating conditions, multiple marginalisation and
  intersectional experiences



## How we gathered data

- One-on-one informal conversations with Disability Representative Organisations to understand DRC/ NDIS Review positions
- One-on-one conversations with other individual experts on different areas related to disability policy, service delivery, community services and infrastructure
- Thematic facilitated conversations with systemic advocates on Education, Housing, Safeguarding and Foundational Supports
- State-by-state consultations on proposed Foundational Supports, local operating conditions, and area-specific needs

- Survey for people with disability about responses to the DRC/NDIS Review and proposed reform (also completed by independent disability advocates)
- Reform: how do we get there? consultations, where we focused on identifying practical solutions for the immediate future



## Written submissions and evidence

Information sent to us and reviewed by the Priorities Project team included:

- Submissions to the Disability Royal Commission and NDIS Review
- Responses to the Disability Royal Commission and NDIS Review
- Responses to other relevant enquiries, like the National Housing and Homelessness Plan and the Early Years Strategy
- Written reform feedback from organisations, committees, and advisory groups
- Studies and academic resources about the experiences of people with disability
- · Examples of programs, supports and services historical and present-day
- Two advocacy organisations consulted with service users and sent through specific Priorities Project feedback gathered from people with disability directly



## Who didn't we speak to? And who wasn't represented?

This project began from the recommendations of the Disability Royal Commission and the NDIS Review, whose recommendations were based on the input received during the submission period. We know that not every person with disability was able to be heard during the Royal Commission. Many people - for example, those with safety or legal considerations and people with disability living or spending time in closed settings - were less likely or not able to contribute. We acknowledge this and ask that the Federal Government considers those who were not able to be heard in both this work and in the Royal Commission and NDIS Review responses.

## WHAT PRIORITIES DID WE HEAR ABOUT?

The Priorities Project was, at its core, about listening. We spent 40 hours over eight weeks in consultation with the independent disability advocacy sector, subject matter experts, and people with disability. Together, we discussed the biggest problems our sector is facing and identified pathways to a better future.

The disability advocacy sector has identified six clear priorities from the reform processes:

- 1. Access and eligibility for disability support
- 2. Housing
- 3. Safeguarding
- 4. Establishing Foundational Supports
- 5. Representation and inclusion
- 6. Advocacy

## 1. Access and eligibility for disability support

- All advocates said similar things: there is almost no support available for the 88% of people with
  disability outside the NDIS. Local government and state-based services have largely wound down
  since the introduction of the NDIS, with the perception that all people with disability would be able to
  access disability support through the NDIS. There are still some existing outlier supports, but these
  are rare and often unable to meet demand.
- Some states have short term support schemes available, but these are not designed for long term support or disability needs. These schemes are usually time-limited, have specific access criteria (NDIS rejection or transition from hospital), offer very low levels of support compared to the NDIS, and do not allow for choice of provider or even individual workers. Some require a financial contribution from people with disability, many of whom live in poverty and find this difficult or impossible. Many advocates spoke about these supports, and not one advocate we heard from thought they met or could meet the needs of people with disability.
- Regional, rural and remote areas experience significantly more systemic disadvantage and may also
  not have access to infrastructure or funding that is expected to exist in larger cities. This needs to be
  a strong consideration in thinking about what is needed for the roll-out of Foundational Supports in
  these areas there will likely be additional foundational investment required to build a strong program
  of supports outside the NDIS.
- Currently, there are no consistent physical places to go to learn about available support and connect
  with other people with disability. People with disability, especially people who do not have access to
  computers or internet, need physical options to seek advice and support.
- Resources are available online, but the information tends to be complex, particularly around
  eligibility and service access, which can be very individualised. Additionally, much of the most useful
  community-based information requires connecting with the right organisations and social media
  groups to benefit.

