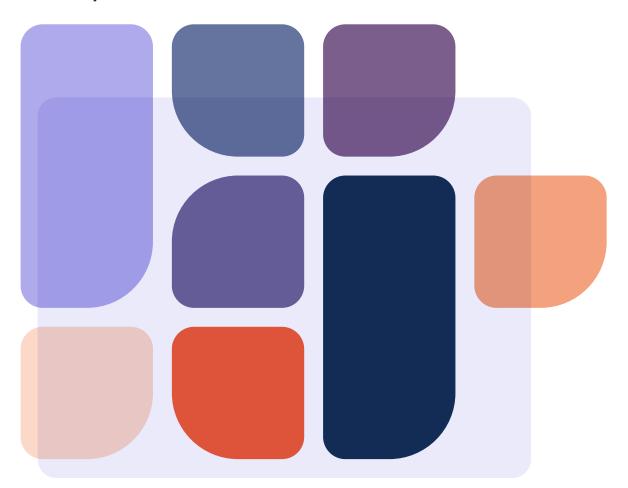


# Working together to deliver the NDIS

Independent Review into the National Disability Insurance Scheme **Final Report** 



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### Dear Ministers for Disability

We are pleased to transmit the final report of the Independent Review of the National Disability Insurance Scheme — *Working together to deliver the NDIS*.

Thank you for placing your trust in us.

Thank you for giving us space to engage deeply with people with disability, their families, carers, and providers and workers, as we all grappled with the challenges the NDIS faces.

Thank you for allowing us to do this Review differently. Throughout our work, we were committed to keeping people informed and working together with people with disability, their families, carers, national and local organisations and many others. This is a major departure from the conduct of most reviews.

The extent of our engagement is reflected in the extraordinary number of submissions we received. We received 3,976 submissions. This is more than three times the number of submissions received by the Productivity Commission in 2011. Engaging much more deeply than is usual was essential to building trust between us and the disability community.

Our recommendations are also about continuing to build trust.

We hope and believe all governments in Australia will work together, rising to the challenge of rebuilding trust, to renew the promise of the NDIS resulting in a more accessible and inclusive Australia for people with disability. To achieve this shared goal, hard work will be required.

This requires everyone to continue the engagement and trust created through this Review in the implementation of the recommendations. It is vitally important that implementation is done by all governments working together in partnership with people with disability, their families and carers.

We would like to thank our fellow Panel members — Ms Judy Brewer AO, Professor Kirsten Deane OAM, Mr Dougie Herd, Mr Kevin Cocks AM and Dr Stephen King — for their expertise and commitment to our shared purpose.

Panel members owe a debt of gratitude to the outstanding Secretariat supporting this Review. David Hazlehurst, the head of the Secretariat, has demonstrated faultless leadership as he and the team tackled an extremely difficult and complex task with challenging deadlines. We also want to thank James Kelly who established the Secretariat in the early part of the Review. All staff in the Secretariat have impressed us with their skills, expertise, experience and commitment. Without our Secretariat, this Review could not have happened.

Our terms of reference gave us three overarching objectives:

- putting people with disability back at the centre of the NDIS
- restoring trust, confidence and pride in the NDIS
- ensuring the sustainability of the NDIS for future generations.



We make 26 recommendations and 139 supporting actions. They are interdependent, based on evidence and are practical. All recommendations and actions must be implemented as a package to achieve a more inclusive and fairer Australia for all people with disability.

We urge all governments to commit to creating a unified ecosystem of supports for people with disability. This should be made up of inclusive and accessible mainstream services, a thriving foundational support system for all people with disability, and a reformed participant pathway in the NDIS for those needing individualised budgets.

This unified ecosystem of supports should be governed by a new disability agreement between governments. This agreement would overcome the separation of the NDIS from the broader disability support ecosystem. It would build on the Australian Disability Strategy to create a single framework for inclusion. It should include transparent sharing of funding and funding risk.

Our reforms recommend a complete rethink of the participant journey. We must return to the principle that NDIS eligibility is based first and foremost on functional impairment rather than medical diagnosis. We must ensure the NDIS experience is centred around the whole person and their disability-related support needs.

We also recommend better support for children and their families in mainstream services through the significant expansion of foundational supports. These services should identify children with developmental concerns as early in life as possible and support them and their parents in their communities. These changes will ensure we get better outcomes for children and their families. New foundational supports are also needed for adolescents and young adults.

We recommend governments take a more active stewardship role in NDIS markets and change incentives to achieve greater efficiency and effectiveness. To ensure better support is available for people with disability, we make recommendations about solving workforce challenges. The scheme will continue to grow, along with the demand for skilled workers, especially allied health workers. Attracting, training and retaining the right workforce is a critical issue to support our reforms and needs to be an immediate priority.

We find that improving service quality and ensuring appropriate safeguards and risk proportionate regulation is essential to improve safety and quality of life for people with disability.

It is in the interests of all people in Australia to secure the future sustainability of the NDIS. Our recommendations, if implemented as a package, will secure the future sustainability of the NDIS as well as delivering better supports for people with disability and a better experience for those in the NDIS.

In addition, we argue that sustainability is more than costs, it also includes the benefits of the NDIS.

Designing, building and operating the ecosystem as a whole, and improving the operation of the NDIS will, together, deliver better outcomes for people with disability. It will also enable governments to provide support in a more responsive, efficient and cost effective way.



Finally, and most importantly, we thank the thousands of people with disability, their families and carers, advocates and representative organisations, providers and workers, for trusting us with their stories and vision for a more inclusive Australia. Ministers, we urge you to listen to their call to be involved in what comes next. The success of implementation depends on governments working in partnership with the disability community.

We commend these reforms to you. Leadership is required by governments, business and community to respect, protect and fulfil the human rights of Australians with disability.

Ten years into the great Australian idea that is the NDIS, the moment has come to renew its promise. To learn from its first decade and to work together to deliver an NDIS that is fit for the future and part of a better Australia for all people with disability.

Yours sincerely

Professor Bruce Bonyhady AM Co-chair, Independent Review of the National Disability Insurance Scheme

Ms Lisa Paul AO PSM Co-chair, Independent Review of the National Disability Insurance Scheme

27 October 2023

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### **Preface**

### **Acknowledgement of Country**



Why stand alone, when we can stand together?

### Debbie Lee

(Proud Yidinji, Wiradjuri, Kamilaroi Jalbu woman) We acknowledge the Traditional Owners and Custodians of Country across this nation on whose lands we all work, play and live. We acknowledge their ongoing connection to land, waters and community. We pay our respect to Elders past, present and emerging.

We extend that respect to all First Nations people. They continue to undertake disproportionate care to sustain this land, their families and communities while facing the ongoing effects of colonisation.

First Nations people experience disability at up to twice the rate of non-Indigenous Australians. Historically discriminatory policies continue to affect the safety and accessibility of supports and services. We recognise that 'disability' is a western concept that does not readily translate into First Nations communities and languages. We acknowledge that, in order to access supports, First Nations people have been required to label themselves as a 'person with disability' or as 'other'. This is at odds with the fundamental First Nations cultural value of inclusion.

We also acknowledge that, to date, the implementation of the NDIS has placed an emphasis on individualised supports. This is often at odds with First Nations culture and values, which place family and community first. This is a source of wider reflection in this report.

We recognise First Nations people with disability experience multiple layers of individual, structural and systemic discrimination (ableism and racism) based on their intersectional identity. This experience is further compounded for First Nations women, Elders, LGBTIQA+SB communities and those living in regional, rural and remote locations.

We need to do better, together, to create a more inclusive and accessible society that recognises and reflects the lived realities of First Nations people.

1

### A word on language and disability

We know language matters when it comes to talking about people with disability. People with disability are too often described in ways that are discriminatory, demeaning or infantilising. We commit to breaking these harmful stereotypes, and demonstrate this by the words we use in this report.

In this report, we use the term 'disability' in the context of the internationally recognised social model of disability. This is a commitment by all Australian governments under Australia's Disability Strategy 2021-31. It describes disability as a social construct. Under this model, intersecting societal barriers are the obstacles to equal participation, not people's impairment.

We acknowledge the historical use of the medical model of disability. Its continued use has had discriminatory and negative attitudinal impacts on people with disability. Where possible, we have strived to avoid use of such terminology.

We use person-first language in this report — person with disability. We acknowledge, however, that preferences vary between different disability communities. Where possible, we have tried to use language commonly used or preferred by a community. Where possible, we have also reflected the language used in submissions received by the Review, to be true to how people described themselves. This has sometimes meant our language is not consistent.

We also at times refer to the very important role of 'family and carers' in the lives of people with disability. In using this term, we wish to make clear that it is meant to be all-embracing. It includes parents, siblings, allies and supporters who play very important roles in the lives of people with disability, both individually and collectively.

## United Nations Convention on the Rights of Persons with Disabilities

We have undertaken the Review with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) front and centre of mind. The NDIS is one of the most important global innovations in disability rights and is essential to Australia meeting its obligations under the UNCRPD. Our recommendations have been developed to uphold this rights-based approach. They aim to promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by people with disability.

### **Definitions and glossary**

In this report we use a range of specialist, technical words and expressions. Some of these words are well known within the disability community. At other times, technical terms can have a different meaning when applied to the working of the scheme.

For example, take the use of 'supports'. In everyday usage, 'supports' can mean 'to give assistance', but within the disability community and the NDIS, it means 'an activity or service that the NDIS provides funding for'.

With that in mind, we have compiled a list of commonly used key words and acronyms. We have tried to avoid the use of jargon and acronyms unless they are well known or help clarify a point.

A glossary with key words and their definitions and a list of acronyms is in Appendix A.

### **Content warning**

This report contains material that may be triggering or upsetting for some readers. If you need support at any time, you can contact the following confidential services which are available 24 hours a day, 7 days a week:

- Beyond Blue Support Service 1300 224 636 or www.beyondblue.org.au
- Lifeline Crisis Support 13 11 14 or www.lifeline.org.au
- 1800Respect 1800 737 732 or www.1800respect.org.au
- 13YARN 13 92 76 or www.13yarn.org.au

If you would like to report a specific incident involving an NDIS provider or worker, you can contact the NDIS Quality and Safeguards Commission.

- 1800 035 544, or
- www.ndiscommission.gov.au/complaints

### **Recommendations and actions**

# Develop a unified system of support for people with disability

### Recommendation 1

Invest in foundational supports to bring fairness, balance and sustainability to the ecosystem supporting people with disability

- 1.1 <u>National Cabinet</u> should agree to jointly design, fund and commission an expanded and coherent set of foundational disability supports outside individualised NDIS budgets.
- 1.2 The <u>Department of Social Services</u>, with state and territory governments, should develop and implement a Foundational Supports Strategy.
- 1.3 <u>National Cabinet</u> should agree to jointly invest in and redesign information and advice and capacity building supports.
- **1.4** <u>National Cabinet</u> should agree to jointly invest in navigation support for people with disability outside the NDIS.
- 1.5 <u>National Cabinet</u> should agree to jointly invest in achieving nationally consistent access to individual disability advocacy services.
- **1.6** All Australian governments should fund systemic advocacy of LGBTIQA+SB people with disability to strengthen representation at all levels.
- 1.7 The <u>Department of Social Services</u> and the <u>National Disability Insurance Agency</u> should improve linkages between the NDIS, Disability Employment Services and related initiatives targeting improved employment outcomes for all people with disability, including NDIS participants.
- **1.8** <u>National Cabinet</u> should agree to jointly invest in a capacity building program for families and caregivers of children with development concerns and disability.
- **1.9** National Cabinet should agree to jointly invest in state and territory home and community care support programs to provide additional support to people with disability outside the NDIS.
- 1.10 The <u>Department of Social Services</u>, with states and territories, should develop a nationally consistent approach for the delivery of aids and equipment outside the NDIS.
- 1.11 <u>National Cabinet</u> should agree to jointly invest in psychosocial supports outside the NDIS to assist people with severe and persistent mental ill-health currently unable to access supports.
- 1.12 <u>National Cabinet</u> should agree to jointly invest in early supports for children with emerging development concerns and disability.
- 1.13 <u>National Cabinet</u> should agree to jointly invest in programs and initiatives to support adolescents and young adults with disability aged 9 to 21 to prepare for and manage key life transition points, such as secondary school, employment and living independently.

Increase the scale and pace of change in mainstream and community inclusion and accessibility and improve the connection between mainstream services and the NDIS

- 2.1 The Attorney General's Department, with the Department of Social Services and the states and territories, should develop a unified and contemporary approach to disability rights, discrimination and inclusion legislation.
- 2.2 <u>All Australian governments</u> should improve the recognition and responsiveness of government services to culturally and linguistically diverse concepts of disability and care by investing in targeted research, education material and capability building for government organisations and staff, professionals and providers who deliver government services.
- 2.3 The Department of Social Services with relevant agencies should develop and trial a mechanism to publicly communicate the performance of current Disability Standards under the Disability Discrimination Act 1992.
- 2.4 <u>All Australian governments</u> should incorporate Disability Impact Assessments into new policy proposal assessment processes.
- 2.5 <u>All Australian governments</u> should take steps to protect the right to inclusive education for children with disability and developmental concerns in early childhood education and care and schools.
- 2.6 <u>National Cabinet</u> should agree to a multilateral schedule to a new Disability Intergovernmental Agreement that replaces the principles for determining the responsibilities of the NDIS and other service systems, including the Applied Principles and Tables of Supports to better clarify respective responsibilities.
- 2.7 The <u>Department of Social Services</u>, working with other Commonwealth agencies, state and territory disability agencies and the National Disability Insurance Agency, should implement a priority work program to improve coordination between complex mainstream settings and the NDIS.
- 2.8 The National Disability Insurance Agency and the Department of Education, with state and territory education and disability agencies, should develop a plan to better connect the NDIS and school education systems and improve educational outcomes for children with disability.
- 2.9 The <u>Productivity Commission</u> should develop an NDIS transport policy that better meets the mobility needs of participants.
- **2.10** The <u>Australian Government</u> should develop a national strategy to improve the quality of the disability ecosystem for First Nations people with disability.
- 2.11 The <u>Australian Government</u> should implement legislative change to allow participants once they turn 65 to receive supports in both the NDIS and the aged care system concurrently and clarify when aged care supports are reasonable and necessary.
- 2.12 The <u>Australian Government</u> should implement legislative or process change to allow access to the NDIS for Disability Support for Older Australians program participants.
- 2.13 <u>All Australian governments</u> should agree as a matter of priority to expand universally available child development checks, to ensure the early identification of children with developmental concerns and disability and enable early intervention.
- **2.14** State and territory governments should commit to and implement the general accidents stream of the National Injury Insurance Scheme.

#### Actions for recommendation 2

- 2.15 The National Disability Insurance Agency and the Department of Social Services, working with state and territory governments and other relevant Commonwealth agencies, should update current arrangements governing the interaction between the NDIS and compensation schemes to reduce overlap and improve participant experiences.
- 2.16 The <u>Disability Reform Ministerial Council</u> should agree to cease the use of 'in-kind' arrangements in the NDIS.

#### Recommendation 3

### Provide a fairer and more consistent participant pathway

- 3.1 The <u>National Disability Insurance Agency</u> should introduce a more consistent and robust approach to determining eligibility for access to the NDIS based on transparent methods for assessing functional capacity.
- 3.2 The National Disability Insurance Agency should introduce a new Access Request and Supporting Evidence Form and accompanying guidance to make the process of applying for NDIS access more transparent and simple.
- 3.3 The National Disability Insurance Agency should change the basis for setting a budget to a whole-of-person level, rather than for individual support items.
- 3.4 The National Disability Insurance Agency should introduce new needs assessment processes to more consistently determine the level of need for each participant and set budgets on this basis.
- 3.5 The National Disability Insurance Agency should allow greater flexibility in how participants can spend their budget, with minimal exceptions.
- 3.6 The National Disability Insurance Agency should adopt a trust-based approach to oversight of how participants spend their budget, with a focus on providing guidance and support.
- 3.7 The National Disability Insurance Agency should reform the NDIS early intervention pathway to provide supports to individuals where there is good evidence the intervention is safe, cost effective and significantly improves outcomes.
- 3.8 The <u>National Disability Insurance Agency</u> should implement reforms to the participant pathway using an iterative, inclusive approach to design and testing, and ensure participants experience a smooth transition to the new arrangements.
- 3.9 The <u>Australian Government</u> should update and clarify legislation to support a more effective approach to determining access.

### Support all people with disability to navigate mainstream, foundational and NDIS service systems

#### Actions for recommendation 4

- 4.1 The National Disability Insurance Agency, through the joint commissioning process described in Action 4.3, should be the lead commissioner of a local navigation function to help people with disability find supports in their community and make the best use of their funding.
- 4.2 The National Disability Insurance Agency, through the joint commissioning process described in Action 4.3, should be the lead commissioner of a Specialist Navigation function for participants who have more complex or specific needs that cannot be reasonably met by general navigation support.
- 4.3 The National Disability Insurance Agency should ideally adopt a joint commissioning approach to deliver local navigation support within a nationally consistent framework developed in partnership with other relevant Australian government and state and territory government agencies.
- 4.4 The National Disability Insurance Agency should design, test and implement the navigation function gradually, prioritising continuity of support for participants and their families and a smooth transition for the workforce and market.

### Recommendation 5

### Provide better support for people with disability to make decisions about their lives

- **5.1** The <u>National Disability Insurance Agency</u> should ensure participants receive accessible information and tailored advice to support informed decision-making.
- The <u>Department of Social Services</u> and <u>National Disability Insurance Agency</u> should both ensure those with cognitive disability or complex communication support needs are connected with capacity building support and other lifelong opportunities to build decision-making skills and experience.
- 5.3 The National Disability Insurance Agency should include an assessment of participants' need for independent decision-making support as part of budget setting and ensure participants can use their NDIS budgets to access independent decision-making supports.
- The Department of Social Services, the new National Disability Supports Quality and Safeguards
  Commission and National Disability Insurance Agency should ensure decision-supporters have access to information, training and resources to assist them in providing best-practice support for decision-making.
- 5.5 The <u>National Disability Insurance Agency</u> should reform the approach to appointing nominees, provide improved training and information to nominees, and increase oversight of nominee decisions.

### Create a continuum of support for children under the age of 9 and their families

#### Actions for recommendation 6

- **6.1** National Cabinet should agree to jointly invest in a continuum of mainstream, foundational and specialist supports to address the needs of all children with disability and developmental concerns.
- 6.2 The National Disability Insurance Agency should reform the pathway for all children under the age of 9 to enter the NDIS under early intervention requirements.
- **6.3** The <u>National Disability Insurance Agency</u> should introduce a more consistent and robust approach to assessing developmental delay.
- 6.4 The National Disability Insurance Agency should change the basis for setting a budget to a whole-of-person level, and introduce a new needs assessment process to more consistently determine the level of need for each child and set budgets on this basis.
- The National Disability Insurance Agency, in partnership with the Department of Social Services and the National Disability Supports Quality and Safeguards Commission, should require early intervention capacity building supports for children be based on best practice principles and evidence.
- 6.6 The National Disability Insurance Agency should develop and implement an approach for ongoing monitoring and evaluation of the effectiveness of early intervention for children.
- 6.7 The National Disability Insurance Agency should implement reforms to support the continuum and pathway for children using an iterative, inclusive approach to design and testing, and ensure participants experience a smooth transition to the new arrangements.