- Assessments that are likely to meet NDIS eligibility criteria can have significant financial cost for
  people with disability. Many people with disability live in poverty and cannot afford the assessments
  they need. They are likely to go entirely without support until that is no longer an option, only
  accessing systems when they are in crisis due to the lack of previous supports. Crisis is expensive,
  unnecessary, and not something people with disability should need to go through to get support.
- The NDIS uses and prefers certain language to prove a person's disability is stabilised, permanent
  and requires ongoing support to get access to the NDIS. Without this knowledge, applications
  frequently are declined or further evidence is requested, meaning people with disability take longer to
  get the support they need.
- The quality of access evidence is dependent on practitioner knowledge of the system. Practitioners
  providing evidence can be sole traders or small businesses. This means knowledge on the application
  process is dependent on its filtering down through peak bodies, professional accreditation, training
  and networking, or through personal experience with NDIS applications. DANA members say that
  application evidence continues to be an issue, suggesting current sector learning processes are not
  working.
- Outside the NDIS, there is no real help and support for aids and equipment. There is some assistance
  available through aged care systems, but for people with disability under 65 there are no clear referral
  pathways to access technology.



## 2. Housing

- Every single consultation talked about housing as a critical issue impacting people with disability.
   People without disability are also experiencing the housing crisis. However, people with disability are disproportionately impacted.
- People with disability also experience more flow-on effects from moving homes. A person who has to
  move house (or move states) may lose access to their support team, specialists, general practitioner,
  or change Local Area Coordinators. This can have major effect on disability support, NDIS plan usage,
  and evidence gathering or reporting, all of which can affect future support allocations.
- Accessible homes are very difficult to find across the country. Most people with disability on the NDIS
  do not qualify for Supported Independent Living or Specialist Disability Accommodation funding.
- The fact that all states have not willingly signed up to the National Construction Code is distressing for people with disability and for advocates.
- We need to change the conversation around accessible housing. Accessible homes are accessible for
  everyone across their lifespan. Building accessible homes to start with means a person can remain
  in their home for longer without significant retrofitting. This value proposition is not understood by the
  general public or by decision makers in the construction space.
- Housing within the NDIS is an extremely complex topic, with multiple different streams and many
  new terms and acronyms to learn (SDA, SIL and ILO are some of the common acronyms). There is a
  strong need for detailed guidance for people who have or need NDIS housing support.
- Outside the NDIS, there is no real support for housing for people with disability. People with disability do not generally have the same ability to compete for housing as people without disability.
- Currently, home modifications are largely only available within the NDIS. This means many people
  with disability who would benefit significantly from home modifications are unable to access them or
  are forced to self-fund if they can afford to.
- There can be significant barriers to home modification nationally renting, being a social housing tenant, councils and planning can all impact the ability to implement home modification regardless of need or available funds.



## 3. Safeguarding

- There is strong agreement across the sector that the current safeguarding system is not working and is not keeping people with disability safe.
- In the NDIS, the Quality and Safeguards Commission focuses on providers, not complaints. People with disability and advocates do not feel complaints are appropriately escalated and dealt with.
- Community Visitor Schemes can be a useful safeguard, but in many areas there are limits to what environments they can access in their work (e.g. accessing disability service sites). Community Visitors are also generally unpaid for their time, meaning safeguarding is currently sitting within an unpaid workforce. The Disability Royal Commission recommended nationalising the program.
- Serious incidents that would be considered criminal in mainstream environments are not always seen
  as criminal within disability service provision. Crimes can be reported as "service incidents". When
  this happens, people with disability are not supported to understand a crime has occurred and seek
  justice.
- The Disability Royal Commission has recommended the closure of segregated or closed settings for people with disability, including group homes, special schools and Australian Disability Enterprises (ADEs). The disability advocacy sector is generally supportive of this recommendation. Segregation is seen as an inherent risk for people with disability.
- Some people with disability who have lived, worked, or attended closed settings group homes, special schools, ADEs, and day services - had good experiences. We need to acknowledge people for whom the current systems and supports are working and who will experience major impact from reforms.
- People with disability are frequently segregated in housing. The Royal Commission has recommended
  the closure of all group homes. However, moving from a segregated environment to a desegregated
  environment doesn't guarantee inclusion. Investment is needed to make sure the community is safe
  and inclusive for people with disability.
- Case management (holistic, whole-person support for people with disability) has been wound down as a support since the NDIS was rolled out, leaving support to be guided by funding availability (e.g. support coordination services, whose goal is to find and engage NDIS supports).
- In Priorities Project consultations, we heard about critical support gaps people with disability who are interacting with the justice system, experiencing behaviours of dysregulation, and people experiencing life transitions (like leaving school or moving interstate).

## 4. Establishing Foundational Supports

- Responses were highly mixed and included:
  - A valuable opportunity for people who aren't accessing 'the system' to have their needs met.
  - A return of some supports that existed previously before the NDIS.
  - More layers of bureaucracy for people to slip through the cracks. This is a particular concern for advocates who have now started navigating Community Connector plans as a precursor to NDIS entry for people with disability.
  - The early information doesn't say much and it's hard to make a clear judgement on proposed support.
  - The most-used phrase in consultation was "The devil's in the details". People want to know what is coming before they can clearly make a judgement on proposed reforms.
- While the sector does not know what the Federal Government has planned for foundational supports, there is strong acknowledgement: things need to change, and the current system is not working.
- This is going to be a big change and it needs to be well managed. Changes should happen on a reasonable timeframe, with a phased approach to ensure nobody is left behind and everyone can participate.
- There needs to be clear information and communication (including accessible formats and language translation) on what will happen, when it will happen, and what the steps to change will be.
- Different areas in Australia have different service environments, needs, and considerations in order to successfully roll out foundational supports. Understanding the environment on a national level needs to be the first step towards a successful second tier of disability support.
- There also needs to be a willingness to do things differently for different areas, needs, and groups of people and to avoid a one size fits all approach.
- While it is true that the NDIS has resulted in the winding down of many disability services outside the NDIS, some services and supports have survived or been funded through other funding streams. We need to understand what is still available to ensure that support continues and is not unnecessarily duplicated.
- Despite broad agreement of its value to people with disability, peer support has been poorly served by
  the individualised funding environment. Many peer support programs are now 'locked' behind NDIS
  funding requirements, leaving people without NDIS plans unable to access them. Those that are
  not funded through NDIS plans typically use Information, Linkages and Capacity Building grants to
  provide the support to people with disability for free. ILC funding is due to end on 30 June 2024 and
  these services are at risk of immediate closure.
- There is broad community concern about what implementation will look like, whether it will be appropriately designed with and for people with disability, and whether it will meet community needs.

## 5. Representation and inclusion

#### We heard:

- People with disability are, and need to be, the key influencers and drivers of change that affects us. Nothing about us happens without us.
- When people with disability are consulted with particularly people with an intellectual disability the consultations are frequently not accessible due to short notice, lack of inclusion support, or lack of accessible information (Easy Read).
- People who have lived, worked or gone to school in closed settings usually don't get asked about
  what they want and need directly. It takes significant outreach and inreach work to find and consult
  with people with disability in closed settings, and it often does not happen or is seen as "too hard".
- People who are in closed settings tend to be underrepresented in disability community feedback and reforms. As the biggest impacted group, there is significant risk of people with no segregation experience guiding the reform process and advising solutions that are not what people with lived experience actually need.

## 6. Advocacy

- Advocates cannot meet existing demand for advocacy support, and do not feel confident that a person
  with disability will get what they need if they are turned away or referred elsewhere.
- Advocates are picking up the slack of complex and inaccessible systems, supporting people to enter the NDIS, with evidence gathering, and with NDIS refusals or requests for further evidence.
- Many advocates are overwhelmed by the needs and questions of people with disability who have come to them after not getting clear answers or help elsewhere.
- Across the different forms of advocacy, advocates are already feeling the pressure to understand and
  respond to proposed reforms, and are also receiving enquiries about proposed reforms already. We
  think this will only increase over time as reform is implemented, and advocates already cannot meet
  existing demand.



## HOW DO THE REFORM PROCESSES ADDRESS THESE PRIORITIES?

The priorities identified in the Priorities Project are not new problems and were also identified throughout the Disability Royal Commission and the NDIS Review. The Disability Royal Commission and NDIS Review were lengthy pieces of work, and it is not possible to discuss every recommendation at length. We have selected some key recommendations and proposed actions that address the priorities identified by people with disability to understand what has been recommended, and where we can build from to create real change.