### Recommendation 7

Introduce a new approach to NDIS supports for psychosocial disability, focused on personal recovery, and develop mental health reforms to better support people with severe mental illness

- 7.1 The National Disability Insurance Agency should introduce a new approach to psychosocial disability in the NDIS based on personal recovery and optimising independence.
- 7.2 The National Disability Insurance Agency should establish an early intervention pathway for the majority of new participants with psychosocial disability under section 25 of the National Disability Insurance Scheme Act 2013.
- 7.3 The <u>National Disability Insurance Agency</u> should establish an integrated complex care coordination approach with public mental health systems for participants with complex needs.
- 7.4 The new National Disability Supports Quality and Safeguards Commission should require providers delivering psychosocial supports to be registered, including demonstrating compliance with a new support-specific Practice Standard.
- 7.5 <u>All Australian governments</u> should prioritise supports for people with psychosocial disability as part of general foundational supports.
- **7.6** All Australian governments should improve access to mental health services for people with severe mental illness and strengthen the interface between mental health systems and NDIS.

### Fund housing and living supports that are fair and consistent, and support participants to exercise genuine choice and control over their living arrangement

#### **Actions for recommendation 8**

- 8.1 The National Disability Insurance Agency should change the budget setting process to ensure that housing and living budgets are consistent and sustainable.
- 8.2 As part of the local navigation function (Action 4.1) the <u>National Disability Insurance Agency</u> should commission Housing and Living Navigators to provide advice on participants' housing and living options.
- 8.3 The National Disability Insurance Agency should design, fund and implement a process for participants to try new living arrangements at key life stages, before they commit to them.
- 8.4 The National Disability Insurance Agency should commission a shared support facilitation function to empower participants sharing supports to exercise joint decision-making.

### Recommendation 9

### Deliver a diverse and innovative range of inclusive housing and living supports

- **9.1** The National Disability Insurance Agency, in collaboration with the new National Disability Supports Quality and Safeguards Commission, should invest in the collection and dissemination of housing and living data and analysis.
- **9.2** The National Disability Insurance Agency should implement a new funding approach for participants sharing living supports to strengthen the focus on service quality and outcomes.
- 9.3 The National Disability Insurance Agency should release more detailed and frequent information on participant demand for 24/7 living supports and Specialist Disability Accommodation (both medium and longer term needs).
- 9.4 The National Disability Insurance Agency should remove the Improved Liveability category for new Specialist Disability Accommodation (SDA) developments, and review the remaining SDA categories and associated Design Standards to evaluate their effectiveness.
- 9.5 The <u>Australian Government</u> should transition responsibility for advising on Specialist Disability Accommodation pricing to the Independent Health and Aged Care Pricing Authority and introduce more flexibility to the way prices are set.
- 9.6 The National Disability Insurance Agency, in consultation with state and territory governments, should commission Specialist Disability Accommodation where needs are not adequately met by the private investor model.
- 9.7 The new National Disability Supports Quality and Safeguards Commission should strengthen Specialist Disability Accommodation (SDA) regulation to ensure dwellings are managed in accordance with the needs of participants and mandate the separation of SDA and living support providers.
- 9.8 All Australian governments should agree and implement an intergovernmental strategy for upgrading or repurposing ageing Specialist Disability Accommodation stock owned by states and territories.
- 9.9 The National Disability Insurance Agency should amend its change of circumstance and Specialist Disability Accommodation (SDA) policies to reduce the bedroom count of ageing SDA dwellings.

#### **Actions for recommendation 9**

- **9.10** The National Disability Insurance Agency should introduce a new Specialist Disability Accommodation (SDA) category for participants funded for shared living supports but not eligible for existing categories of SDA.
- **9.11** All Australian governments should agree and publish a targeted action plan for housing under Australia's Disability Strategy.

# Markets and support systems that empower people with disability

### Recommendation 10

Invest in digital infrastructure for the NDIS to enable accessible, timely and reliable information and streamlined processes that strengthen NDIS market functioning and scheme integrity

#### **Actions for recommendation 10**

- **10.1** The <u>Australian Government</u> should develop and fund an easy-to-use centralised online platform that provides information on all locally available supports and services for participants and Navigators.
- The <u>National Disability Insurance Agency</u> and the new <u>National Disability Supports Quality and Safeguards Commission</u> should enable better two-way information sharing with third party online platforms to encourage digital innovation that builds on the centralised online platform.
- **10.3** The <u>National Disability Insurance Agency</u> should transition to fully electronic payments and improve visibility of NDIS payments.
- **10.4** The <u>Australian Government</u> should invest in the underpinning digital infrastructure and capability needed to protect the integrity of the NDIS.
- **10.5** The <u>Australian Government</u> should develop and implement a clear transition path for existing Plan Managers.
- **10.6** The <u>Australian Government</u> should design and roll out an NDIS digital transformation strategy and roadmap to bring together and sequence all initiatives in the NDIS digital landscape.

### Recommendation 11

Reform pricing and payments frameworks to improve incentives for providers to deliver quality supports to participants

### **Actions for recommendation 11**

11.1 The <u>Department of Social Services</u> should develop a new NDIS pricing and payments framework to be administered by the National Disability Insurance Agency and the Independent Health and Aged Care Pricing Authority, including better ways to pay providers to promote the delivery of efficient and quality supports and continuity of supply.

### **Actions for recommendation 11**

- 11.2 The <u>National Disability Insurance Agency</u> should progressively roll-out preferred provider arrangements for capital supports to better leverage its buying power and streamline access for participants.
- 11.3 The <u>Australian Government</u> should transition responsibility for advising on NDIS pricing to the Independent Health and Aged Care Pricing Authority to strengthen transparency, predictability and alignment.
- 11.4 The <u>Australian Government</u> should review and refine the pricing and payments framework once underpinning reforms have been implemented

### Recommendation 12

Embed, promote and incentivise continuous quality improvement in the market, supported by a dedicated quality function in the new National Disability Supports Quality and Safeguards Commission

#### **Actions for recommendation 12**

- 12.1 The <u>Australian Government</u> should establish and appropriately resource a quality function within the new National Disability Supports Quality and Safeguards Commission led by a dedicated Deputy Commissioner for Quality.
- **12.2** The new <u>National Disability Supports Quality and Safeguards Commission</u> should make quality improvement a priority in capacity-building initiatives and audit processes.
- **12.3** The new <u>National Disability Supports Quality and Safeguards Commission</u>, working with the Department of Social Services, should design, test and implement an approach to measure and publish metrics of registered provider performance.

### Recommendation 13

### Strengthen market monitoring and responses to challenges in coordinating the NDIS market

- 13.1 The <u>Australian Government</u> should undertake more active, evidence driven market monitoring to identify issues with access to quality supports early and take more timely and appropriate action.
- 13.2 The National Disability Insurance Agency should progressively roll-out provider panel arrangements for allied health supports in small and medium rural towns or where participants face persistent supply gaps.
- **13.3** The <u>National Disability Insurance Agency</u> should develop matching tools to support participants and Navigators to pool demand for supports.
- 13.4 All Australian governments through the <u>Disability Reform Ministerial Council</u> should agree and publish a provider of last resort policy to ensure participants have continued access to supports where markets fail.

Improve access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements

#### **Actions for recommendation 14**

14.1 The National Disability Insurance Agency, in partnership with First Nations representatives, communities, participants and relevant government agencies should progressively roll-out alternative commissioning arrangements for both First Nations communities and remote communities, starting as soon as possible.

### Recommendation 15

### Attract, retain and train a workforce that is responsive to participant needs and delivers quality supports

#### **Actions for recommendation 15**

- 15.1 The Australian Government should design and trial workforce attraction and retention initiatives.
- **15.2** The <u>Australian Government</u> should develop targeted and flexible migration pathways for care and support workers.
- **15.3** The <u>Australian Government</u> should develop an integrated approach to workforce development for the care and support sector.

### Recommendation 16

### Deliver safeguarding that is empowering and tailored to individuals, their service needs and environments

- 16.1 The <u>Disability Reform Ministerial Council</u> should agree a Disability Support Ecosystem Safeguarding Strategy to coordinate activities to support the safeguarding of people with disability.
- **16.2** The National Disability Insurance Agency should design, pilot and implement a new individual risk assessment and safeguard building process.
- 16.3 The <u>Department of Social Services</u>, working with the National Disability Insurance Agency, the new National Disability Supports Quality and Safeguards Commission and other agencies where relevant, should ensure participants can consider and access a wider range of safeguarding supports.
- 16.4 <u>State and territory governments</u>, with support from the Department of Social Services, should ensure participants can access high-quality, nationally consistent Community Visitor Scheme offerings that interface with the NDIS.
- 16.5 <u>State and territory governments</u> should establish or improve adult safeguarding agencies to deliver a universal service offering for the safeguarding of all people at risk of harm, including people with disability.

Develop and deliver a risk-proportionate model for the visibility and regulation of all providers and workers, and strengthen the regulatory response to long-standing and emerging quality and safeguards issues

### **Actions for recommendation 17**

- 17.1 The <u>Department of Social Services</u> and the new <u>National Disability Supports Quality and Safeguards Commission</u> should design and implement a graduated risk-proportionate regulatory model for the whole provider market.
- 17.2 The <u>Department of Social Services</u> and the new <u>National Disability Supports Quality and Safeguards Commission</u> should develop a staged implementation approach to transition to the new graduated risk-proportionate regulatory model.
- 17.3 The <u>Australian Government</u> should amend the *National Disability Insurance Scheme Act 2013* to remove the link between a participant's financial management of their plan and the regulatory status of their support providers.
- 17.4 The <u>Department of Social Services</u>, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should expand the coverage of worker screening requirements.
- 17.5 The <u>Department of Finance</u> and the <u>Department of Social Services</u>, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should improve, streamline and harmonise worker screening processes for care and support workers.
- 17.6 The new National Disability Supports Quality and Safeguards Commission should be resourced to strengthen compliance activities and communications to respond to emerging and longstanding quality and safeguards issues, and market developments and innovation.

### Recommendation 18

### Reinvigorate efforts to urgently drive reduction and elimination in the use of restrictive practices

- 18.1 <u>All Australian governments</u> should agree a joint action plan for meaningful collaboration and a stronger focus on corrective actions against providers to reduce and eliminate restrictive practices, and review interventions and practices that may be harmful.
- 18.2 The new National Disability Supports Quality and Safeguards Commission, working with other agencies as relevant, should work with behaviour support practitioners and providers to urgently improve the quality of behaviour support plans, enhance quality of life for participants and eliminate poor provider practices.
- **18.3** The new <u>National Disability Supports Quality and Safeguards Commission</u>, working with state and territory agencies, should better support providers to deliver on their role in reducing and eliminating restrictive practices.

### Stewardship of the united ecosystem

### Recommendation 19

### Embed effective quality and safeguarding institutions and architecture across the disability support ecosystem

#### **Actions for recommendation 19**

- **19.1** The Disability Reform Ministerial Council should agree a Disability Supports Quality and Safeguarding Framework.
- 19.2 <u>All Australian governments</u> should prioritise greater collaboration, consistency and timely exchange of data and information to ensure effective quality and safeguarding, including expanding the coverage of the NDIS Quality and Safeguards Commission to become the National Disability Supports Quality and Safeguards Commission.
- **19.3** The <u>Australian Government</u> should ensure the new National Disability Supports Quality and Safeguards Commission has the resources, powers and approach to proactively and effectively regulate the disability supports market.

### Recommendation 20

### Create a new compact between Australian governments

#### **Actions for recommendation 20**

- 20.1 <u>National Cabinet</u> should agree a new Disability Intergovernmental Agreement to underpin delivery of a comprehensive and unified disability support ecosystem.
- 20.2 <u>National Cabinet</u> should agree new funding arrangements to align incentives and share costs in the disability support ecosystem.
- 20.3 <u>National Cabinet</u> should establish a new permanent Disability Advisory Council reflective of the diversity of people with lived experience of disability to advise Disability Reform Ministers.
- 20.4 <u>National Cabinet</u> should develop a dedicated First Nations Schedule under the new Disability Intergovernmental Agreement to embed a First Nations Disability Forum and an independent sector-specific accountability mechanism.
- 20.5 <u>National Cabinet</u> should establish a Disability Outcomes Council to monitor and publicly report on the performance of all governments in meeting the outcomes, commitments and benchmarks outlined in the Disability Intergovernmental Agreement.

### Recommendation 21

### Clarify accountability for sustainability and governance of the disability ecosystem

- 21.1 <u>National Cabinet</u> should be accountable for the sustainability of the unified disability ecosystem, including the NDIS.
- 21.2 The <u>Department of Social Services</u>, in consultation with state and territory governments, should review existing National Disability Insurance Agency operational guidelines to identify and prioritise opportunities to strengthen the *National Disability Insurance Scheme Act 2013* and Rules.

#### **Actions for recommendation 21**

- 21.3 The <u>Australian Government</u> should ensure that the Minister responsible for the NDIS remains a Cabinet Minister.
- The <u>Australian Government</u> should clarify roles of relevant agencies for administration market stewardship, pricing, policy, regulation, commissioning and legislation.

### Recommendation 22

### Embed a highly skilled, person-centred, disability aware culture across all disability agencies and governments

#### **Actions for recommendation 22**

- 22.1 When undertaking capability reviews, the <u>Australian Public Service Commission</u> should have regard to the capacity, capability and culture of the National Disability Insurance Agency, National Disability Supports Quality and Safeguards Commission, and Department of Social Services to deliver relevant reforms.
- 22.2 The National Disability Insurance Agency and the new National Disability Supports Quality and Safeguards Commission should publish biennial culture and capability plans, supported by independent audits and staff, participant and stakeholder surveys.
- 22.3 The <u>Australian Government</u> should re-design the Participant Service Guarantee to prioritise high quality, transparent and efficient decisions and improved participant experience.
- The <u>Disability Reform Ministerial Council</u> should agree measurable culture and capability outcomes as part of new funding arrangements.

### Recommendation 23

### Measure what matters, build an evidence base of what works, and create a learning system

- 23.1 <u>National Cabinet</u> should agree to replace the current NDIS Outcomes Framework with a new Disability Support Outcomes Framework.
- The Department of Social Services, in consultation with the National Disability Insurance Agency, the new National Disability Supports Quality and Safeguards Commission and the Independent Health and Aged Care Pricing Authority, should establish and manage an NDIS Evidence Committee to provide guidance on reasonable and necessary disability supports.
- 23.3 The <u>Department of Social Services</u> should establish a new Disability Research and Evaluation Fund to coordinate and fund research and independent evaluation activities.
- 23.4 <u>All Australian governments</u> should agree to jointly invest in actions to improve disability data quality and sharing.
- 23.5 The <u>Australian Government</u> should ensure that all disability reporting mechanisms facilitate the collection, analysis and publication of intersectional indicators.

### A five year transition

### Recommendation 24

### Establish appropriate architecture to implement reforms

#### **Actions for recommendation 24**

- 24.1 The <u>Disability Reform Ministerial Council</u> should agree architecture to support implementation and delivery of the NDIS reform agenda.
- **24.2** The new NDIS Review Implementation Advisory Committee should report to the Disability Reform Ministerial Council every six months or as needed.
- 24.3 The new NDIS Experience Design Office should commission agile projects to design and test reforms to the participant pathway.

### Recommendation 25

### Coordinate and consult on amendments to relevant legislation to enact proposed reforms

### **Actions for recommendation 25**

The Department of Social Services, with input from the National Disability Insurance Agency and NDIS Quality and Safeguards Commission, should review the recommendations from this Review and develop a proposed package of legislative reforms.

### Recommendation 26

### Develop an implementation roadmap that factors in critical dependencies and risks and ensures a smooth transition for existing participants

- **26.1** <u>National Cabinet</u> should agree and publish an implementation roadmap.
- **26.2** The <u>National Disability Insurance Agency</u> should ensure existing participants experience a smooth and fair transition to the new participant pathway.
- **26.3** The new NDIS Review Implementation Working Group should coordinate communications across relevant agencies to regularly update and inform stakeholders on implementation progress.



"It has been life changing. Our daughter's development would not be possible without the support we have been able to access due to the NDIS.

Without the NDIS we would not have been able to afford such supports and it would have had devastating impacts on our health, finances, relationships and overall well being."

- Carer 1

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The Review's terms of reference gave us three overarching objectives:

- 1. Putting people with disability back at the centre of the NDIS.
- 2. Restoring trust, confidence and pride in the NDIS.
- 3. Ensuring the sustainability of the NDIS for future generations.

We believe the three are interconnected and must be considered together. This belief has guided our work.

People with disability must be at the centre of the NDIS. But more than that, they must be at the centre of a new comprehensive disability support ecosystem. One which is fair and supports all people with disability. The NDIS cannot achieve sustainability without improving outcomes for people with disability. The NDIS cannot earn trust, give confidence and provide certainty — to people with disability, their families and carers, the wider Australian community and governments — without being sustainable.

There is no quick fix or easy solution to achieving these objectives. There is no 'one area' to target. The only way to achieve all three objectives is to look at disability support holistically — both inside the NDIS and beyond — and to consider what needs to be done to ensure people with disability are able to realise their rights as full citizens.

As a result, each and every one of our 26 recommendations and 139 actions must be considered as a whole. Together, they provide a practical blueprint for an ecosystem that will put people with disability at the centre. For that to happen, it will need to be well-planned, well governed, and designed and delivered in partnership with people with disability and their families and carers.

In the days after the launch of the NDIS on 1 July 2013, Stella Young — comedian, journalist, disability rights activist — wrote:

"While the National Disability Insurance Scheme is finally here, already making a difference to the lives of some people with disabilities, we are nowhere near living in a society that treats disabled people with dignity and respect. We're not even close.

In the long journey to the implementation of the NDIS, it's been difficult to keep our expectations in check. We've been so excited about a better deal that it's been easy to get carried away with what that might look like.

But there are things the NDIS cannot do for us as Australians with disability.

There are some barriers that we face in our lives that no amount of funding can address, like discrimination and prejudice. Ramps won't start appearing

where once there were stairs. Our libraries won't be filled with books in

alternative formats. Negative attitudes towards people with disability

won't magically be replaced with acceptance and respect.

We have miles to go before we sleep."

- Stella Young 2

Stella was - and is - right.

The NDIS has delivered a better deal for hundreds of thousands of Australians, breaking down many of the barriers that shut people with disability out of the everyday lives that their fellow citizens take for granted.

But there is still more to do to achieve the vision for the NDIS.