## 1. Access and eligibility for disability services and supports

Both the Disability Royal Commission and NDIS Review acknowledge access and eligibility as an issue. One key recommendation from the Disability Royal Commission is the development of 'provider of last resort' options across states and territories to ensure there is always a support option for people with disability. The NDIS Review has recommended the development of a unified system of support for people with disability (including the introduction of foundational supports), as well as recommending support for all people with disability to navigate mainstream, foundational and NDIS service systems.

## 2. Housing

Housing is a big topic in both the Disability Royal Commission and the NDIS Review. The Disability Royal Commission has recommended the phase-out of group homes, and the NDIS Review made significant recommendations for changes to NDIS housing. These recommendations and their action items include the introduction of Housing and Living Navigators, the option to trial new living arrangements before committing, and facilitating decision making between people sharing supports. Many actions are about Specialist Disability Accommodation, including administrative and pricing changes, strategies for upkeep and transition, and the commissioning of more SDA housing by the NDIA to address need.

## 3. Safeguarding

Both the Disability Royal Commission and NDIS Review discuss safeguarding as a key issue, including reducing and eliminating restrictive practice usage. The NDIS Review recommends 'embedding effective quality and safeguarding institutions and architecture across the disability support ecosystem' broadly, while the Disability Royal Commission recommends the implementation of a 'one-stop shop' complaints process. The Review also acknowledges that there is a need for safeguarding processes to ensure people with disability do not fall through the cracks during reform, recommending an implementation roadmap, founding an NDIS Review Implementation Working Group, and highlighting the responsibility of the NDIA to ensure transitions are smooth and fair. In addition, both pieces of work support a nationally available and consistent Community Visitor Scheme.



## 4. Establishing Foundational Supports

The NDIS Review defined the term 'foundational supports', acknowledging the strong need for support for people with disability outside the NDIS. The Review recommended investment in and design of foundational supports at both the federal and state/territory levels, including the development of a Foundational Supports Strategy.

## 5. Representation and inclusion

Co-design and consultation are big themes across the Royal Commission and NDIS Review, including in announcements and socialisation of the work. There are no specific recommendations to increase share decision making or increase the lived experience of the NDIS workforce in the NDIS Review. There is a recommendation to embed a 'highly skilled, person-centred, disability aware culture across all disability agencies and governments'.

The Disability Royal Commission makes strong recommendations for First Nations disability leadership, with a recommendation for the establishment of a First Nations Disability Forum and a focus on developing First Nations workforces in remote communities.

## 6. Advocacy

Both the Disability Royal Commission and the NDIS Review affirm the importance of independent disability advocacy. The Disability Royal Commission final report has strong recognition of the importance of independent disability advocates throughout its final report, recommending that the NDIA co-designs a program to connect people living in supported accommodation with independent disability advocacy. The NDIS Review final report asks the National Cabinet (not just the Federal Government) to fund advocacy supports, noting that advocacy plays a critical role in promoting, protecting and defending the human rights of people with disability.

## WHAT ELSE CAN WE DO TO ADDRESS THESE PRIORITIES?

Priority 1: Access and eligibility for disability services and supports

## 1. Pilot Community Inclusion Hubs for people with disability

"There is no place to go for good, collated information on community supports, programs, equipment etc. Family have to become keyboard researchers to find out about options. It takes months of work and often multiple purchases or hours of negotiating with health professionals to find the right piece of equipment or activity to suit the person with the disability. The time that takes is not valued, seen or recognised, it is just expected." —**Person completing survey on behalf of a person with disability** 

#### WHAT IS IT?

We recommend piloting a disability-led, place-based approach to disability community, connection and support. Community Inclusion Hubs would serve as local hubs for information and resources, initial connections to disability services and supports, spaces for disability groups to meet, host activities or run information sessions, host libraries and equipment for hire, and provide space for accessible co-working or networking. They should also provide walk-in support for people experiencing crisis. There is massive potential in having dedicated disability spaces across the country, and these locations could also support the proposed roll-out of foundational supports, potentially host Navigators, and be a key resource for reform activities as well.