# The NDIS came from people with disability and united governments

In 2010, people with disability, their families and carers and service providers joined forces to create Every Australian Counts — a grassroots campaign that drew on support from more than 200,000 ordinary Australians. Every Australian Counts galvanised public and political support for the NDIS.

Later in 2011, the Productivity Commission released its landmark Inquiry into Disability Care and Support — finding the existing disability services system was "underfunded, unfair, fragmented, and inefficient".<sup>3</sup>

The Productivity Commission recommended a disability insurance scheme to provide individual budgets to meet the reasonable and necessary support needs of people with significant and permanent disability. The individual supports were to be built on a firm foundation of community and mainstream supports for all people with disability. This model was intended to empower participants to participate in their community and have choice and control over their supports.

On 1 July 2013, the NDIS was launched with unanimous support from all political parties and all Australian governments. Its introduction was a public policy miracle based on a collective desire to change Australia for the better.

It was a practical demonstration of the nation's desire to realise its commitment to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The national rollout of the NDIS was completed on 1 July 2020, just three years ago. In the space of a decade, the NDIS went from an idea, to changing lives for the better. The realities faced by people with disability were moved from the political margins to become the core business of all governments and a headline issue in national affairs. The introduction of the NDIS embedded Australia's obligations under the UNCRPD in legislation.

Most importantly, more than 610,000 people now receive life changing support — including almost half who have never received support before.<sup>4</sup>

The NDIS is world leading in its development and design but people with disability are marginalised globally. The NDIS was introduced at a time when many other countries were reducing support for people with disability after the global financial crisis. Its progress is also being watched carefully around the world, to see how greater investment and support through a social insurance approach can deliver both economic and social benefits.

### The NDIS has transformed lives and Australia

We have come a long way from what life was like for a person with a disability before the NDIS. The NDIS has changed the lives of hundreds of thousands of people with disability and their families for the better. Its introduction has transformed the nation, creating social and economic benefits. It has made our country stronger and fairer.

"I have a spinal injury... equipment, care and assistance costs basically eat away at any reasonable chance of decent ongoing life or retirement.

I have a life because of the NDIS... I just want to say it has changed my life.

I can breathe. My stress has reduced immeasurably. I could not be more appreciative. The difference... it just can't be explained."

- Participant <sup>5</sup>

"It has been life changing. Our daughter's development would not be possible without the support we have been able to access due to the NDIS.

Without the NDIS we would not have been able to afford such supports and it would have had devastating impacts on our health, finances, relationships and overall well being."

- Carer 6

As a social insurance scheme, the NDIS also creates benefits to people without disability and is an important part of Australia's safety net. No one knows when they might acquire a disability or have a child or grandchild who is born with a disability and may need the NDIS.

"The NDIS has been absolutely wonderful for my sister. She has carers that have established genuine relationships with her... She loves to go out for coffee, spend time with her peers in group settings where she can participate by being helped by carers with activities such as art... If it wasn't for the NDIS, my sister quite simply wouldn't have a life at all, she would be sitting in a chair in the care facility she lives in doing very little."

- Carer 7

It is easy to forget how bold a step the NDIS was — and is. No other nation has anything like it. Today it is one of the pillars on which the decency and fairness of Australia society stands.

### Our Review continues the journey of the NDIS

For all it has achieved, the NDIS is not perfect. The benefits are not being shared equally. The problems with the operation of the NDIS have been well known in the disability community. They have been the subject of several inquiries and reviews, including the Productivity Commission's 2017 report on NDIS costs, Joint Standing Committee reports and the review of the *National Disability Insurance Scheme Act 2013* (NDIS Act) in 2019 (Tune Review). But these problems have persisted, to the point it became increasingly clear a reset was needed.

On 18 October 2022, the Commonwealth Minister for the NDIS, the Hon Bill Shorten MP, established the independent NDIS Review to examine the design, operations and sustainability of the scheme, including markets and workforce. Our terms of reference are at Appendix B. The Panel was asked to report back to Disability Reform Ministers by October 2023.

We have been mindful in the development of this report of additional initiatives announced during 2023 that directly affect the NDIS:

- On 28 April 2023, National Cabinet agreed to an NDIS Financial Sustainability
   Framework that provides an annual growth target in the total costs of the scheme of no more than 8 per cent by 1 July 2026.
- On 9 May 2023, the Australian Government committed \$910 million over five years to improve the effectiveness and delivery of the NDIS and support and safeguard people with disability.
- On 29 September 2023, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) released its final report, with 222 recommendations.

We welcome the interest of the First Ministers of every government in the NDIS through National Cabinet. Many of our recommendations will require action by all Australian governments. We also recommend monitoring of inclusion in Australia by National Cabinet.

We also welcome the investments by the Australian Government in the capacities and capabilities of the National Disability Insurance Agency (NDIA) and the NDIS Quality and Safeguards Commission (NDIS Commission) after many years of staff caps. Both organisations will need enhanced capability to undertake the reforms outlined in this Review.

While our Review and the Disability Royal Commission were different in scope and focus, there have been many common observations and recommendations. These include:

- promoting inclusion and the human rights of all people with disability
- strengthening the governance of disability policy and reform as a whole
- improving quality and safeguards
- responding to the experiences of First Nations people with disability
- improving the accessibility and inclusiveness of mainstream services.

### We heard from thousands of people

The issue of trust was central to our terms of reference. We understood that rebuilding trust started with us. With the support of Ministers, we undertook to do this Review differently to other government reviews by amplifying the voices of people with disability and their families, carers, representative organisations, providers and workers and their representatives.

We wanted to hear from as many people as possible. We provided many different ways for people to be involved. We particularly wanted to create opportunities for people who don't usually participant in government reviews to have their say.

Our approach included (see Appendix C for further details):

- inviting submissions to the Review in different formats: written, verbal by phone,
   video, Auslan, artwork and poetry
- hosting workshops and meetings where we invited people to share their experiences and discuss ideas with us
- partnering with disability representative and carer organisations so they could engage in depth over months on key topics of interest with the communities they represent
- attending events and forums hosted by the disability community, providers and others
- engaging in hundreds of meetings to hear directly from individuals and organisations
- collaborating closely with small groups of people with lived experience and other disability expertise, who helped us test and improve our ideas for improving the participant experience of the NDIS and on better ways to support children and families
- drawing on the evidence, perspectives and insights of previous reviews.

We were humbled by the community's response.

Since October 2022, we travelled to every state and territory — including remote and regional areas — and met thousands of people. We received 3,976 submissions, more than three times the number received by the Productivity Commission in 2011.

### The voices of people with disability have been at the centre of our thinking.

Their voices, their feedback and their ideas have resulted in a set of recommendations based on their lived experiences and expertise.

While we have laid out a blueprint for reform, we also know there is much detailed work still to come to implement our recommendations. This work must continue the way it has begun — in partnership with people with disability. Continuing the engagement is the only way to ensure the success of these reforms and to continue to rebuild trust. The title and theme of our report *Working together to deliver the NDIS* must continue following the release of our Review.

### We have considered the key challenges

In June 2023, we released our *What we have heard* report. After carefully reviewing all the evidence, we identified five key challenges that had to be addressed:

- 1. Why is the NDIS an oasis in a desert?
- 2. What does reasonable and necessary mean?
- 3. Why are there many more children in the NDIS than expected?
- 4. Why aren't NDIS markets working?
- 5. How do we ensure the NDIS is sustainable?

The What we have heard report also identified additional areas for improvement, including quality and safeguards and housing and living.

Addressing these key challenges and areas for improvement is essential to creating a trusted and sustainable NDIS that puts people with disability at its centre.

### Why is the NDIS an oasis in the desert?

The NDIS was designed to be one part in an ecosystem of supports to ensure Australians with disability were able to enjoy the same opportunities as others in the Australian community.

Every government in Australia — including local councils — committed to the goals outlined in the National Disability Strategy 2011-2020 and again in Australia's Disability Strategy 2021-2031. Despite these repeated commitments, there appears to have been insufficient progress in making mainstream services more accessible and inclusive.<sup>8</sup>

In addition, the Productivity Commission in 2011 recommended all people with disability or affected by disability would have access to information, linkage and referral services to ensure support from any system outside the NDIS, including mainstream and community services. It also recommended community capacity building activities to support people with disability to participate in their local communities, and the continuation of home and community care services for people with lower-level needs or shorter-term disability. These have not been fully delivered.

The significance and complexity of introducing the NDIS saw governments prioritising its rollout and getting people into the scheme as quickly as possible. While understandable, this came at the expense of continuing to reform mainstream services to make them more accessible and inclusive.

Important programs and services that supported all people with disability were also rolled into the scheme, leaving those who were not eligible for the NDIS without many former supports. While governments may have hoped the Information, Linkages and Capacity Building (ILC) program would meet the needs of people with disability outside the scheme, its wide scope, limited funding and reliance on small, short-term grants

meant gaps remained. In addition, Local Area Coordinators, who were meant to support those outside the scheme and have a role in inclusion and building social and community capital, were diverted into planning for NDIS participants.

The ramifications are felt throughout the NDIS and in the wider disability community today.

"The failure of tier 2 has left significant support gaps and seen the closure of many community services. More and more organisations are only interested in offering services to those with NDIS plans and certain line items in those plans."

- Carer 9

In trying to correct for the underfunded, inconsistent and unfair arrangements that existed prior to the NDIS, governments have come to rely on the NDIS as the dominant, and in some cases only, source of supports for people with disability — the oasis in the desert. This is to the detriment of all people with disability, particularly those outside the scheme, and is contributing to ongoing inequality between participants and those who are not eligible for the NDIS.

"It seems to be a box ticking process. If your disability is listed then you get some support, but if it isn't then the answer is simply no help required.

There seems to be no support to help those with a disability that is permanent and cannot be cured that affects ability to learn at school when the education department does nothing to help either... My children cannot get the support they need to be successful and meet their potential at school because I cannot afford private tutoring or technical supports for them to use whilst at school and home. Their specific learning disabilities are not recognised by NDIS"

- Carer for person with disability not on the NDIS 10

### What does reasonable and necessary mean?

Problems with the NDIS access and planning process were the most commonly raised issues during this Review. At best, people described the planning process as confusing and frustrating. At worst, it was described as traumatic.

As we outlined in our *What we have heard* report, we believe a lack of clarity about what supports should be considered reasonable and necessary is at the heart of many of the scheme's issues including:

- stressful, time-consuming and poor planning experiences
- inconsistent and inequitable decisions about funding
- disputes between participants and the NDIA.

It has contributed to a breakdown in trust between participants and the NDIA. It has also placed pressure on the sustainability of the scheme.

The criteria for reasonable and necessary supports were deliberately kept broad, to make sure supports can be tailored to the individual. However, this has made it difficult for NDIA decision-makers to make consistent decisions. Participants don't understand what supports are considered reasonable and necessary or how the NDIA applies it when making decisions. They don't know what evidence to provide to show their supports are reasonable and necessary, or how evidence will be used. Inconsistent and unclear decisions are making participants feel untrusted, disempowered and angry.

"Arbitrary rules — what is reasonable and necessary to me is not the same as it is to my planner... Being told a service is not reasonable and necessary by your planner but knowing someone (whom is in the exact same situation) else's planner has approved it."

- Participant 11

This type of inconsistency frequently arises when arbitrary tests of what may be deemed reasonable and necessary (or not) are applied to the costs of every individual support, rather than to the whole budget, based on a participant's agreed needs. This adds unnecessary layers of complexity to decision-making within an already complex process. It reduces participant choice and control. By breaking things down to the smallest level, we have lost sight of the big picture and the whole person.

In addition, applicants for the NDIS have to put forward the worst versions of themselves to gain support. The access and planning process uses a deficit model that is disempowering and counter to the vision for the NDIS to uplift and empower people with disability to participate socially and economically.

The process to determine a participant's reasonable and necessary supports is now a contested, disempowering, stressful argument. It creates rigid plans that prevent participants from responding to changes over time. Such inflexibility acts as a perverse incentive to seek reviews of plans. It may result in wasteful expenditure on reports to justify a new or more of a specific type of support when, in fact, time and money would be saved if there were greater flexibility within a whole budget approach to reasonable and necessary support.

"As a participant I have found the whole process stressful & defeating"

- Participant 12

These failings are compounded in First Nations and culturally and linguistically diverse communities, who are routinely subject to decisions being made without recognition and understanding of their culturally specific concepts of care, disability and community obligations.

This narrow, adversarial approach is one of the reasons why there has been a breakdown of trust between people with disability and the NDIA. The NDIA is considered not to value the experience and insights or trust the motives of participants; and participants lose trust in the motives, processes and personnel of the NDIA. Rebuilding this trust is essential to fixing the NDIS.

### Why are more children in the NDIS than expected?

In our *What we have heard* report, we found many more children are entering the scheme than was expected. This partly reflects overall higher rates of disability among young children than was expected by the Productivity Commission in 2011. It is also a consequence of fewer supports for children with disability in mainstream settings.

With so few supports outside the NDIS, it is not surprising that parents are fighting to get their children with developmental concerns or disability into the NDIS. After receiving early intervention supports, they are reluctant to leave the scheme for fear of being left without support. In addition, early intervention has not always been based on best practice and there has been too little support for families. All have combined to produce poor outcomes for children and families. These failings have also placed financial pressure on the scheme.

The prevalence of disability and developmental concerns in children, currently 20 per cent of all Australian children, makes this a mainstream issue requiring a mainstream response. With children making up half of all NDIS participants, it is clear mainstream supports aren't meeting the needs of children and families, who are turning to the NDIS as the only source of support.

"Because there are so few services offered outside the NDIS, families are forced to push for access to the NDIS and maximum plan funding - even when that model might not lead to the best outcomes for their child."

- Healthy Trajectories Child and Youth Disability Research Hub 13

This starts with inconsistency across mainstream services for identifying disability and developmental concerns early. It leaves some children missing out on critical early intervention that can improve their life outcomes.

Within the NDIS, supports are skewed towards those delivered in clinical settings. This does not reflect best practice, where effective support is primarily delivered in natural settings, where children live, play and learn. With little guidance or information about how best to support their child, families are often left isolated and stressed.

"My kids miss out on social/community participation opportunities with kids like them and instead spend huge amounts of their free time and school time doing draining one on one therapy with the clinics that we can get a spot in — where the practices are not necessarily neuro-affirming."

- Carer 14

Providing an individualised budget does not address the ways in which mainstream services are failing to adequately support children with disability and developmental concerns. It is producing poor outcomes. Australian children and their families deserve better.

### Why aren't NDIS markets working?

Markets in the NDIS have not worked as originally imagined. Competition has not encouraged innovation or increased the diversity of services for all participants in all locations. In some cases, it has led to poor, or even no services. Of greatest concern is that a failure of competition and regulation has opened the door to exploitation and abuse. As the Disability Royal Commission has rightly identified, this cannot be allowed to continue.

Critically, the focus on market competition has neither driven inclusion nor helped to nurture connections with family, friends and community. In fact, sometimes the exact opposite has occurred.

Workforce quality, training, and retention are also major issues. These failings undermine outcomes for participants and contribute to increasing scheme costs.

"Workforce shortages are real and impacting the sector across the board.

It reduces the capacity of support providers to provide consistent and reliable supports."

- Provider 15

NDIS markets are not like other markets. They are social markets that need effective stewardship. Poor market design is creating perverse incentives and regulatory oversight is not proportionate to risk. The current fee-for-service model rewards providers for the volume of supports they deliver, with little incentive to improve quality, be innovative or responsive to the needs of all participants. Price caps have become price floors.

"I try to use mainstream services and products rather than go to disability specific market due to the ridiculous prices charged by providers. As has been stated time and again, an able bodied person can go to an allied health professional and be charged \$90, but I go for the same service and because I am NDIS funded I get charged more than \$200 ... Not only is it discriminatory but also costs the government more dollars, and the person with disability gets less support"

— Participant 16

# The NDIS must be sustainable

It is in the interests of everyone in the disability sector — including people with disability, service providers and governments — to secure the future sustainability of the NDIS.

In 2013, just as the NDIS was being launched, Dr Simon Duffy, a British social policy reformer visited Australia. He warned:

"Another economic issue that has bedevilled public services and individualised funding is the impact that any new system has on demand for that funding. It is clear that if you design a system in the wrong way you

can invite new levels of demand, generate inflationary expectations and increase costs in ways that seem totally detached from the real level of need in the community. Often this money goes into services — but does not benefit people."

- Dr Simon Duffy<sup>17</sup>

This year, Dr Duffy and NDIS participant Dr Mark Brown were invited by the Disability Advocacy Network Australia to review the NDIS. They concluded:

"The most important problem is that the growing cost of the NDIS will eventually break the bond of trust between people with disabilities and society as a whole. Unless these problems are addressed economic pressure will almost certainly undermine political support for the NDIS. In fact a strong case can be made for treating sustainability as a fundamental foundation of any system of human rights."

- Dr Simon Duffy and Dr Mark Brown<sup>18</sup>

They make the point that a human right which cannot be sustained is a human right denied.

We share their concern. Despite not yet reaching maturity, the NDIS already supports more than 610,000 people (101,000 more participants than projected by the Productivity Commission in 2017) and costs Australian taxpayers more than \$35 billion in 2022-23 (\$8 billion more than projected in 2017). Based on current policy settings, the scheme is projected to continue growing to be \$92 billion in 2032-33, significantly exceeding the 2017 estimates made by the Productivity Commission. <sup>19</sup>

We also know that there remains unmet and unrevealed demand in some areas that could lead to further growth in costs in the near-to-medium-term. For example, we know First Nations and culturally and linguistically diverse people are underrepresented in the scheme. People with disability in regional and remote Australia are also underrepresented in the scheme. There is a large group of people with disability with high support needs that are being cared for by elderly parents. They will need greater support from the NDIS in the future.

There is no single issue driving the growing cost pressure of the NDIS.

The lack of foundational supports and lack of accessible and inclusive mainstream services available to people with disability pushes people towards the NDIS. Other service systems also push people towards the NDIS because it is uncapped, and what is considered reasonable and necessary isn't well defined.

The lack of trust between participants and the NDIA, driven by the adversarial planning process, and at times a 'use it or lose it' approach by the NDIA, has encouraged people to fight for as much support as possible. It is a rational response to fear that support will be taken away at the next planning meeting. People also do not trust the NDIA to respond in a timely or adequate way if circumstances change.

Service providers have responded to market settings that reward the volume of supports provided rather than quality of supports or outcomes for participants. Prices that do not always reflect the full cost of complexity also drive provider behaviour. Because there is not enough visibility of transactions, fraud is difficult to identify.

As we have said, there is no single factor driving increased costs. And as a result, there is not one simple solution. Both poor design and implementation issues are driving the behaviour of everyone in the system. These flaws have to be addressed. Everyone has a role to play to ensure the scheme is sustainable. Reform must start now.

# Understanding and responding to intersectional needs

In our *What we have heard* report, we emphasised that recognising the complexity of identity and need is essential to building a responsive, safe and inclusive society for people with disability.

First Nations people with disability, women with disability, people from culturally and linguistically diverse and LGBTIQA+SB communities experience intersecting layers of individual and structural discrimination impacting all aspects of their lives. This discrimination means some people are less likely to seek help.

Our disability support system is underpinned by western concepts of disability and care. This means our policies, programs, institutions and services often respond poorly to culturally and racially diverse concepts of disability and care. This further compounds experiences of inequality and discrimination, especially for First Nations people who face ongoing impacts of colonisation and a history of dispossession, not only of culture and Country, but of their bodies.

This supports a cycle of discrimination and disadvantage that affects the accessibility, quality and safety of supports received. This lack of safety can incite fear, trigger trauma, re-traumatise people and lead them not to seek available supports.<sup>20</sup> We must do more to break these cycles of discrimination and disadvantage.

People with disability do not fit neatly into the three support tiers envisaged by the Productivity Commission in 2011. All mainstream services, institutions and systems must become accessible and responsive to the needs of all people with disability. We need to work in new ways which focus better on the intersectional needs of the people that these systems serve.

In response, we have taken a deliberately intersectional approach across the development of each recommendation and action. Rather than addressing these issues in siloed ways, we have woven them into a vision for the future of disability supports, which sees each individual with a disability as a whole person with interconnected needs, challenges and strengths that are recognised and valued throughout Australian society.

# A question of balance

In summary, what we have been told and what we have observed is a disability support system which is out of balance. This is in many ways not surprising, given the disruption caused by introducing the NDIS. The fact that it is world-leading has meant that there was no 'guide book' before the scheme commenced.

Governments have come to rely on the NDIS as the dominant, and in some cases only, source of supports for people with disability. This has resulted in an unbalanced disability support system that relies too heavily on the NDIS at the expense of an inclusive, accessible and thriving broader disability support ecosystem of mainstream and foundational supports.

We have gone from a rationed system with few options, no choice and almost no control. Now, we have a system where the rhetoric of choice and control is not supported by the experiences of people with disability. For many, poor availability of services, complexity of navigating what is available and difficulty in moving between providers means, in practice, there is little to no choice and control.

Before the NDIS, disability supports were largely generic and did not always cater to people's individual needs and circumstances. Now, in an attempt to respond to the diversity of people's needs and circumstances, the scheme has become incredibly complex and confusing.

The quality of supports across NDIS markets are highly variable, and as the Disability Royal Commission concluded, sometimes lead to harm. There is little to no measurement or transparency of the quality of supports, making it difficult for people to make informed decisions. Unintended consequences of the payment model have incentivised activity rather than participant outcomes.

A good life is one enriched by connections to family, friends and community.

These connections need to be nurtured by the scheme. This means individualised,
market-based delivery needs to be balanced with approaches that build social capital.

The strongest feedback we have received is that people want an end to the complexity and uncertainty. They want a system that is easier to navigate, fairer, and more consistent. They also want more support outside the NDIS.

Our reforms are designed to return balance to the system.

We want a better balance between the NDIS and the rest of the disability ecosystem. We want a better balance between individualisation and complexity. We want a better balance between individualised, market-based delivery and approaches that build social capital. A better balanced system will be a more sustainable system.

Our recommendations, therefore, seek to create a better balanced system by responding to the challenges identified in the *What we have heard* report.

# Our reform blueprint

Our **26 recommendations and 139 actions** provide a reform blueprint to put people with disability back at the centre of the NDIS, restoring trust, confidence and pride in the scheme, and ensuring its sustainability for future generations.

To achieve this vision, our recommendations focus on four areas.

# A unified system of support for people with disability

The NDIS should be one part of an overarching unified system of support for people with disability. This system must be based on human rights and deliver real measurable outcomes for all people with disability. It should include a spectrum of accessible and inclusive mainstream services, foundational supports and individualised funded packages through the NDIS. Systems should work together so that people get the right support at the right time.

Taken together, the reforms in this area are designed to develop a unified system of support for people with disability, including supports to those who are now missing out. They are about shifts across all services (including the NDIS) and society to create a better, more inclusive and accessible life for all people with disability and a trusted and sustainable NDIS.

# In practice, this could look like..

Mehrdad's daughter Roya has just been diagnosed with cerebral palsy and mild intellectual disability. The doctor who confirmed the diagnoses provides Mehrdad with the latest information on cerebral palsy, and contact details for a local Navigator. Mehrdad gets in contact with the Navigator, who links Mehrdad with an organisation that runs peer support groups with local

families in a similar situation. The Navigator also explains the process and information needed to apply for the NDIS. When Roya starts to receive NDIS support, a NDIS Lead Practitioner and the Navigator work with Roya's family and her childcare centre to understand Roya's needs. They put in place a range of supports, including advice from an occupational therapist and physiotherapist to help with positioning, and communication support, so Roya is included in play and learning activities with other children. Mehrdad is reassured by the advice given by the Lead Practitioner, who understands the extra supports very young children with cerebral palsy need. Roya is happy and thriving.

# Invest in foundational supports to bring fairness, balance and sustainability to the ecosystem supporting people with disability

Foundational disability supports (see Recommendation 1) are disability-specific supports that are available to all people with disability and, where appropriate, their families and carers. They are available outside of individualised budgets. As the name suggests, they are the supports that set the foundations for a good life that should — by right — be available to all people with disability. They are also foundational to the sustainability of the NDIS and therefore are foundational to this Review.

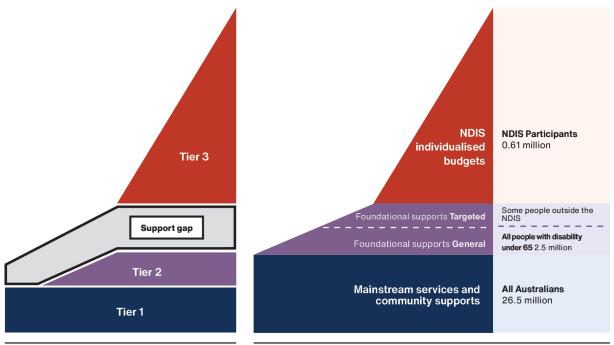
We recommend the Australian Government, and state and territory governments, jointly invest in foundational disability supports, with a particular investment in supports for children with disability and developmental concerns. These supports will be aimed primarily at the 2.5 million Australians with a disability under the age of 65 and will ensure the NDIS is no longer the sole source of disability support.

Foundational supports should include general supports available to all people with disability under the age of 65, and where appropriate, their families and carers. General supports include navigation support, information and capacity building for individuals, families and communities.

Foundational supports should also include targeted supports. These are primarily for people under the age of 65 who are not eligible for an individualised budget through the NDIS and are in most need of additional support. Targeted supports include home and community care-type supports, aids and equipment, early childhood supports, psychosocial supports and supports for adolescents and young adults.

Foundational supports will ensure there is a graduated system of support for all people with disability and reduce the inequity between people in the NDIS and those who are not. Foundational supports will be delivered in ways that build on local community strengths.

Figure 1
Vision for an integrated, graduated model of supports for all people with disability



**Current state -** Disconnected system

Future vision - Connected, balanced and fair system

We believe the fairness, trust and sustainability of the NDIS depends on the full and effective delivery of foundational supports. Foundational supports are fundamental and like preventative healthcare, the smartest investment governments can make.

Increase the scale and pace of change in community inclusion and accessibility and improve the connection between mainstream services and the NDIS

All Australians with disability have a right to accessible and inclusive mainstream services. But despite ten years of the National Disability Strategy, change has been slow, and many services remain inaccessible. This has a profound impact on the lives of people with disability and is placing financial pressure on the NDIS. Services need to improve in health care, education, transport, and community groups and clubs (see *Recommendation 2*). Local governments also have an essential role in building inclusive communities and providing accessible services.

The framework which governs the relationship between the NDIS and other service systems — the Applied Principles and Tables of Support (APTOS) — has failed. It is based on the idea that there is a hard line between the NDIS and other systems.

Despite its intent, it has led to seemingly endless arguments about who does what and who pays for it.

We recommend the APTOS be replaced with a multilateral schedule (see Action 2.6) under the new Disability Intergovernmental Agreement (see Action 20.1). The schedule should clarify the core principles for how the NDIS and other services systems will operate, provide detail on shared responsibilities and update responsibilities. Memoranda of understanding between the NDIA and mainstream services should be developed to agree detailed working arrangements, guided by the principle that systems must work together to support people. This is critical in all areas but particularly for health, justice and school education.

# Provide a fairer and more consistent participant pathway in the NDIS

As a standard setter within the disability service system, the NDIS should ensure people with disability are at the centre of service delivery and empowered to exercise their rights. As noted above, problems with the access and planning process were the most commonly raised issues in submissions and during consultations. They have also been the subject of many previous reviews and inquiries.

While everyone agrees the process needs significant reform, we are acutely aware of the anxiety that comes with change. Previous attempts at reform — most notably the introduction of Independent Assessments in 2021 — were not done in consultation with the disability community and, as a result, provoked considerable anxiety and anger. These were a short-cut algorithm driven approach to planning that was never validated or transparent.

Our proposed approach to the participant pathway (see Recommendation 3) is fundamentally different to Independent Assessments. People with disability, as well as experts, must be involved in implementing our new approach to ensure budget setting is fair and can be trusted.

The access and planning process is central to the participant experience of the NDIS. It is also central to the sustainability of the scheme. For these reasons, it was the focus of much of our work and the area of some of our deepest engagement. For much of this year, we met with a small group of individuals and representatives from Disability Representative Organisations to focus solely on access and planning (for further details on this work see <u>Appendix C</u>). We thank this group for the generosity of their time and expertise — their input has been invaluable.

An overview of our reformed participant pathway is at Figure 2 and summarised below.

These changes will create an NDIS experience that is fair, certain and empowering.

# Proposed participant pathway

Participant pathway	Participant experience	Experience enabler
Find out about disability and supports available	Mainstream services are informed and equipped to refer people with disability to navigators and/or the right information to help them get the supports they need.	Mainstream services will understand their responsibilities and be connected with the NDIS and foundational supports.
Access a navigator	Navigation is consistently available for all people with disability across Australia and delivered locally by people who are connected and understand local communities.	Navigators are run locally, but are accountable to nationally consistent training and oversight.
Access inclusive local and mainstream support	Navigators will help people to find and coordinate support they need in their community and achieve what is important to them.	Mainstream supports are more accessible and foundational supports will be more available locally.
Find out about the NDIS	Navigators and the NDIA will help people with disability understand what the NDIS is, who it is for and how to make an access request if required.	The same accessible information will be available to participants, navigators and the NDIA.
Apply to the NDIS	Applicants can use a fairer and simpler approach to making access requests and providing evidence to support their request. They will have access to a navigator and mainstream and local supports while their request is being processed.	Evidence required for access will be clear and proportionate.
Complete assessments to understand need & set a budget	A comprehensive assessment of need is undertaken by a skilled assessor. This will include a discussion of the risks in a participant's life and what safeguards could be put in place in response. Participants will have as long as they need to ensure they are understood and will be able to view the assessment and add missing information before the budget is set.	Skilled Assessors will use self-reporting and strength-based interviews to assess need.
Receive a budget	Participants receive approved funding in a flexible budget and, if eligible, a home and living budget and stated supports for assistive technology, equipment, and other one-off capital costs.	Funding allocation process will be designed with people with disability and the sector.
<b></b>		
Develop a plan of action	Participants are supported by navigators to develop a plan of action to use their budget in a way that meets their needs, and to implement safeguards to manage risk.	Navigators have access to specialist advice.
<b></b>		
Access supports	Navigators can help identify potential supports and providers that may meet the needs of participants – this could mean helping to switch providers. Navigators help coordinate supports for those who need it.	Online platform supports participants and navigators to find quality providers in their area.
V		
Check-in on progress	Participants get the level of support they need to make sure supports are working for them and that they have effective safeguards in place. Participants are trusted to spend their funds in a way that helps them live an inclusive life. Navigators help to quickly respond to change in circumstances.	Data is collected through the electronic payments system.

# **Applying to the NDIS**

Access to the NDIS should be based first and foremost on significant functional impairment and need — and only secondly on medical diagnosis. A focus on functional impairment will enable multiple disabilities to be considered — which when taken together, result in significant functional impairment.

We recommend significant reform to the access process to make it more equitable (see Actions 3.1 and 3.2). This includes making the process of applying for the NDIS clearer and simpler; clarifying definitions of key eligibility criteria for section 24 and section 25 of the NDIS Act; and standardised approaches to determine whether eligibility criteria are met.

Many participants receive automatic access to the NDIS through an access list. These lists were introduced during transition to the full scheme to accelerate access for some people with disability likely to be eligible for the scheme. However, they have led to a focus on medical diagnosis rather than function and disability-related support needs. They have also led to inequity, with some participants automatically eligible while others are not and favouring those with means to obtain a diagnosis. We recommend removing automatic access under the access lists.

# In practice, this could look like..

Andrea experiences anxiety and has autism and epilepsy. She is confident she understands the process of applying for the NDIS with help from her peer supporter Josie, who went through the process last year. The form is easy to understand and there is lots of information to help her work her way through, including what information she needs to provide. With Josie's help, Andrea provides key information on her situation and gets in touch with her general practitioner (GP) for the functional assessment. Her GP contacts a local Navigator for help to understand the functional assessment and then fills it in for Andrea. Andrea's involvement in the application process is supported by accessible information in Easy Read and her NDIA Needs Assessor tailors meetings to her sensory needs. It is clear all of Andrea's disabilities and needs are taken into account to determine her eligibility. Andrea is connected to a local Navigator, Dheeran, to find foundational supports nearby while she waits for a decision.

# Complete assessments to understand need and set a budget

Planning meetings currently combine an assessment of support need, budget setting and planning in a complicated and stressful experience for people with disability. We recommend changing what is now described as planning into three separate steps to create a process that is clear, transparent and focused on support needs.

We recommend a transparent process for information gathering as part of the assessment of support need. This has been designed to ensure a participant's disability-related support needs are at the centre throughout. The person leading the assessment will be the person agreeing the NDIS budget with the participant. They should be an agent or employee of the NDIA with high level expertise in disability, and spend sufficient time with participants so they feel heard. Only essential information should be collected.

Evidence to support the assessment should come from the participant, any treating professional if required, and take into account holistically the participant's life circumstances. Where assessments may assist the process, they should be transparent, valid, accepted by people with disability and appropriate to the circumstances of the participant.

Where additional information is needed, the NDIA should commission and pay for professional assessments and reports. This will remove a significant inequity in the current process, which favours those who have the ability and means to collect or purchase additional information.

Assessments should be the basis of long-term plans and forward-looking, for instance, taking account of progressive conditions. They should be more flexible for participants and take account of life transitions, including finishing school, moving out of home or seeking employment.

# In practice, this could look like..

Andrea is granted access to the NDIS. She is visited by an Assessor who does an assessment of her support needs. It takes a few hours and Andrea gets overwhelmed, so they decide to break up the assessment over a couple of different days. This also lets the Assessor see Andrea at different times to build a better picture of her day to day needs. The information from Andrea, her doctor and the results of the assessment are used to determine her budget. The results of the assessment are shared with Andrea.

# Receive a budget

NDIS budgets should be set at the whole-of-person level, rather than built line by line for each support need. This was always the intention of the scheme. Budget setting should focus first and foremost on support needs and intensity, which should be determined through the previous stage.

Participants should be informed of the outcome from the budget setting process by the same person who led the assessment.

# Develop a plan of action

Once the budget has been set, participants and their families should receive more help creating a real plan of action, using their funds to achieve their goals. Detailed planning should be undertaken once the budget is set. This should have much more flexibility in how funds are spent than now.

The NDIA should take a trust-based approach in how participants use their budget and make it easy for participants to comply with rules. Compliance should be encouraged through guidance and support, with more hands-on interventions used where there are serious risks or history of issues.

All participants should have access to a Navigator to help plan and access their supports. Navigators should be the agents of participants and help them find and coordinate the supports they need across mainstream, foundational and individualised budgets in the NDIS (see Recommendation 4).

Navigators will also have an important role in amplifying and giving voice to people with disability and ensure people with intellectual disability, or who find it difficult to express their needs and preferences, have access to support for decision-making (see Recommendation 5).

# In practice, this could look like...

Andrea receives her approved budget. Dheeran, her Navigator, sits down with her to carefully work through her needs assessment. Together they find local services that meet Andrea's needs and fit with her budget. To build Andrea's community connections, Dheeran helps her to join an online peer support group and a local crafting group. Dheeran checks in with Andrea regularly to see if her supports are still working for her. Andrea understands she can work with Dheeran to change providers.

# Ensuring existing participants experience a smooth and fair transition to the new participant pathway

We understand that one of the most fundamental objectives of the NDIS is to provide certainty. Certainty for people with disability. Certainty for families and especially, certainty for ageing parents. This is reflected in one of the key objectives for this Review: restore trust, pride and confidence in the NDIS.

The finer details of this new approach to budget setting and plan implementation, including approaches to assessment and the way information is used to set a budget, should be the subject of deep engagement with the disability community.

While we have laid out a blueprint for reform, much work remains in implementation. We urge all governments to continue to work in partnership with people with disability, their families, providers and organisations to implement these changes. These processes need to be transparent, valid and based on lived experiences so they can be trusted.

We recognise that change for participants can be very difficult. We have recommended a guide to transition (see Action 26.2) to ensure participants are given time to understand and have a say in changes before they are affected by them. Changes to access and budget setting processes for children and young people should only be implemented once widespread foundational supports are in place.

# Create a continuum of support for children under the age of 9 and their families

Approximately 20 per cent of children experience learning difficulties, developmental concerns, developmental delay, or are found to have disability.<sup>21</sup> In other words, learning difficulties and disability are mainstream issues.

This is why we recommend significant changes to the way the disability support ecosystem and the NDIS support children and families (see Recommendation 6). We want more and better support for children, both in and out of the scheme to improve outcomes. Our approach includes:

- significant investment by governments in foundational supports outside the NDIS for children in the early years (under the age of 9) (see Action 1.12).
- better screening to pick up developmental concerns as early as possible in mainstream settings (see Action 2.13).
- early intervention services based on best practice principles and evidence (see Action 6.2). Support should be guided by a Lead Practitioner (key worker).
   Support should be delivered in natural settings wherever possible — homes, early childhood settings and schools.

We want children and their families to have every opportunity to lead ordinary lives, included in their local communities.

Our recommendations will support more children in existing services, such as maternal and child health, integrated child and family centres, early childhood education and schools — reducing the need for families to access the NDIS and leading to better long-term outcomes for children.

# In practice, this could look like..

Amira and Kareem are parents of 3 year old Malik. Educators at Malik's childcare have raised concerns he is not reaching some of his developmental milestones. The educators refer the family to a local Navigator. The Navigator explains they will need to visit their GP to complete a developmental evaluation. The GP's evaluation suggests Malik may be eligible for the NDIS. The Navigator helps Amira and Kareem use the information from the GP to apply for the NDIS. When Malik is granted access to the NDIS, he is appointed a Lead Practitioner to guide Malik's supports. The Lead Practitioner provides Amira and Kareem with information on how they can practice communication skills with Malik in everyday activities and developing his motor skills through playing at the park.