The idea of place-based community inclusion and support hubs is not new, and exists across many sectors, including within the disability sector. Notable examples include the <u>Paterson Street Hub operated</u> by First Peoples Disability Network and the <u>Safe Haven Program</u> in New South Wales.

#### WHO SHOULD BE INVOLVED?

Pilot Hubs should be federally funded as a foundational support for three years, with the view to evaluate and extend the program at the end of the trial period. In order to make sure all implemented Hubs are accessible and culturally appropriate, there should be a funded co-production group involving intersectional disability representative organisations, including National Ethnic Disability Alliance and First Peoples Disability Network.

#### WHERE WILL IT HAPPEN?

Pilot sites should be selected on the basis of representation across geographic areas (metro/regional/rural/remote), available infrastructure, and community needs.

#### **HOW CAN WE GET STARTED?**

- Partner with key disability community organisations, including FPDN, to design and roll out pilot Hubs.
- Partner with local councils in identified pilot areas to identify available and accessible locations for proposed Hubs, including appropriate modifications if required.
- Block fund the supervision and operation of Hubs, including strategic oversight, individual Hub management and employees, and funding to trial different Hub activities and events.
- First Peoples Disability Network (FPDN) currently runs the Paterson Street Hub in Tennant Creek. We recommend FPDN as the key partner to lead project evaluation for pilot Hubs.

## 2. Establish a disability aids and equipment scheme outside the NDIS

#### WHAT IS IT?

Trial a new disability aids and equipment scheme, similar to the Goods, Equipment and Assistive Technology Scheme currently running in the aged care sector. For the disability community, maximum funding for items should be significantly larger than \$2500. We recommend a maximum of \$5000 for lower risk or cost items and a \$15,000 maximum for higher intensity assistive technology.

#### WHO NEEDS TO BE INVOLVED?

The Federal Government will need to establish a new funding body similar to JobAccess. There should also be an existing service scan to identify all assistive technology practitioners across the country to establish delivery pathways and identify gaps, as not all geographical areas have access to assistive technology currently.

#### WHERE WILL IT HAPPEN?

- National delivery using a 'hub and spoke' approach, with the new dedicated scheme body at the centre, and assistive technology providers funded to fulfil and provide ongoing support for assistive technology orders.
- The Federal Government should commit to establishing a nationalised aids and equipment process as a foundational support.
- Establish an Assistive Technology Roundtable of all current assistive technology providers in the country. This includes providers who are developing or customising assistive technology for free or low cost.

#### **HOW SHOULD IT BE FUNDED?**

As a targeted foundational support (for people with disability who are not eligible for the NDIS)

## **Priority 2: Housing**

## 1. Trial specialist housing Navigators as part of NDIS reform

#### WHAT IS IT?

Trial a new Navigator workforce that specifically focuses on disability housing, including SIL/SDA eligibility and applications, finding accessible and affordable housing for any person with disability who needs support, social housing applications, and innovative housing solutions. Housing Navigators should not just support people with disability, but also engage with construction peak bodies, SDA developers and other key housing availability actors to advocate for accessible and available housing for people with disability.

#### WHERE SHOULD IT HAPPEN?

Specialist Navigators should be trialled at selected locations in line with the NDIA Navigator roll-out.

#### WHO SHOULD BE INVOLVED?

The Navigator workforce administration has not yet been made clear, but it is expected that the NDIA will recruit and administer Navigation supports. In order to utilise existing Housing expertise, it is recommended that the NDIA connects with existing disability housing organisations, advocates,

#### **HOW CAN WE GET STARTED?**

- The NDIA should agree to include specialist Housing Navigators in their response to the NDIS Review.
- When recruiting Navigators, the NDIA should look to the existing disability housing expertise across the sector and hire people with lived and/or professional experience of housing systems and processes.
- The NDIA should, as part of the Navigator roll-out, develop a plan for Specialist Navigator trial sites.
   This allows the opportunity for other kinds of specialist navigation. Specialist Navigators should be allocated to trial sites for a period of at least two years.