Introduce a new approach to NDIS supports for psychosocial disability, focused on personal recovery, and develop mental health reforms for people with severe mental illness

We propose a new approach to NDIS supports for people with psychosocial disability (see *Recommendation 7*), focused on personal recovery. This should be combined with broader mental health reforms outside the NDIS to better support people with severe mental illness.

As part of foundational supports, we recommend an investment in what the Productivity Commission described as 'the missing middle' of mental health and psychosocial disability supports.<sup>22</sup> This investment has long been called for by mental health experts and community mental health organisations. It is an important underpinning to NDIS sustainability.

We also recommend a new pathway into the NDIS for participants with psychosocial disability together with better workforce training. This pathway should be based on early intervention, best practice psychosocial supports and specialist navigation to improve outcomes.

# In practice, this could look like..

Brett has a borderline personality disorder which significantly impacts his daily life and resulted in a breakdown in his relationships with his family and friends and his fellow workers. He has a significant psychosocial disability and the mental health treatments he has received have made no difference. Brett enters the NDIS through the early intervention pathway. This is because his psychosocial disability is likely to be permanent and also has a significant impact on his daily life.

He is connected to Mary, through the local navigator hub and she introduces him to a service provider that has experience and expertise supporting people with psychosocial disability. With Mary's support, Brett chooses the webbased resources, joins a peer support group and the social skills program offered by the service. He also decides to ask his family and some work colleagues to attend the educational programs run for family and friends. Mary helps Brett connect with a new mental health service who bulk-bills and he continues treatment.

After two years, Brett considers that his daily living and social interaction skills have improved but comes to recognise that he will have significant disability support needs throughout his life. He asks Mary to assist him with transferring to lifetime supports through a section 24 application. Mary assists him with his access application and he transfers to lifetime psychosocial supports through the NDIS under section 24. This is administratively easier because he is known to the NDIA. Brett feels that the early intervention service provider helped him be as independent as he could be, supported him to seek further treatment and come to terms with having a lifelong disability. The early intervention service helped him to understand what the NDIS could offer and how to change his supports to his changing needs and improve his confidence and skills in managing his psychosocial disability and his mental wellbeing. He gets on better with his family, friends and work colleagues.

Housing and living supports which are fair, consistent, more diverse and innovative

Many participants with housing and living supports in their plans still have limited choice over where, how and with whom they live. There is inconsistency in what are considered reasonable and necessary housing and living supports, including who receives funding for single living arrangements with no sharing of supports or only sharing of overnight support.

Housing and living supports need to be provided in a fair, consistent way. Participants with similar levels of need, in similar circumstances, should have access to similar levels of funding. They should promote choice, recognise rights and be consistent with the long-term sustainability of the scheme (see Recommendation 8).

The budget setting process should be more transparent and be based on shared support, except in specific circumstances. These shared supports should promote social and community participation and enhance natural safeguards. Most importantly, this does not mean housing arrangements need to be shared — participants should have greater flexibility in how they use their funding. This is evidenced by reforms in Western Australia before the introduction of the NDIS, which led to the development of individualised living options. We anticipate this will be a catalyst for more innovative housing solutions.

There is a critical shortage of affordable and accessible housing in Australia. To address this, Australian Governments should publish a targeted action plan for housing under Australia's Disability Strategy. This should include a requirement to build all new social housing to Gold Level Livable Housing Design Guidelines or equivalent, and a commitment for all remaining jurisdictions to sign up to the National Construction Code Livable Housing Design Standards.

The supply of Specialist Disability Accommodation (SDA) is not always meeting the needs of participants. To enable the delivery of best practice sharing of living supports, and stop 'closed system' houses operated by support providers, there should be a new category of SDA (see Recommendation 9).

# In practice, this could look like..

Cate is a 25-year-old NDIS participant who wants to move out of the family home. Cate is supported by her Navigator to apply for a change of circumstances review and assessed as needing a housing and living budget, including 24/7 living support. With help from a Housing and Living Navigator she explores options for living arrangements that fit within her budget. They find a vacancy in a share house with two others, one of whom Cate already knows. The existing residents and Cate all think it is a good fit. Recognising this is Cate's first time living away from family, Cate receives funding to try the arrangement before committing to it. Bill, the Shared Support Facilitator, works with the participants in the house to work out how joint supports will be shared and what they should expect of their provider. Unfortunately, one of the residents moves out of the house a couple of weeks after the trial ends. Cate finds she does not get along with the new resident. The Navigator helps Cate to find another option.

# Markets and support systems that empower people with disability

The NDIS was designed to offer choice and control to people with disability through a market-based system of supports. However, NDIS markets have not encouraged innovation and in some cases has resulted in further segregation and isolation, placing people at risk of exploitation and abuse. The regulatory framework has not responded to changes in the market, and we have heard growing concerns about over servicing, over charging, fraud and sharp practices.

We have heard people want to see change to how the market operates. They want improved information, changes to pricing and an increase in both the size and quality of the workforce. Our recommendations go directly to addressing these issues and provide governments with a pathway for people with disability to have better access to safe, quality and timely supports, including addressing gaps in thin markets.

# Invest in digital infrastructure to provide more useful information

Providing more useful information (see Action 10.2) to participants, governments and providers is essential to improve quality and help participants find supports that suit their needs. In addition, the NDIA needs to move to electronic payments to ensure scheme integrity. No organisation or worker supporting people with disability should be able to fly under the radar.

# Reform pricing and payments

We recommend governments take a more active role by shifting away from a 'one-size-fits-all' market approach and reforming the pricing and payment regulatory frameworks (see Recommendation 11).

Responsibility for advising on pricing should be transitioned to the Independent Health and Aged Care Pricing Authority (IHACPA) to ensure pricing is transparent, better balances cost considerations with quality and outcomes, and ensure governments use their buying power in the market. IHACPA should use a data-driven approach and consult with the Department of Social Services, the NDIA, the new National Disability Supports Quality and Safeguards Commission (National Disability Supports Commission) (see Recommendation 12) and the broader sector when advising the Australian Government on prices.

Prices should be differentiated to recognise complexity of participants' lived experiences and should cover the cost of having suitable qualified, skilled and supervised workers in the services that support them.

Over time, as we better understand how to measure outcomes for participants, we should carefully explore how prices could better reward providers to support participants' independence and connection to community.

# In practice, this could look like..

Anna, an NDIS participant, needs to replace her 11 year old manual wheelchair and has approval for a new manual wheelchair. Her NDIS budget includes adequate funds to purchase, service and maintain a new chair, as well as funds for an occupational therapist to support Anna to select a wheelchair that best meets her needs. Anna goes online where she can easily find a list of wheelchair suppliers approved by the NDIA panel that sets fair prices and terms and conditions for NDIS participants. Before making a final decision about buying her new wheelchair, Anna checks with her peer network for their insights. She also ensures the supplier's service agreement covers the costs of future maintenance and servicing of the wheelchair.

# Raise the standard of service delivery

The highest quality service providers should be rewarded and low quality service providers must improve (see Recommendation 12). There should be a new dedicated Deputy Commissioner for Quality in a new National Disability Supports Commission. Continuous improvement will also be enabled through better data and market monitoring. Transition to electronic payments and improved information data collection from Navigators will help strengthen market monitoring and coordination of NDIS markets (see Recommendation 13). Provider of last resort policy and arrangements are also needed urgently to ensure continued access to critical supports where markets fail.

Improve access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements

It is clear community-led and place-based alternative commissioning approaches would improve outcomes for First Nations communities and for all participants in remote communities (see Recommendation 14). A lack of culturally-safe supports often means First Nations participants need to choose between supports that are not culturally safe or not getting supports at all. Drive-in drive-out and fly-in fly-out models in remote communities are not working to communities' satisfaction.

Alternative commissioning is an opportunity for communities to create their own services. The effective implementation of the NDIS in these communities needs to be built community-by-community.

Governments should partner with local Aboriginal Community-Controlled Organisations and build on local governance structures in line with the priority reforms in the National Agreement on Closing the Gap. A whole-of-community approach should be explored to join-up service delivery across other care and support systems, such as aged care and health.

Attract, retain and train a workforce that is responsive to participant needs and delivers quality supports

Workforce reform is another critical issue. Our recommendations provide a path to build a more capable workforce (see Recommendation 15). We propose a renewed focus on recognising workers' qualifications and experience and quality of services, as well as better workforce planning across the entire care and support sector.

To improve worker training, we recommend continuing to develop micro-credentials and portable training and sick and carers leave schemes, so their training credentials and leave credits would travel with workers as they move across the care and support sector. These skills and qualifications could be linked to worker screening, so they are visible when new workers are employed.

# In practice, this could look like..

Viv is casually employed and provides in-home care and support services to multiple clients — including to some who are NDIS participants and others who are aged care recipients. As part of the portable training scheme trial, Viv earns training credits for the time they spend providing support to both NDIS participants and aged care clients. After a period of time, Viv builds up enough credits to undertake a short course on supporting people with complex needs. This helps them to deliver better supports to their clients, counts towards the completion of a full qualification and furthers their career.

Deliver safeguarding that is empowering and tailored to individuals, their service needs and environments

The Disability Royal Commission made clear that much more needs to be done to protect against harm, exploitation and abuse. We recommend improved safeguarding that responds to differing needs and circumstances (see Recommendation 16) and developing and delivering a risk-proportionate model to regulate all providers and workers (see Recommendation 17). There also needs to be a stronger drive to reduce and eliminate the use of restrictive practices (see Recommendation 18).

As part of a new effective quality and safeguarding architecture across the entire disability support ecosystem (see Recommendation 19), a new Disability Supports Quality and Safeguarding Framework should be agreed by all Australian governments (see Action 19.1). The current framework was developed for the transition to the NDIS and is out of date.

As a priority, the NDIS Commission must focus on implementing a risk-based and proportionate approach to safeguarding and regulation, and expand on quality of supports delivered to participants.

The NDIS Commission needs to urgently increase trust by becoming more responsive to participants' needs.

Once the urgent priorities to do with the NDIS are met, a new National Disability Supports Commission should have responsibility for the regulation of all Australian Government funded disability supports across the entire disability ecosystem — expanding the coverage of the current NDIS Commission (see Action 19.2).

The National Disability Supports Commission should work closely with state and territory disability regulators and other agencies in the disability supports ecosystem. The right parties must have the right information at the right time to take action to prevent or respond to risks of abuse, violence, exploitation and neglect. Digital capabilities, data analytics skills and an enhanced regulatory intelligence function within the National Disability Supports Commission and a proactive approach to keeping people with disability safe will be essential (see Action 19.3).

# In practice, this could look like..

Ben is a sole trader wanting to deliver social and community participation activities to a small number of participants. Ben completes an online application and acknowledges his obligations under the Code of Conduct and confirms he has a valid Worker Screening Check. After using the online application form, Ben is directed to apply for 'Basic Registration', with a link to the relevant Practice Standards and other information on the National Disability Supports Commission's website. He completes a self-assessment and attests to complying with the Practice Standards. The National Disability Supports Commission assesses Ben's application and he is informed he has satisfied the requirements and is registered to provide these supports.

# Stewardship of the unified ecosystem

We propose governments plan, fund, operate and govern an ecosystem of support for all people with disability — not just the NDIS.

# Create a new compact between Australian governments

A new compact between Australian governments will see a refreshed approach to working together (see Recommendation 20) and clear accountability for sustainability and governance of the disability ecosystem (see Recommendation 21).

The compact should be underpinned by a Disability Intergovernmental Agreement (Disability IGA) (see Action 20.1). The Disability IGA should bring together all aspects of disability support in a unified disability support ecosystem. This includes aligning incentives and cost shares to deliver better outcomes for people with disability (see Action 20.2) and close gaps in support provision. This alignment of interest, which has been absent in the financial arrangements in the first ten years of the scheme, will be an important driver of system sustainability. It will also lead to fewer debates about which system should be responsible for supports and who will pay on a case-by-case basis.

The National Agreement on Closing the Gap is a commitment by all governments and First Nations people to work in new ways to drive better outcomes. The National Agreement on Closing the Gap identifies strengthening the community-controlled disability sector as a priority. The Disability IGA should include a dedicated schedule that embeds First Nations decision-making and an independent accountability mechanism (see Action 20.4).

To ensure genuine action and a focus on outcomes, we recommend the creation of a Disability Outcomes Council (DOC) (see Action 20.5). The DOC will comprise people with disability and other experts who will hold all governments to account for creating a more inclusive Australia. This idea is similar to the National Agreement on Closing the Gap between governments and Aboriginal and Torres Strait Islander peaks. The DOC will offer a high status, public report to Parliament on progress for people with disability in the same way that occurs for First Nations people under Closing the Gap reporting. We also recommend embedding a highly skilled, person-centred, disability aware culture across all disability agencies and governments (See Recommendation 22). This is a necessary condition for effective implementation of our proposed reforms.

# Measure what matters, build an evidence base of what works, and create a learning system

Building the quality, availability and use of disability data is essential to increasing our understanding, improving transparency and making evidence-based decisions about the future of the disability ecosystem. To be successful, our approach needs to be supported by comprehensive disability data and data improvements that reflect the experience of all people with disability (see Recommendation 23). Investment in integrated and longitudinal data is needed now so we can respond to the needs of people with disability throughout their lives (see Action 23.4).

A new Disability Research and Evaluation Fund (see Action 23.3) will support the ongoing research and evaluation efforts of governments, academics and community researchers. The new Disability Research and Evaluation Fund could be seeded with funds from the NDIS 'Reserve Fund' with the interest used to fund research. These investments can build the foundations for a culture of continual learning and innovation for the NDIS and the broader disability ecosystem.

An NDIS Evidence Committee (see Action 23.2) should provide guidance on what disability supports should be considered reasonable and necessary.

# A five-year transition

These reforms are significant. Taken together, they represent wholesale reform of the disability ecosystem. To work, they need to be implemented as a package, with careful sequencing to ensure the most important foundations are in place before other reforms occur. That's why the implementation process will take time and require further engagement with people with disability, the sector, and all levels of government.

It took 10 years to get to where we are today, and we should not expect changes of the scale we are proposing to happen overnight. Some actions can be prioritised to make short-term improvements to the participant experience, while other long-term reforms will require a staged roll out and, therefore, more significant design, engagement and testing.

To set transition up for success, governments should work with the sector to develop a five year implementation roadmap (see Action 26.1). This should take into account critical dependencies, implementation risks, community engagement and necessary legislative reforms.

These reforms will affect everyone with a stake in the NDIS, including people with disability and their families, Disability Representation Organisations, service providers, workers and governments. Implementation arrangements should be sensitive to this and ensure inclusive and representative governance with people with disability (see Action 24.1), a best practice approach to implementation that gives stakeholders a genuine voice in the process, and a smooth transition for participants already in the scheme (see Action 26.2).

Some of our proposed reforms will require changes in relevant legislation. Governments will need to coordinate and consult closely with the disability community on any changes (see *Recommendation 25*).

To build trust in the process of this reform, we recommend creating an NDIS Review Implementation Advisory Committee (see Action 24.1), to include people with disability and monitor and advise government on implementation. This should be supported by the right coordination and expertise in government to deliver a holistic and well-designed package of reforms.

This reform will take time, but our recommendations and actions will deliver a social and economic dividend for decades.

# Sustainability as an outcome of our reforms, not the driver

Our terms of reference sought recommendations from us on how to support the sustainability of the scheme. During the course of our work, National Cabinet agreed to an NDIS Financial Sustainability Framework with a target to contain annual growth in the scheme to 8 per cent by 1 July 2026.

From the beginning of the Review, it has been our belief that the NDIS must be well-managed. It should support those most in need, based on a clear, fair and consistent assessment of reasonable and necessary needs.

We have looked beyond the NDIS. In our view, you cannot improve the NDIS without fixing the ecosystem in which it sits. We believe a sustainable scheme to be an outcome of our reforms, not the driver. A person-centred, fairer NDIS, embedded in a balanced ecosystem of support that is easy to navigate and delivers high quality supports will result in a sustainable scheme.

By improving the NDIS and the ecosystem around it, it is possible to get better outcomes for all people with disability in a more efficient and cost-effective way.

All governments are accountable for the sustainability of the disability ecosystem. It is impossible for the NDIS to be sustainable without a commitment by governments to improve foundational supports outside the NDIS and make mainstream services more accessible and inclusive. This is the most important way to improve scheme sustainability and reduce pressure for NDIS support.

The reformed participant pathway is designed to give an improved experience where people are supported, valued and heard. The needs-based approach to budget setting will prioritise evidence based supports that lead to a more predictable and manageable scheme. Our recommendation for Navigators will help participants access NDIS supports, better manage their budget and choose supports that improve their lives and long-term outcomes.

Investing in data collection, quality and sharing data will improve outcomes, move the scheme towards an evidence based scheme and promote value for money investments.

An enhanced near real time payment system will improve the transparency of transactions, deter fraudulent and sharp practices and make the scheme less wasteful.

We understand that amongst the disability community, the term sustainability has become synonymous with cuts. We want to be clear that we have not designed these reforms to fit targets agreed by government. We have been focused on securing the enduring success of the NDIS — one which improves participant experiences and outcomes and provides value for money.

Based on Review analysis, our proposed reforms will help secure the future of the scheme and will meet National Cabinet's NDIS Financial Sustainability target over the medium and long term.

# A Final Word

To the disability community, we want to be clear these reforms are for you. You have played an essential role in shaping this Review. You have shown through your extraordinary and extensive engagement that you are ready to be part of the next stage of this incredible journey of world-leading reform.

Every person with disability, every family member, every carer, every disability service provider, every worker and every government is a custodian of the NDIS.

Now, we must work together to realise the promise to make every Australian count.

We must do this for people with disability and their families today and for future generations.

It was a united disability sector, together with all governments and all political parties, which gave Australia the NDIS.

Now, more than ever, we need to Work together to deliver the NDIS.

# Part one

# A unified system of support for people with disability

"I think what makes that particularly worse for the person with a disability is it's complex and there is no single service or someone that can represent their views other than an advocate to navigate those complexities."

- Person with disability<sup>23</sup>

Foundational disability supports for every Australian with disability54
Inclusive mainstream services coordinated with the NDIS
A fair, consistent and empowering NDIS experience8
Support for all people with disability to better navigate mainstream and disability supports
Support to empower people with disability to make decisions about their lives
Better support for children and their families inside and outside the NDIS
Recovery-focused psychosocial supports in the NDIS and the broader mental health system
Housing and living supports that are fair, consistent and promote choice
A more diverse and innovative range of inclusive housing and living supports146

# Foundational disability supports for every Australian with disability

There are currently a range of disability-specific supports that are available for people with disability, families and carers outside of NDIS individualised budgets. These supports have a long history in the disability support system, both before and after the introduction of the NDIS. They were described as 'tier 2' supports by the Productivity Commission, and the Information, Linkages and Capacity Building (ILC) program from 2015.<sup>24</sup>

We propose to build on the original idea through an improved framework of disability support that we call foundational supports. We believe the term foundational supports best describes what they are — the supports that offer people with disability a foundation to live a good life, included in the community, regardless of whether they are in the NDIS or not. Foundational supports are essential to a joined-up disability support ecosystem that ensures people with disability inside and outside the NDIS can access the right support at the right time and place.