#### **HOW SHOULD IT BE FUNDED?**

There is little information available about the Navigator role at present, but it is assumed Navigators will be funded by the standard NDIA operating budget.

#### 2. Establish a home modification scheme outside the NDIS

#### WHAT IS IT?

Broaden the accessibility and availability of home modifications by establishing a home modification scheme outside individualised NDIS funding. This scheme should be run at a national level with a similar application and approval process to JobAccess, the nationalised system providing funding, assistive technology and workplace modifications for people with disability.

#### WHO SHOULD BE INVOLVED?

The Federal Government will administer this scheme at the application, assessment and approvals level. Modification work will be undertaken by approved providers, as with the current process for JobAccess workplace modifications.

#### WHERE SHOULD IT HAPPEN?

At the national level.

#### **HOW CAN WE GET STARTED?**

- Establish a new home modification scheme with a similar design to the JobAccess process.
- It is recommended that the Federal Government also commissions a home modifications scan to identify the non-financial barriers to home modifications for people with disability. There are many significant gaps in who can access home modifications including people living in social housing.
- Once identified, any gaps should be resolved. This may involve legislative changes or directives to Government departments and initiatives, as well as collaboration across the aged care or veterans' support sectors.

#### **HOW SHOULD IT BE FUNDED?**

As a targeted foundational support - support for people with disability who are not eligible for the NDIS.



## **Priority 3: Safeguarding**

"Understanding, wholistic case management, good planning and problem solving. Appointments and being passed from one service to another for people's multiple needs is exhausting. We need someone to do a lot of the research for us and provide morale support as we go." —Person with disability

## 3. Pilot specialist case management supports for people most in need as a precursor to 'provider of last resort' recommendation implementation

#### WHAT IS IT?

The Federal Government should establish a specific pilot of holistic case management to understand the need for case management in the current disability environment. We heard about many situations in which people with disability could use this support, including:

- · Transitioning from the justice system
- Young people with behaviours of dysregulation who may become at risk of not being able to live at home
- · Children and young people with disability in out of home care
- Family case management for families where both a parent and a child have a disability, or where there are several children with disability with different support needs
- Times of transition, like moving interstate or changes in functional capacity including suddenly acquired disability

The Disability Royal Commission has recommended the implementation of a provider of last resort scheme, designed to address thin markets, enable service access for people in crisis situations, and access to case management for people at risk of violence, abuse, neglect and exploitation. Piloting specialist case management would play a key role in both the establishment of a provider of last resort scheme and in identifying where similar schemes and processes are currently operating or have operated in the past, building the evidence base for a nationwide expansion. After the trial period, the Federal Government should evaluate and consider the roll-out of independent case management for more cohorts and to more jurisdictions.

#### WHO NEEDS TO BE INVOLVED?

This work will be delivered by the Federal Government as part of foundational supports. An independent evaluation with an academic partner with specific experience in co-design with people with disability will be required to evaluate the effectiveness.

#### WHERE WILL IT BE DELIVERED?

Selected trial sites nationally. We recommend including separate pilots for adults and children to fully test the value of specialist case management across different groups.

#### **HOW CAN WE GET STARTED?**

- Decide on key pilot sites and cohorts to focus on.
- Engage with existing independent disability advocates in pilot areas to understand current service delivery needs.

#### **HOW SHOULD IT BE FUNDED?**

This should be run as a dual pilot with specific sites for children and adults. Priorities Project consultations indicated strong need for specialist case management in Queensland, and we recommend piloting in South Australia to build off existing ECEI pilot infrastructure.



## **Priority 4: Establishing Foundational Supports**

1. Mapping what people with disability need from foundational supports, and what existing services and supports are at risk of closure

#### WHAT IS IT?

Foundational supports must start from a clear picture of currently available services and supports, including thin markets, existing services and support and specific area needs. The service landscape is complex, with many supports having wound down, major service gaps, and existing programs and projects that are about to lose funding - such as remaining local government home and community care programs and projects funded under NDIS/DSS Information, Linkages and Capacity Building funding.