# There is a lack of accessible and affordable foundational supports

A fair and equitable Australia is one where people with disability not only have access on equal terms to mainstream services and supports, but also complementary foundational supports to meet their disability-related needs.

The NDIS was designed to deliver individualised supports to roughly one-in-fifty Australians, with the vast majority of the one-in-five Australians living with disability supported through community-based foundational supports and mainstream services. The scheme was designed to be one part in a much larger ecosystem of supports to make everyday life inclusive and accessible to Australians with disability.

The Melbourne Disability Institute found that 90 per cent of people with disability, families and carers surveyed in a 2022 study believe current supports and services outside the NDIS are inadequate in meeting the needs of people with disability. <sup>25</sup> This research is consistent with the feedback from people with disability, both inside and outside the NDIS, families and carers, the disability sector, researchers and governments about the lack of available and appropriate foundational supports.

We have heard people want greater access to support and more help to find it.

"Outside the NDIS there is very little available to support children with disability and their families both in terms of specialist disability supports, and mainstream services."

- Healthy Trajectories Child and Youth Disability Research Hub 26

"There was a home and community program in my community but nobody told me about it. I could have got help earlier if I had of
known about it."

- Person with disability 27

We have also heard that the support that is available is unaffordable for many.

"The overwhelming majority of Australians with disability are reliant on programs outside of the NDIS to access supports and services...

Many people living with disability struggle to access the support an services they need and must either self-fund or go without."

- MS Australia 28

"Without access to the NDIS, people with communication disabilities are extremely limited in avenues for speech pathology support.

Whilst there has been much discussion of Tier 2 supports, in practice these are restricted and many supports — such as independent community hubs for assistive technology — have been shut down."

- Speech Pathology Australia 29

The gap between those inside and outside the NDIS is unfair. People with disability who are eligible for the NDIS have access to a wide range of tailored supports, while those who are ineligible struggle to find the right support to meet their needs. This leads to poorer outcomes for people with disability. Ultimately it impacts on NDIS sustainability as more people seek access to an individualised NDIS budget to meet their support needs.

"The advent of the NDIS has heightened the delineation between

activities and supports that are offered on a commercial basis (fee for service)

and those offered on a non-commercial basis (generally available to

all people with disability regardless of whether the person has an

individualised budget)"

- Swinburne University, ILC Research Activity 30

# The lack of foundational supports reflects decisions taken during the NDIS roll-out

The over-reliance on the NDIS reflects decisions taken during its roll-out.

The significance and complexity of introducing the NDIS saw governments prioritise transitioning people into the scheme as quickly as possible. While this was the right approach at the time, it came at the expense of disability supports outside the scheme that all people with disability rely on.

With the introduction of the NDIS, all governments significantly increased funding for disability services. Over the past decade, this has increased from \$8.2 billion in 2012-13 to \$31.3 billion in 2021-22.<sup>31</sup> This expenditure has been primarily focused on NDIS support. Supports within the NDIS made up more than 93 per cent of all disability funding in 2021-22.<sup>32</sup>

All Australian governments continue to increase their contributions to the NDIS each year. This commitment has not wavered, reflecting the strong ongoing political and public support for the scheme.

At the same time, there has been a lack of clarity on responsibilities for disability support outside of the NDIS. The Productivity Commission noted the need to resolve uncertainty about responsibilities for disability services outside the NDIS in both the 2017 review of NDIS costs and the 2019 review of the National Disability Agreement (NDA).<sup>33</sup>

All governments agreed to the implementation of the ILC program and Local Area Coordination (through the Partners in the Community program), alongside the roll-out of the NDIS, to ensure all people with disability would have opportunities to participate in their community. Unfortunately, issues with the implementation of both programs meant some people with disability were left without support — in particular people outside the NDIS.

# We have heard about a range of issues with current foundational supports

Our recommendations for foundational supports have been informed by extensive consultation with people with disability, their families and the disability community. People's priorities included:

- The current ILC program was intended to provide information, advice and capacity building supports for people with disability. We have heard that the program has largely funded short-term supports, not provided adequate and effective supports, and has not sufficiently increased inclusion or made mainstream services more accessible.
- The current Partners in the Community program (LACs) has been directed by the National Disability Insurance Agency (NDIA) to prioritise planning for participants because of resource constraints in the NDIA. Consequently, they have not had sufficient time to help people with disability outside the NDIS.
- Individual disability advocacy plays a critical role in promoting, protecting and defending the human rights of people with disability. We have heard there is approximately twice as much demand for advocacy in comparison to supply.
   This means advocacy organisations are unable to meet the support needs of all people with disability.<sup>34</sup>
- There are significant supports gaps across foundational supports for disadvantaged communities. We have heard that there is a lack of available and appropriate supports for Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities and rural and remote communities. There is also no dedicated Disability Representative Organisation for LGBTIQA+SB communities, which has left a critical gap in the prioritisation of a safe and inclusive society for gender and sexually diverse people with disability.
- There are limited supports focused on early intervention, prevention or low intensity support needs for people with disability outside the NDIS, including children with emerging developmental concerns and disability, and adults with psychosocial disability or chronic health conditions.
- Home and community care (HACC) programs that support people under 65 years of age with less intensive disability needs, including for people with chronic health conditions, are inconsistent and underfunded in most states and territories. The NDIS and HACC or equivalent programs are poorly connected, and there are insufficient HACC-style supports outside the NDIS, including for people who lost access to these supports during the transition to the NDIS.<sup>35</sup>
- Assistive technology for people outside the NDIS is under-funded, fragmented, and complex.<sup>36</sup> There are approximately 108 different schemes in addition to the NDIS where assistive technology can be provided, each with different eligibility criteria.<sup>37</sup> In comparison to the NDIS, these schemes often have long wait-times,

co-payments, and poor ongoing support. The Independent Living Centres which provided free and independent advice on assistive technology before the NDIS have closed.

- Psychosocial support programs outside the NDIS are inadequate and fragmented.
   Many people are unable to access the supports they need, negatively affecting their quality of life and employment opportunities. In 2020, the Productivity Commission estimated that around 154,000 of the 290,000 people with severe and persistent mental illness were unable to access psychosocial supports.<sup>38</sup>
- Support for children with disability or developmental concerns outside the NDIS is lacking. In 2021, 22 per cent of Australian children were developmentally vulnerable on one or more domains of the Australian Early Development Census by the time they reached school.<sup>39</sup> This represents one in five children. The inadequacy of mainstream and foundational supports outside the NDIS results in poor outcomes for families and children and drives many to seek access to the NDIS because there is nowhere else to go. Situating early supports inside the NDIS disconnects children from mainstream services that promote positive child development.
- Adolescents and young adults with disability continue to fare poorly in comparison to their non-disabled peers across a range of indicators.<sup>40</sup> There are few supports available outside the NDIS for adolescents and young adults as they transition to independence.
- Current approaches to disability employment are not working. Over half (53 per cent) of people with disability aged 15 to 64 are in the workforce, compared with 84 per cent of people without disability.<sup>41</sup> This gap of over 30 per cent remains largely unchanged since 2003<sup>42</sup>. The combination of discrimination, low expectations, poorer school outcomes and less higher education results in limited opportunities for paid employment, lower incomes and reliance on government payments. A lack of affordable supports outside the NDIS also presents significant challenges to people with disability accessing the support they need to enter the workforce.

We have found that as a result of these issues, many people with disability apply for and stay in the NDIS for fear of a lack of support outside of it, even when supports outside the scheme might better meet their needs. People who cannot access the scheme are missing out on vital supports and services, which only serves to increase their future needs. This leads to poorer outcomes and puts pressure on the NDIS.

# The Panel's vision

# A thriving foundational support sector is essential to a unified disability support ecosystem

A unified ecosystem of support for people with disability should include the foundational supports needed for the 2.5 million Australians with disability under 65 and, where appropriate, their families and carers. People aged over 65 will likely benefit from foundational supports (such as information and advice), but should receive most of their supports from the aged care system.

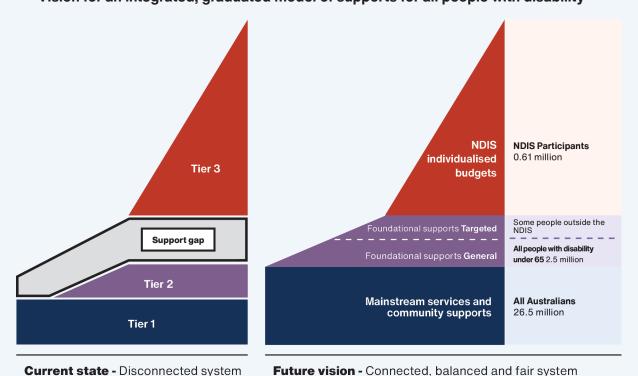
Greater investment in foundational supports would not only deliver better outcomes for people with disability, families and carers, but also contribute to the sustainability of the NDIS. Foundational supports will help support people to be more independent and connected, therefore reducing the need for more intensive supports over time.

Investment in foundational supports should be guided by a Foundational Support Strategy, ideally jointly designed, funded and commissioned by all governments. It should ensure good planning, coordination and accountability, with suitable governance to track and measure outcomes.

Like preventative healthcare, foundational supports are the smartest investments governments can make.

Figure 1 (as seen on page 35)

Vision for an integrated, graduated model of supports for all people with disability



# Invest in foundational supports to bring fairness, balance and sustainability to the ecosystem supporting people with disability

\*Legislative change required

To develop the national architecture and strategy for foundational supports...

### Action 1.1

<u>National Cabinet</u> should agree to jointly design, fund and commission an expanded and coherent set of foundational disability supports outside individualised NDIS budgets.

This should follow the recommended principles for joint funding (see Action 20.2) and be formally agreed as part of the Disability Intergovernmental Agreement (see Action 20.1). As an immediate step, National Cabinet should develop and release a Foundational Supports Statement of Intent. The Statement should define foundational supports through two streams of activity (general and targeted), including the new Navigator function (see Recommendation 4). The Statement will represent a commitment from all governments to all people with disability that foundational supports will be developed and funded as a critical part of an effective and sustainable disability ecosystem.

# Action 1.2\*

# The <u>Department of Social Services</u>, with state and territory governments, should develop and implement a Foundational Supports Strategy.

The Strategy should provide a clear plan to make foundational supports more widely available and more outcomes focused. The Strategy would be a schedule to a new Disability Intergovernmental Agreement (see Action 20.1). The Strategy should be focused on improving the planning, coordination, implementation, and accountability of foundational supports across jurisdictions. Foundational supports should be co-designed, co-funded, and co-commissioned across all jurisdictions. The Strategy will incorporate the current Information, Linkages and Capacity Building program. The Strategy should be supported by a dedicated advisory group made up of Disability Representative Organisations and people with disability.

To plan, fund and deliver general foundational supports...

### Action 1.3

<u>National Cabinet</u> should agree to jointly invest in and redesign information and advice and capacity building supports.

These services are currently delivered through the Information, Linkages and Capacity Building program. This should improve the consistency, quality and coverage of information and advice and individual capacity building supports at a national, state and local level. The emphasis should shift from one-off disconnected project-based funding to reliable and longer-term funding for organisations who deliver advice and capacity building support that is available to all people with disability.

### Action 14

<u>National Cabinet</u> should agree to jointly invest in navigation support for people with disability outside the NDIS.

This should ensure people with disability outside the NDIS receive fair, adequate and appropriate navigation supports (see Recommendation 4). It should support people to determine their own goals, connect with mainstream services, community supports and foundational supports and participate in their community.

# Action 1.5

<u>National Cabinet</u> should agree to jointly invest in achieving nationally consistent access to individual disability advocacy services.

To ensure people with disability have access to effective individual advocacy support there should be better coordination of funding and activities across the Commonwealth National Disability Advocacy Program, and state and territory advocacy programs. Funding increases should have regards to the findings from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, and the National Disability Advocacy Framework and Disability Advocacy Work plan.

# Action 1.6

<u>All Australian governments</u> should fund systemic advocacy of LGBTIQA+SB people with disability to strengthen representation at all levels.

This requires a commitment to funding under the Department of Social Services Disability Representative Organisation Program. Currently there are no Disability Representative Organisations in this area. This is to ensure systemic representations of this culturally, gender and sexually diverse community are rights-based, informed by the social model of disability and enable in-depth consideration, elevation and representation of these distinct and complex communities. The development of a tailored model to represent this intersectional cohort should be led by Disability Representative Organisations and LGBTIQA+SB peak bodies. Jurisdictions should also review their systemic advocacy funding arrangements to include supports for building capacity of systemic LGBTIQA+SB advocacy. Ongoing funding should enable equal representation of LGBTIQA+SB people relative to existing systemic advocacy efforts.

### Action 1.7

The <u>Department of Social Services</u> and the <u>National Disability Insurance Agency</u> should improve linkages between the NDIS, Disability Employment Services and related initiatives targeting improved employment outcomes for all people with disability, including NDIS participants.

This should address issues with how the systems work together identified in the 2021 Disability Employment Strategy. It should include a joint action plan linking different elements of the ecosystem that contribute to improved employment outcomes for people with disability, including initiatives that build employee confidence and capability to employ people with disability. A particular area that needs attention is promoting peer worker support in the NDIS. The action plan should be informed by recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, the Disability Employment Services Program Review, the current NDIS Participant Employment Strategy and other related inquiries.

### Action 1.8

<u>National Cabinet</u> should agree to jointly invest in a capacity building program for families and caregivers of children with development concerns and disability.

Communities and families will be better supported through universally available family programs which include information, peer support and creating and

implementing a vision for their child for a valued and included life. This will mean families have access to timely support, be empowered with information and resources and connected with other families so they can build skills and confidence to support their child. This should be underpinned by mainstream service systems building workforce capacity to identify developmental concerns and disability, and greater support from Navigators for families (see Recommendation 4).

To fund and deliver targeted foundational supports...

### Action 1.9

<u>National Cabinet</u> should agree to jointly invest in state and territory home and community care support programs to provide additional support to people with disability outside the NDIS.

This would support people with disability across Australia, including people with chronic health conditions, to access domestic and personal assistance in their home and community. To ensure service quality and equitable coverage, this investment should be supported by an agreed nationally consistent framework and a benchmark for minimum support standards and coverage.

# Action 1.10

The <u>Department of Social Services</u>, with states and territories, should develop a nationally consistent approach for the delivery of aids and equipment outside the NDIS.

This should be focused on improved planning and coordination of aids and equipment between the NDIS, health and aged care sectors and across jurisdictions. It should also identify an efficient and effective mechanism to fund aids and equipment outside the NDIS. This could include the provision of some aids and equipment (such as hearing assessments and aids) as a targeted foundational support.

# Action 1.11

<u>National Cabinet</u> should agree to jointly invest in psychosocial supports outside the NDIS to assist people with severe and persistent mental ill-health currently unable to access supports.

Consistent with the recommendations of the Productivity Commission's 2020 Mental Health Inquiry, this would expand and consolidate the Australian

Government's Psychosocial Support Program and existing state and territory psychosocial support programs to help address the significant unmet need. The expansion would be managed and delivered under the National Mental Health and Suicide Prevention Agreement and updated based on findings from a service gap analysis currently being led by Health Ministers (due for completion by March 2024).

# Action 1.12

<u>National Cabinet</u> should agree to jointly invest in early supports for children with emerging development concerns and disability.

This is a key element of a proposed continuum of mainstream, foundational and specialist supports for children with disabilities (see Recommendation 6). It should include support from a Lead Practitioner to help children who are not eligible for the NDIS to build their skills and participate in everyday activities. The Lead Practitioner should provide families with information about child development, building their confidence and knowledge to support their child in everyday routines. This should be in addition to the proposed capacity building program (see Action 1.8). It should also include implementing and evaluating a range of other early support models. The delivery of these early supports should be closely linked to and integrated with mainstream services, particularly education and early childhood services.

# Action 1.13

<u>National Cabinet</u> should agree to jointly invest in programs and initiatives to support adolescents and young adults with disability aged 9 to 21 to prepare for and manage key life transition points such as secondary school, employment and living independently.

This should include support to help build the capacity of young people who are not eligible for the NDIS to transition to secondary school and remain engaged in education, and to prepare for employment by developing job-ready skills and confidence. It should also involve decision-support training programs to prepare for major life transitions (see Action 5.2). The Foundational Supports Strategy (see Action 1.2) will help to guide the delivery of this funding across the wide range of ages and corresponding need for multiple program and initiatives. The delivery of these supports must be closely linked to and integrated with mainstream services, particularly education and employment.

## Inclusive mainstream services coordinated with the NDIS

All Australians rely on mainstream services such as health, education and transport. There are also a range of programs and activities based in the community such as those run by community groups, non-government organisations, sporting clubs, local councils, employers, church groups and charities.

Ensuring people with disability can use the same services and participate in the same activities as everyone else is a fundamental human right. More inclusive and accessible mainstream and community services will not only produce better outcomes for people with disability but can also reduce the need for more specialist supports over time.

The NDIS should operate within an ecosystem of services that work together to ensure people with disability can access the right mix of supports at the right time in a connected and inclusive way.

### Progress to make Australia's mainstream services inclusive and accessible has been slow

Prior to the roll out of the NDIS, all Australian governments had agreed to make their mainstream services more inclusive and accessible. This was set out in the first National Disability Strategy (NDS), which ran from 2010 to 2020.<sup>43</sup> However, progress has been slow, with governments prioritising the rollout of individualised supports under the NDIS. People with disability continue to face barriers accessing the supports they need and participating in their community.

Being able to access mainstream services is a human right under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>44</sup> Australia meets its UNCRPD obligations through, for example, the NDIS, Australia's Disability Strategy, 2021-2031 (ADS), the *Disability Discrimination Act 1992* (DDA), state and territory disability legislation, disability action plans, standards for accessibility, and policy impact assessments.

In spite of good intentions, Australia's approach to inclusion, including legislation, has not been strong or comprehensive enough to drive change at an acceptable pace or equally for all groups of people with disability. Complaints under the DDA have more than doubled between 2017-18 and 2021-22.<sup>45</sup> We have heard concerns with how fit-for-purpose and contemporary Australia's approach is to disability rights, discrimination and inclusion legislation, including the current DDA.<sup>46</sup>

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has also highlighted the need for a stronger and more comprehensive legal framework, including a Disability Rights Act, which would protect and promote the human rights of people with disability and shift the legislative burden away from individuals with disability reporting discrimination.<sup>47</sup>

### There is a lack of coordination across systems to support people with disability

The introduction of the NDIS and its often complex interface with many mainstream services has made navigating multiple systems more difficult. Many of the issues raised consistently by people with disability stem from the failure of government agencies to agree on shared responsibilities and working arrangements under the current Applied Principles and Tables of Support to Determine Responsibilities of the NDIS and other service systems (APTOS).<sup>48</sup>

The principles, roles and responsibilities outlined in APTOS have not translated into consistent collaboration on the ground. The underlying structure of APTOS may be part of the problem — it assumes people with disability will be supported by the NDIS or another system. In reality, they need support from both. This leaves people with disability confused about how and where to find and use supports, and in some cases with no access to support at all.

Clear responsibilities and effective coordination between agencies are critical for all people with disability. Mainstream services often have their own eligibility criteria and access requirements, which can be inconsistent and contradictory. In some cases, access to one support can preclude access to another complementary or necessary support, such as access to assistive technology, supports for children with developmental delay, or some supports provided in educational settings.<sup>49</sup>

Without sufficient planning and integration, people with disability can experience not only complexity and inconvenience, but also negative health outcomes and risks to safety and wellbeing.

"...instead of using the entry of the NDIS to encourage much needed,
more sophisticated program intersection protocols and collaboration
opportunities, the APTOS have reinforced program boundaries and the
one dimensional, transactional approach of the old disability systems.
In doing this, the APTOS have made it more difficult for people using
the NDIS concurrently with other programs to get the 'joined up' services

they need. The APTOS have been neither reviewed nor amended as the scheme has evolved. Rather than a level playing field of program responsibilities, their existence has entrenched the historical divide between programs and ensured program interactions focus on who pays, rather than the needs of the person with disability requiring their concurrent support."

- Young People in Nursing Homes National Alliance 50

The risk of negative safety and wellbeing outcomes are exacerbated for First Nations people, particularly for First Nations women. There is inconsistent education, understanding and knowledge of First Nations concepts of disability and care, ways of being and cultural obligations. This inconsistency undermines efforts to improve outcomes for First Nations people with disability, resulting in real harm to Australia's most systemically marginalised population.

"Lack of communication between service providers and communities is evident and a huge problem in supporting mob with disability"

- First Peoples Disability Network 51

## There remain significant problems with how the NDIS interacts with specific mainstream service systems

When issues occur at specific intersections of the NDIS and mainstream services, this can create confusion and ambiguity for participants. At best this is frustrating and time consuming. At worst it can put the health, wellbeing and safety of people with disability at significant risk. Despite being the subject of repeated calls for change over the last ten years, the problems remain significant. We have heard about challenges that remain unresolved at the interfaces between the NDIS and the transport, child protection, justice, school education, hospitals, aged care and mental health systems.

#### **Transport**

Transport is an essential enabling function for people to live connected, productive, and fulfilling lives. Notwithstanding the slow progress to full accessibility in public transport, the NDIS has a vital role in providing transport supports for people that cannot use public transport due to their disability.<sup>52</sup>

However, the lack of a clear long-term NDIS transport policy and continued reliance on the Australian Government's Mobility Allowance means the assessment and funding of transport supports is not tailored to participant needs.<sup>53</sup> This has led to inconsistent decisions, insufficient funding in plans, inequitable outcomes, and an overreliance on cross-billing arrangements with state and territory taxi subsidy schemes.<sup>54</sup> Opportunities to potentially leverage community transport networks to better support all people with disability have also been missed.

#### Child protection

All children have the right to live in a safe family environment. Sadly, children with disability are less likely to have placement stability, are more likely to live in non-home based settings, and are more likely to be at risk of experiencing harm.<sup>55</sup> We have heard of inconsistencies in service provision between the NDIS and child protection, with children and families caught between the two systems while disputes continued about who should provide support and pay for it.<sup>56</sup>

In addition, poor collaboration between the National Disability Insurance Agency (NDIA) and state and territory agencies means information sharing via the NDIS portal is not consistent, there is duplicative and unintegrated screening and risk assessments, along with inconsistent planning and coordination for complex situations such as when a young person transitions to life after care.<sup>57</sup>

#### **Justice**

People with disability, especially those with cognitive and psychosocial disabilities, are overrepresented in the justice system. In 2018, the Australian Institute of Health and Welfare found that 29 per cent of the Australian adult prison population had a disability.<sup>58</sup> 95 per cent of First Nations people who appear in court charged with criminal offences have an intellectual disability, a cognitive impairment or a mental illness.<sup>59</sup>

We have heard that the contested responsibilities when delivering supports to participants who interact with the justice system means supports can cease or be denied when participants enter custody or remand. There can also be disagreement between the NDIA and justice systems over whether certain supports are meeting needs arising as a result of a functional impairment or needs arising as a result of offending behaviour. This disagreement is complicated by the fact that the two categories of need have a complex relationship that is difficult to distinguish between, and have been left open to interpretation in the *National Disability Insurance Scheme Act 2013* (NDIS Act), NDIS Rules and the APTOS.

As with the child protection, mental health and hospital interfaces, we have heard of the difficulties arising due to the absence of specialist case management and integrated planning and funding arrangements.<sup>63</sup> This is a long standing and critical issue as participants who interact with the justice and youth justice systems often have complex needs that need to be met by multiple state and territory agencies and the NDIA working together.

#### Early childhood and school education

Slow progress toward inclusion affects all people with disability but has a profound impact on the life trajectory of children and young people. Failing to include children in the early years can set them on what Inclusion Australia described as the 'polished pathway' to lifelong segregation.<sup>64</sup> Inclusion in early childhood education and care is crucial for later outcomes and a strong transition to school. However, participation rates are low for children with disability and developmental concerns and transition to school is often poorly managed. <sup>65</sup> This can have devastating consequences such as isolation and poor educational outcomes.

The NDIS can exacerbate this exclusion in schools. Its individualised approach often fails to integrate with the classroom experience, and can undermine inclusion for children with disability. This approach also creates perverse incentives whereby some students only receive supports in class if they are a participant, even though schools are provided funding (through disability loadings) for meeting the disability needs of their students. <sup>66</sup>

Families and young people continue to report a lack of support, exclusions and barriers to receiving an inclusive education experience.<sup>67</sup> We have heard about the high levels of school refusal, home schooling and even no schooling for children with disability, particularly children who are neuro-diverse. This impacts on lifelong outcomes and increases reliance on specialist supports provided through the NDIS.

#### Hospitals

Despite recent efforts driven by Disability Reform Ministers and the NDIA, including the introduction of Hospital Liaison Officers, we have heard that significant delays when discharging some participants from hospitals remain a problem. This occurs when participants in hospital inpatient care are medically cleared for discharge but have no safe destination available outside of hospital. As a result, participants must remain in hospital until appropriate supports are available. This comes at a great cost to the participant and the wider health system, leading to worse outcomes for the participant, fewer inpatient beds for other patients, and longer waiting times for ambulances and elective surgeries.

In addition, we have heard about a lack of clear discharge and transition plans, poor communication and information sharing between the NDIA and health systems, inconsistent decision-making and drawn-out NDIA planning procedures with barriers to completing plans (such as waiting on specialist advice and assessments). <sup>69</sup> As with the mental health system, the effective provision of concurrent supports within hospital settings can be marred by inconsistent understanding of responsibilities and poor working relationships.

There is a need for more step-down facilities, when people with disability leave hospital, because while they are ready to move out of an acute medical setting, they are not ready to move home or their long-term support and living needs may not be clear.

#### Aged care

As all people age, the likelihood they develop disability or further disability increases, and their support needs may change. However, the NDIS was never meant to replace the aged care system — they were meant to work together.

Under current legislation, when a participant turns 65 they cannot access more intensive aged care supports, such as the 24/7 nursing care offered in residential aged care settings, without giving up their NDIS supports. As the Royal Commission into Aged Care Quality and Safety noted, there is more funding per person in the NDIS when compared to the aged care system. This means older Australians with disability are not necessarily accessing the services that best meet their needs.

In addition, when the NDIS rolled out, the Disability Support for Older Australians (DSOA) program, now closed to new entrants, was established for some people ineligible for the NDIS due to age. While DSOA is similar to the NDIS, having two systems operating leads to inconsistencies, inefficiency and unfairness. For example, two residents in the same home can have different funding arrangements and their care cannot be effectively coordinated.

#### Mental health

We know that to provide the best support possible and increase the chances of recovery, sufficient and timely clinical and community services must be provided concurrently with disability supports. However, we have seen that there are too few clinicians and significant waitlists in some areas, and a shortage of community mental health services for people who need more intensive support than general practice services, but less than specialised state and territory mental health services.<sup>72</sup>

This failure of coordination between the NDIS and the mental health system contributes to poor outcomes being achieved for participants with psychosocial disabilities. The NDIA has also failed to use its significant role in mental health to influence the delivery of mental health services more broadly.

## Temporary arrangements put in place during NDIS implementation remain unresolved

During the roll-out of the NDIS, governments put in place temporary arrangements that were meant to be reviewed and resolved once the NDIS was in place. Two arrangements that are still unresolved were raised in our engagements with participants, governments and the sector.<sup>73</sup>

#### 1) The National Injury Insurance Scheme

For people who suffer catastrophic injuries that result in disability, the Productivity Commission recommended a National Injury Insurance Scheme (NIIS) be established alongside the NDIS.<sup>74</sup> Of the four originally proposed streams of the NIIS, only the motor vehicle and workplace accident streams were established. This has left significant gaps that push people into the NDIS. Arrangements between the NDIS and existing compensation schemes are also inconsistent, which can result in overlap with the NDIS and create additional stresses and costs.<sup>75</sup>

#### 2) In-kind programs

In-kind programs are disability-related services funded by the NDIS but delivered by state and territory governments. In-kind arrangements are inefficient, and were intended to only be a transitional arrangement. However, delivery of personal care in schools and specialist school transport schemes continue to be on an 'in-kind' basis — with states and territories delivering these services on behalf of the NDIS. This ensures service continuity and maintenance of the status-quo while the long-term arrangements are not agreed. However, it has prevented reform and constrained choice and control for participants and their families.

#### The Panel's vision

More investment in inclusive and accessible mainstream services and new working arrangements to resolve specific NDIS and mainstream interface issues

Stronger inclusion and accessibility requirements across governments are needed to reduce discrimination and uphold the human rights of people with disability, outlined in the UNCRPD and DDA.

Governments should significantly increase inclusion and accessibility, including through legislation, disability action plans, and service standards. The needs of people with disability should be more genuinely considered as a part of government policy making processes, rather than treated as an afterthought or ignored entirely.

Governments must develop a unified and contemporary approach to disability rights, discrimination and inclusion legislation. This should consider the proposed Disability Rights Act, and ensure that the DDA and state and territory legislation are complementary of one another and achieve meaningful change to the lives of people with disability.

A multilateral schedule under the proposed Disability Intergovernmental Agreement (IGA) should be developed that strengthens and clarifies core principles, provides detail on shared responsibilities and updates and corrects existing individual responsibilities. It will set the foundations for how service systems will work together and be held accountable. It should include how shared planning and funding would work, how performance would be monitored and evaluated, along with feedback loops to update the instruments used to assign responsibilities. The new schedule would replace the APTOS.

"Mainstream agencies should have a good relationship with the NDIA relating to the portfolio eg. housing, education, health etc. at a policy level so they can consider joint resources on particular topics...

There needs to be less of "This is not mine, it's yours", "No it's not, it's your agencies responsibility not mine"

- Carer<sup>76</sup>

Participants who interact with hospitals, correctional facilities, mental health facilities and the child protection system often require dedicated and highly coordinated approaches to ensure they receive the right supports. A new approach to coordination and case management for complex settings should be developed cooperatively between the NDIA and state and territory agencies.

The NDIS and the aged care system should ensure NDIS participants aged over 65 receive the most effective and efficient supports for ageing related needs. By bringing DSOA clients into the NDIS, the proposed approach to 24/7 living supports (see Action 8.1) will be able to operate effectively for all residents in a house. This would ensure equity and dignity for older Australians with disability. The NDIS and the mental health system should ensure NDIS supports are provided concurrently with essential clinical supports for people with severe psychosocial disability. The NDIS and systems involved in child development should ensure children receive appropriate early supports and are included within mainstream and community service settings.

The incomplete NIIS should be built out to include general accidents, aligned with the original vision of the NDIS and NIIS. As originally envisaged, clients of no-fault accident compensation schemes should be supported by those schemes, with no cost shifting to the NDIS. Where personal injuries are covered by fault-based accident compensation schemes, settlements should not be deliberately structured to shift costs onto the NDIS. In-kind arrangements by governments were only intended to be a transitional arrangement and should be phased out once key policy issues are resolved for delivery of personal care in schools and specialist school transport.

Increase the scale and pace of change in mainstream and community inclusion and accessibility and improve the connection between mainstream services and the NDIS

\*Legislative change required

To increase mainstream and community inclusion and accessibility...

#### Action 2.1\*

The Attorney General's Department, with the Department of Social Services and the states and territories, should develop a unified and contemporary approach to disability rights, discrimination and inclusion legislation.

This should improve and harmonise legislation including the Commonwealth *Disability Discrimination Act 1992* (DDA) and state and territory legislation. It should also consider the Disability Rights Act proposed by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This should include assessing the effectiveness and appropriateness of current Disability Standards under the DDA. It should also assess the effectiveness of disability action plans across jurisdictions in creating more inclusive and accessible mainstream services and communities for people with disability, and identify opportunities for nationally consistent reporting requirements, approaches and obligations.

#### Action 2.2

All Australian governments should improve the recognition and responsiveness of government services to culturally and linguistically diverse concepts of disability and care by investing in targeted research, education material and capability building for government organisations and staff, professionals and providers who deliver government services.

Inclusive and accessible government funded services require increased knowledge on what disability and care look like in a variety of cultural contexts. Priority should be given to research and capability building initiatives that improve understanding across government services of how culturally-specific beliefs, relationships and familial obligations influence needs, help-seeking behaviours and experiences of government services. This should be supported by investments in community-led, culturally relevant communication products that promote increased understanding of government services and supports in culturally and linguistically diverse communities. This should be underpinned by efforts to embed a highly skilled, person-centred, disability aware culture across all disability agencies and governments (see Recommendation 22). Reforms to disability rights, discrimination

and inclusion legislation should have regard to Federation Funding Agreements and practical clauses to promote inclusion and accessibility (see Action 20.2).

#### Action 2.3\*

The <u>Department of Social Services</u> with relevant agencies should develop and trial a mechanism to publicly communicate the performance of current Disability Standards under the *Disability Discrimination Act 1992*.

This mechanism should be easy to find and understand, and allow people to know whether a service is delivering at a higher quality than the minimum standard, such as through a star rating system. The mechanism should be trialled to highlight performance of mainstream providers against current Disability Standards, for example the Disability Standards for Education. These standards could be included in the Disability Outcomes Framework (see Action 23.1) and reported to National Cabinet by the proposed Disability Outcomes Council (see Action 20.5). This approach should have regard to the findings from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

#### Action 2.4\*

<u>All Australian governments</u> should incorporate Disability Impact Assessments into new policy proposal assessment processes.

This should ensure adequate consideration of the impact of new policy on people with disability. This should have regard to the new Disability Rights Act proposed by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and all state and territory disability rights and inclusion legislation.

#### Action 2.5\*

<u>All Australian governments</u> should take steps to protect the right to inclusive education for children with disability and developmental concerns in early childhood education and care and schools.

Existing legislative instruments should be strengthened to clearly define inclusive education and include stronger accountability and monitoring of schools' compliance against their legal obligations. The needs-based disability loadings each school receives and the use of that funding to benefit students with disability should be reported publicly. The overall performance of schools against their legislative and financial obligations should be measured and publicly reported. This should be supported by greater training for all education staff to understand the laws, policies, programs and inclusive education approaches to teaching and learning.

To improve the connection between the NDIS and mainstream services...

#### Action 2.6\*

National Cabinet should agree to a multilateral schedule to a new Disability Intergovernmental Agreement that replaces the principles for determining the responsibilities of the NDIS and other service systems, including the Applied Principles and Tables of Supports to better clarify respective responsibilities.

This should clarify distinct system responsibilities and shared responsibilities (who does what and how) where a participant requires integrated planning, funding and supports. Shared accountability, including monitoring of outcomes and key performance indicators, for operationalising interface-specific arrangements, should be set out in bilateral schedules and Memoranda of Understanding.

Agreed responsibilities should be incorporated into the NDIS Participant Support Rules and other NDIS Rules governing reasonable and necessary supports, including expectations for shared planning and information sharing. The multi-lateral schedule should set parameters for sharing costs for complex case resolution to ensure meeting the needs of people with disability are prioritised rather than who pays for what.

#### Action 2.7

The <u>Department of Social Services</u>, working with other Commonwealth agencies, state and territory disability agencies and the National Disability Insurance Agency, should implement a priority work program to improve coordination between complex mainstream settings and the NDIS.

As a first step, the program should ensure Memoranda of Understanding are progressed immediately for the justice, hospitals, mental health and child protection interfaces in each jurisdiction. A best practice case management for complex settings approach should be developed and implemented. This should include assertive outreach to identify and support people with disability interacting with complex settings prior to them commencing NDIS access. The roles of Specialist Navigators, key mainstream agency workers and key National Disability Insurance Agency workers should be formalised as a panel of decision-makers to ensure system coordination to meet complex needs. Where necessary, this should include shared planning and shared funding. The roles of the Hospital Liaison Officers and the Justice Liaison Officers should be reviewed and clarified

within the new case management for complex settings arrangements. The NDIS Complex Support Needs Pathway should be reviewed and updated to reflect these new case management arrangements. This should build on the improved working arrangements between the NDIA and hospital staff developed through the National Operational Plan for improved hospital discharge.

#### Action 2.8

The <u>National Disability Insurance Agency</u> and the <u>Department of Education</u>, with state and territory education and disability agencies, should develop a plan to better connect the NDIS and school education systems and improve educational outcomes for children with disability.

This should be focused on ensuring consistent, fair and appropriate support arrangements for participants in school settings across Australia. The plan should outline how the school education system and NDIS will work together to ensure funding and supports are complementary, connected and outcomes focused. This could include schools operating as hubs within the community to host delivery of NDIS funded services after hours. The plan should also outline options for how to better plan, coordinate and streamline NDIS funded supports in school settings. The plan should sit as part of a dedicated Memorandum of Understanding for the school education and NDIS interface (see Action 2.6).

#### Action 2.9

The <u>Productivity Commission</u> should develop an NDIS transport policy that better meets the mobility needs of participants.

The policy should define mainstream transport systems and NDIS responsibilities and outline how they should work together to ensure people with disability are able to move around in their local communities. The policy should also update current systems for determining mobility needs with a needs-based, individualised assessment that has a clear and consistent distinction between ordinary day living expenses and additional-disability related costs, along with transport-related capacity building. Following the development of the policy, the National Disability Insurance Agency in collaboration with state and territory governments will be responsible for implementation. Implementation of the new policy will include cessation of the current taxi subsidy cross-billing arrangements.