Instead of a government-level analysis, we propose that the disability community map existing disability services and supports with the co-development and implementation of a new citizen science tool to collect disability data. Data collected would feed directly into the National Disability Data Asset and provide a clear picture of inclusion in Australia across different areas and services, including mainstream services and supports.

#### WHO WILL BE INVOLVED?

DANA will be the key coordinator and primary funding administrator of the citizen science project, with distribution and data capture happening through its members and people with disability. In order to be truly effective, the NDIA will need to encourage data capture and involve Local Area Coordinators.

#### WHERE WILL IT HAPPEN?

This project must happen at the national level with the right national partners in order to be effective.

#### **HOW DO WE GET STARTED?**

- Commit funding at the Federal level for Foundational Supports mapping and the co-development of an appropriate citizen science tool.
- The Federal Government should coordinate a citizen science roundtable involving DANA and appropriate data bodies, like universities, the Australian Institute of Health and Welfare, the Melbourne Institute, or the Australian Bureau of Statistics. Sharing knowledge on the benefits of better data collection and strengthening data gathering partnerships will contribute to wider knowledge of disability across Australia.

#### **HOW WILL IT BE FUNDED?**

Block funding allocation as part of the DSS transition.

## 2. Invest in peer support best practice to solidify peer work as a key foundational support

#### WHAT IS IT?

Peer support - where people with disability learn from each other, not from service providers or health professionals - is an important source of knowledge and connection for many people with disability, as well as a key economic opportunity for those delivering peer support. Peer support delivery has been fragmented throughout the NDIS roll-out and maturity period, with organisations either delivering through time-limited grants or locking services behind NDIS funding allocations. We recommend trialling a peer support program with a robust lived experience career and education pathway, led by people with disability, to develop and entrench this key foundational support. It is suggested to offer a two-year fixed grant to the appropriate organisation to develop best practice training and curriculum.

#### WHO WILL NEED TO BE INVOLVED?

Community Disability Alliance Hunter, or CDAH, are one of the premier disability-led peer support organisations in Australia, with a strong history of peer support innovation and delivery dating back ten years. It is recommended that CDAH be funded to develop a new peer-led peer work model, associated curriculum, and training offerings. To test and implement the model and training for the roll-out of Foundational Supports, the grant period should run for at least two years.

#### WHERE WILL IT HAPPEN?

This should be piloted in the Hunter region, where there are existing strong disability communities and the appropriate peer organisations with experience dating back to the last period of significant change - the trialling and roll-out of the NDIS in 2013. The proposed peer work curriculum and training will be available nationally at the conclusion of the project. DANA will support this project, distributing materials through its members and through its role as the National Coordination Function for Disability Representative Organisations.

#### **HOW CAN WE GET STARTED?**

Commit funding for the development of a peer-led peer networking model, curriculum and training offerings.

#### **HOW WILL IT BE FUNDED?**

Pilot project - block funding, with the goal to develop the peer support sector and secure peer support as a foundational support going forward.

### 3. Test a key foundational support in areas with existing critical needs

#### WHAT IS IT?

Supports or programs that seem simple can make huge differences to the ability of people with disability to access their community. To understand the impact foundational supports can have, we recommend trialling community transport services for people with disability across several trial sites. Trials should be appropriately evaluated and used to inform further roll-out of foundational supports.

#### WHO WILL NEED TO BE INVOLVED?

The Federal Government will need to partner with trial site local government areas for project delivery.

#### WHERE WILL IT BE DELIVERED?

Community transport as a foundational support should be trialled across several sites across metropolitan, regional, rural and remote areas. During the Priorities Project consultations, Alice Springs was mentioned as an area with a strong need for community transport. DANA recommends that Alice Springs be a community transport trial site as a result.

#### **HOW DO WE GET STARTED?**

- Select key trial community transport sites, ensuring a range of areas.
- Work together with local government (councils) to identify infrastructure, transport and workforce needs to establish effective trials.
- Fund trials for a set period of time (at least 2 years), including impact and evaluation studies.

#### **HOW WILL IT BE FUNDED?**

As a pilot program to understand foundational supports' potential impact, with view to establishing as a broader foundational support.

"More individual advocacy, so people don't have to wait to receive these services. Better access to mainstream services. Foundational supports that are well funded, do not have a waiting list and easy to access. Peer support programs esp. for people with adult onset disability and children would be really important."— **Advocate** 

## **Priority 5: Representation and inclusion**

"There needs to be true collaboration in the best interests of our community for this to work. Those with a conflict of interest need to step back and let the system thinkers and designers step in. Then the government needs to fund local solutions to meet peoples needs." —Disability advocate

### 1. Set up a Lived Experience Transition Taskforce to guide reform

#### WHAT IS IT?

An accessible taskforce of people with disability who have experienced segregation to design and advise on the transition towards desegregation. The taskforce should meet regularly before, during and in the post-transition process. It should have a focus on people with an intellectual disability, who are most impacted by desegregation. The taskforce should meet with relevant bodies, including the NDIA and the Department of Education on a regular basis. Applications could be screened by Inclusion Australia in a similar way to the National Disability Data Asset process currently being undertaken by DANA. The Taskforce will dictate engagement activities and any needed projects to support reform, and further funding allocations should be expected.

#### WHO NEEDS TO BE INVOLVED?

As the peak body for people with an intellectual disability, we recommend Inclusion Australia be funded to design the taskforce recruitment and meeting processes, as well as managing ongoing inclusion support to ensure the process is accessible.

#### WHERE WILL IT HAPPEN?

This will be for the funded peak body to design, however, the Federal Government should consider that the Taskforce may need to meet in person for best accessibility.

#### **HOW CAN WE GET STARTED?**

- Secure a partnership between the necessary peak body organisations and the key government stakeholders.
- Fund Inclusion Australia to design and run an accessible Taskforce for the duration of reform.

#### **HOW SHOULD IT BE FUNDED?**

Ongoing Federal funding as part of reform - until 12 months after the last people with disability have transitioned from closed settings.

## **Priority 6: Advocacy**

## 1. Invest in advocacy: the foundational support to make foundational supports work

#### WHAT IS IT?

DANA has previously costed the current needs of the independent disability advocacy sector. An urgent injection of \$91 million AUD is needed to adequately resource current needs until June 2025. It is expected that these needs will increase significantly as the Federal Government responds to recommendations and begins reform. To learn more about current conditions in the advocacy sector and what is needed for change, read our Advocacy Funding Submission.

#### WHO NEEDS TO BE INVOLVED?

The Federal Government can increase existing advocacy funding allocations to meet existing needs.

#### WHERE WILL IT HAPPEN?

Funding is required at a national level. Advocates operating in rural, remote and very remote areas face increased operating, travel and training costs and need larger funding injections to do the same work.

#### **HOW DO WE GET STARTED?**

- Urgently allocate increased funding to the independent disability advocacy sector until the National Disability Advocacy Program (NDAP) ends in June 2025.
- Enshrine advocacy as a key support in the Foundational Supports Strategy and discussion between the Federal Government and state/territory governments.

#### **HOW SHOULD IT BE FUNDED?**

As a general foundational support for all people with disability, with permanent stable funding as a part of foundational supports.

"Frankly, I feel there are not people who are trained to make the community inclusive. Real people on the ground who will go around raising awareness of disability and helping people and families not feel lonely and isolated." — **Advocate** 

## **NOTES**

- <sup>1</sup> A report by Anglicare measured the affordability of available rental properties for a person receiving the Disability Support Pension over a single weekend in 2021. They found that only 0.3% of rental properties available were affordable for a person on the Disability Support Pension in 2021.
- Vu, B., Khanam, R., Rahman, M. et al. (2020) found that, in order to have an equivalent standard of living to people without disability, a person with disability needed, on average, a 50% (short term) increase in disposable income. Over time, disability needs tended to increase, and a 63% increase in disposable income was needed long term to achieve equivalent standard of living. This all means that the money people with disability do have does not go as far as the same income would for people without disability a compounding inequality with major life impact.