#### Action 2.10

The <u>Australian Government</u> should develop a national strategy to improve the quality of the disability ecosystem for First Nations people with disability.

Designed and implemented in partnership with a new First Nations Disability Forum (see Action 20.4), the national strategy will address persistent gaps in the investment, coordination and development of culturally accessible and safe services for First Nations people with disability. It would also facilitate performance monitoring for First Nations people with disability against all Australia's Disability Strategy and the National Agreement on Closing the Gap (Targets and Priority Reforms). The national strategy should be supported by a First Nations Disability Investment Fund that prioritises the implementation of actions already identified by the Disability Sector Strengthening Plan and the forthcoming National Disability Insurance Agency First Nations Strategy.

#### Action 2.11\*

The <u>Australian Government</u> should implement legislative change to allow participants once they turn 65 to receive supports in both the NDIS and the aged care system concurrently and clarify when aged care supports are reasonable and necessary.

The National Disability Insurance Agency and the aged care system should institute a new joint model of cooperation, including a shared assessment model. This should ensure greater choice for older participants. This will require the Australian Government to change the clause in section 29(1)(b) of the *National Disability Insurance Scheme Act 2013* and allow participants over the age of 65 to have expanded access to aged care system supports, including residential aged care, while remaining eligible for complementary NDIS supports.

#### Action 2.12

The <u>Australian Government</u> should implement legislative or process change to allow access to the NDIS for Disability Support for Older Australians program participants.

Once all remaining Disability Support for Older Australians (DSOA) participants have moved to the NDIS or aged care system, DSOA should cease.

#### Action 2.13

<u>All Australian governments</u> should agree as a matter of priority to expand universally available child development checks, to ensure the early identification of children with developmental concerns and disability and enable early intervention.

This approach should build on existing good practice of maternal and child health services in states and territories and internationally for regular health and development checks for young children. It should be implemented by mainstream services working with children including maternal child health, early childhood education and care and general practice. This aims to ensure that developmental concerns and disability are consistently identified early across all jurisdictions. There should also be a national approach to minimum data requirements. This should mean needs are met earlier and greater data on need is available to inform the design of future supports.

#### Action 2.14

State and territory governments should commit to and implement the general accidents stream of the National Injury Insurance Scheme.

Implementation of the National Injury Insurance Scheme (NIIS) should bridge the gap for people who suffer catastrophic injury through a general accident and are not currently eligible for the existing streams of the NIIS or the NDIS (such as those aged 65 and over) or rely on the NDIS instead of the NIIS.

#### Action 2.15

The <u>National Disability Insurance Agency</u> and the <u>Department of Social Services</u>, working with state and territory governments and other relevant Commonwealth agencies, should update current arrangements governing the interaction between the NDIS and compensation schemes to reduce overlap and improve participant experiences.

Arrangements in the interfaces between the NDIS and existing accident compensation schemes should ensure that supports are not being shifted to the NDIS, that overlap is minimised, and that participants eligible for both have certainty on what support is provided and where.

#### Action 2.16\*

The <u>Disability Reform Ministerial Council</u> should agree to cease the use of 'in-kind' arrangements in the NDIS.

This is a long running issue that needs to be resolved while balancing other priorities. Governments should consider removing specialist school transport and personal care in schools from the NDIS and returning them to be state and territory government responsibilities. Agreement to a national benchmark for service quality and access for specialist school transport should be a pre-condition.

# A fair, consistent and empowering NDIS experience

We have heard overwhelming evidence from participants and families that the participant pathway needs a wholesale overhaul. We agree.

This is required across the three key areas of the participant pathway:

- 1. Accessing the NDIS
- 2. Budget setting
- 3. Implementing a budget

A different approach is also needed for those who require early intervention support.

#### The current approach to accessing the scheme is inequitable and isn't always targeted to those people with disability who require the most support

There are two pathways to access set out in the *National Disability Insurance Scheme Act 2013* (NDIS Act): section 24 (disability requirements) and section 25 (early intervention). However, the introduction of diagnostic lists, known as access lists, by the National Disability Insurance Agency (NDIA) has meant there is an additional pathway. Through this pathway, some applicants experience very different evidence requirements to prove eligibility compared to those not covered by an access list. The key distinction between the different access lists is that List A and List D effectively provide automatic access based on diagnosis, while List B provides streamlined access based on diagnosis.

Figure 3
High-level overview of the different access pathways

Section 24 (s24)	Section 25 (s25)	Access Lists
Disability Requirements Access under section 24 for people with disability with permanent impairment, substantially reduced functional capacity and lifetime support needs	Early Intervention Access under section 25 for people with disability with permanent impairment who are likely to benefit from early intervention supports and are best supported by the NDIS	Automatic access:  List A - Conditions likely to meet section 24 eligibility  List D - Conditions for those under 7 likely to meet section 25 eligibility  Streamlined access:  List B - Conditions likely to meet permanent impairment criteria for section 24 or section 25

The lists have played an important role during the initial roll-out of the NDIS. They helped the NDIA manage its resourcing limitations and shortened wait times by helping decisions move more quickly. They have also continued to provide benefits after transition, such as ensuring more timely decisions and support for applicants with conditions that are clearly permanent and lead to substantially reduced functional capacity.

At the same time, the access lists have led to unintended consequences. Now that we are at full scheme, access lists are creating inequity between people with a condition on a list, and people with a similar level of need but with a different condition not on a list. This is driving access to be based on diagnosis, rather than functional impairment and need.

We have heard some applicants with conditions not included on an access list are not getting the supports they need because the access process is too complex or it is too difficult to gather the required evidence.

"I have been unable to access the NDIS because the application process is so horrible to engage with... I am suffering and there is nowhere I can turn for help. The NDIS needs to serve all disabled people, not just those who can work the system."

- Person with disability 77

We have heard that the current Access Request Form is complex, particularly for those who are unfamiliar with the NDIS, its processes and jargon. Many questions are structured in such a way that interpretation is difficult for participants and treating professionals alike. There are additional barriers for participants from culturally and linguistically diverse backgrounds, those with lower levels of literacy, intellectual disability or limited informal supports due to its lack of accessibility.

"Current forms are cumbersome and inefficiently designed, with an emphasis on the requirement for the use of correct phrasing to obtain approvals as opposed to a narrative that conveys what supports the patient requires"

- Royal Australian College of General Practitioners 78

Many people with disability who haven't applied or had an unsuccessful application have indicated this is because "getting supporting documentation for the access request was

too challenging".<sup>79</sup> Decisions on access are too often being influenced by the amount or type of supporting evidence provided to the NDIA, rather than need. This favours better resourced applicants, those better equipped to navigate a complex process and those with strong advocates to navigate on their behalf.

"My child's specialists have to rewrite medical documents in 'NDIS speak' for the NDIA to accept them. These specialists are not trained in completing NDIS Access Request Forms... and nor should they have to be... I want help from specialists who are excellent in their field, not because they are adept in NDIS semantics."

- Carer 80

## The way participants receive NDIS funding is adversarial and leads to inequitable funding outcomes

The concept of 'reasonable and necessary supports' is a key driver of the current challenges with planning. Under the NDIS Act, supports must meet the criteria of being reasonable and necessary in order to be funded. However, this is a legally technical, complex, broad, discretionary concept that has irresolvable tensions. 81

"Feeling like it depends on the planner and their personality rather
than solid processes and procedures as to how my plan might
turn out"

- Participant 82

Reasonable and necessary was deliberately kept broadly defined in the legislation to enable the scheme to flexibly respond to individual need and circumstance. This flexibility of response has come at a price. There is a lack of clarity and confusion and what the scheme should fund is contested. This means reasonable and necessary can play out in inconsistent ways and creates an expectation gap for participants between what supports are wanted and what the NDIS can sustainably deliver.<sup>83</sup>

"I always feel like I'm taking a bit of a wild stab in the dark when it comes to funding therapies... I guess it's hard to write procedures that are good for everyone, especially given the different ways that the same disability might affect different people."

- NDIA Planner, National Delivery 84

The current approach of requiring every individual support to be considered reasonable and necessary has further compounded the problem. The confusion and contested nature of what is reasonable and necessary can therefore play out for every single support item for a participant. Planners end up in the middle of the expectation gap between what supports participants request and what the NDIS can fund. Planners rely on external evidence from treating professionals and providers to try and bridge this gap. This means supports are approved (or not) on the basis of the sufficiency of evidence and/or the ability of the individual or their family and supporters to advocate. This means funding is not always directly linked to need.

"NDIS is not consistent with decisions... saying [something] is NOT approved but yet others get it (that need it less)... only because of who made the decision on the day at NDIA"

- Participant 85

Many participants have told us that their experience of the planning process is stressful and traumatising. Participants and families point to the adversarial nature of the process, which often pits them against a planner who they feel is trying to limit their budget, rather than working to find the best way to support them. Planning meetings are described as negotiations or worse. Planners take a deficit-based approach to assessing need, and participants must present themselves in the worst light to better justify each support they are seeking.

"In my experience, planners have not wanted to know how my disability affects my everyday life."

- Participant 86

"The next round (of so called planning) we face will be the ninth time in the past year that our daughter's deficits and difficult circumstances will have been trawled through in detail in order to seek reasonable and necessary supports for her."

- Carer<sup>87</sup>

### Participants receive inconsistent and insufficient support to implement their plan

We have heard that participants are not being sufficiently supported to understand or implement their plan. While a significant amount of scheme resourcing is consumed managing the planning process described above, limited support is available to participants once a plan has been approved.

The plans provided to participants are inflexible and difficult to understand. They feature complex language and confusing support categories. The rules guiding how funding can be spent are opaque and confusing. We have heard participants find it difficult to understand exactly how their funds can be spent. Some are afraid to breach complex guidelines. This creates inequities between those who have learnt to navigate the scheme and those who require more support to make the most of their funding.

Itemised plans allocated to a multiplicity of support categories can disempower and frustrate participants. The NDIS was designed on an assumption of participants acting like empowered consumers in a marketplace. Instead, they face arbitrary barriers that disempower them and limit decisions on how to spend funding.

"You're allocated a certain amount of money in your plan, but it's too compartmentalised, it's inflexible. You might use up all the money in one portion, while you still have the money in a different section that can't cross over. You can't use the money for just what needs to be done.

It's got to be done within a specific range."

- Participant 88

These issues are compounded by the culture of fear and mistrust that exists around plan reviews. Itemised plans work best when there are regular reviews to check they are still appropriate and can change if needed. They are not suited to long periods without being revisited. The NDIA currently conducts frequent plan reviews for participants to ensure items remain appropriate and are meeting need. However, many participants are fearful of plan reviews and will allow plans to roll-over to avoid having to go through a traumatising review process.

"I am too terrified to have to face a plan review and have to justify my needs when I see what has happened to other people... [I] can't leave my house as no one can transport my electric wheelchair and I am too scared to... request a vehicle modification as scared about having a plan review and having my current funding cut."

- Participant 89

#### There is no specific approach for those who would benefit from and require early intervention

The original vision for early intervention in the NDIS has not been realised. The intent was to fund cost-effective interventions aimed at reducing the impacts of long-term disability by improving outcomes for people with disability and reducing long term costs. The Productivity Commission linked eligibility for early intervention to consideration of whether the intervention would be safe, significantly improve outcomes and be cost effective.<sup>90</sup>

We have heard that access to the scheme through section 25 (early intervention) has been operationalised without a rigorous link between eligibility and the three key criteria: existence of evidence that early intervention for the participant would be safe, significantly improve outcomes and be cost effective. Early intervention participants appear to be predominately receiving the same approach as those who enter through section 24 (disability requirements).

There are also few mechanisms available to support participants to understand the purpose of early intervention, especially for adults. Participants are given little help to understand what good outcomes from early intervention might look like, what sorts of supports would best help achieve this, or how to adapt when a chosen approach is not working.

"The early intervention pathway for adults is unclear and not well understood by planners and assessors. Many people do not know that they can access it, how it can support them, what supports are available and what evidence is needed to meet the criteria."

- MS Australia 91

#### The Panel's vision

The participant pathway should deliver a fairer and more consistent approach to accessing, funding and implementing disability supports

We are proposing a package of reforms to significantly improve the participant pathway.

We are recommending changes to the way people apply for access to the scheme, how information is gathered from participants to assess need and how individual budgets are set. We are also recommending more support for participants to create a plan for spending once their budgets have been set. The next section provides further detail on support for participants once their budgets have been set.

These reforms would make the planning process clearer, more consistent and less adversarial, and funding outcomes fairer and more consistent.

"Get it right. It can be an amazing change in people's lives.

In my family it has changed the NDIS participants life in so many

positive ways. She is living the life she wants, working in the

community and earning a real wage for the first time in her life.

She is a member of her local gym, loving & attending recreation

activities of her choice and making new friends and loving her life!"

- Carer92

### An effective approach to access is essential for the sustainable operation of the NDIS

The future pathway should be clear about who the NDIS is for and what evidence is needed to support an access request. This should be complemented by reforms to significantly increase support outside of the NDIS (see Recommendations 1 and 2).

When a person wants to access the NDIS, there should be consistent approaches to determining whether they meet the eligibility criteria. There should be further clarification of the legislation to support a more effective approach to determining access. They should not have to pay for additional evidence required to meet NDIA requirements. This would remove financial and administrative barriers and provide everyone with the same improved access pathway.

As the access pathway would be improved for all participants under this approach, automatic access under access lists should also be removed.

### There should be increased investment in getting the budget right for each participant

The new participant pathway should feature a more structured way to gather information about the participant, their circumstances and their support needs. The new process would feature a consistent needs-based assessment process to set budgets at a whole-of-person level. The budget should be based primarily on support needs and intensity, rather than functional impairments. There is not a one-to-one relationship between functional assessments and support needs and hence the reasonable and necessary budget. Focusing on support needs is also intrinsically more person-centred and strengths-based than the functional assessments and deficit-based approach used currently. There would no longer be any need to produce expensive reports to justify individual support items each time a plan is reviewed.

Focusing on the whole person, their circumstances and their support needs would also end the current unhelpful and inappropriate focus on establishing a primary or secondary disability. Budgets will be linked to support need not diagnosis.

The new approach to information gathering to inform budgets would require a support needs assessment. The assessment should be completed by a skilled and qualified Needs Assessor who is a trained allied health practitioner or social worker, or similar, with disability expertise. They should spend multiple hours completing the assessment. This would include reviewing any existing information provided by the participant and trusted professionals and then meeting with the participant to understand their goals, strengths, circumstances and level of support needs. This may also involve meeting key people in the participant's life, where appropriate. This process may also be carried out over multiple sessions at the participant's request. In complex cases, a multi-disciplinary team could be involved. The assessment meeting(s) should take place in an environment where themperson with disability feels most comfortable.

"How can you empower me? Centre me - not my disability in the process. I am a whole person, not just my disability.

Respect the opinions of not just my specialist supports,
the people who know me best, but ME as to what I need to
fulfil my goals."

- Carer<sup>93</sup>

The Needs Assessor should be the decision-maker and determine the amount and type of support needed. A detailed record of the assessment should be automatically available.

Delivering this would require government making a significant investment in the time spent on each person's assessment and the experience, training and qualifications of the Needs Assessor. This is a good investment, as accurate assessments of needs are the bedrock of a fair and sustainable NDIS.

Gathering information about participants and their circumstances in a more consistent manner and assessing their support needs in a more structured way would ensure the scheme gets budgets right the first time. When coupled with greater flexibility in how funding can be used, this new process means participants would require fewer reviews. Assessments should also become more forward looking, particularly for participants with a progressive condition.

### There should be more support for people with disability to understand how they might use funding

The future system should separate the determination of the budget from developing a plan of action to use the funding. It should also take a trust-based approach in how participants can use their budget, and make it easy for participants to comply with rules. Compliance should be encouraged through guidance and support, with more hands-on interventions used where there are serious risks or history of issues.

Reforming the participant pathway is a long-term vision that will require significant reforms to be designed and implemented with people with disability and the sector, while taking some action now to begin improving people's experience and outcomes.

Achieving this will require a significant investment in and uplift of capabilities in the NDIA. The new NDIA access and assessment workforce would need to have significant experience, training and qualifications to understand the impact of disability on a person's life. The Assessors would also need sufficient time to build up a comprehensive picture of support needs and meet participants in their homes or other preferred settings. This will help to reset the relationship between the NDIA and participants and their families and supporters.

#### Overview of the proposed participant pathway

Participant pathway	Participant experience	Experience enabler
Find out about disability and supports available	Mainstream services are informed and equipped to refer people with disability to navigators and/or the right information to help them get the supports they need.	Mainstream services will understand their responsibilities and be connected with the NDIS and foundational supports.
Access a navigator	Navigation is consistently available for all people with disability across Australia and delivered locally by people who are connected and understand local communities.	Navigators are run locally, but are accountable to nationally consistent training and oversight.
Access inclusive local and mainstream support	Navigators will help people to find and coordinate support they need in their community and achieve what is important to them.	Mainstream supports are more accessible and foundational supports will be more available locally.
Find out about the NDIS	Navigators and the NDIA will help people with disability understand what the NDIS is, who it is for and how to make an access request if required.	The same accessible information will be available to participants, navigators and the NDIA.
Apply to the NDIS	Applicants can use a fairer and simpler approach to making access requests and providing evidence to support their request. They will have access to a navigator and mainstream and local supports while their request is being processed.	Evidence required for access will be clear and proportionate.
Complete assessments to understand need & set a budget	A comprehensive assessment of need is undertaken by a skilled assessor. This will include a discussion of the risks in a participant's life and what safeguards could be put in place in response. Participants will have as long as they need to ensure they are understood and will be able to view the assessment and add missing information before the budget is set.	Skilled Assessors will use self-reporting and strength-based interviews to assess need.
<u> </u>		
Receive a budget	Participants receive approved funding in a flexible budget and, if eligible, a home and living budget and stated supports for assistive technology, equipment, and other one-off capital costs.	Funding allocation process will be designed with people with disability and the sector.
<b>V</b>		
Develop a plan of action	Participants are supported by navigators to develop a plan of action to use their budget in a way that meets their needs, and to implement safeguards to manage risk.	Navigators have access to specialist advice.
Access supports	Navigators can help identify potential supports and providers that may meet the needs of participants – this could mean helping to switch providers. Navigators help coordinate supports for those who need it.	Online platform supports participants and navigators to find quality providers in their area.
V		
Check-in on progress	Participants get the level of support they need to make sure supports are working for them and that they have effective safeguards in place. Participants are trusted to spend their funds in a way that helps them live an inclusive life. Navigators help to quickly respond to change in circumstances.	Data is collected through the electronic payments system.

#### Provide a fairer and more consistent participant pathway

\*Legislative change required

#### Action 3.1

The <u>National Disability Insurance Agency</u> should introduce a more consistent and robust approach to determining eligibility for access to the NDIS based on transparent methods for assessing functional capacity.<sup>^</sup>

This should include an agreed definition of substantially reduced functional capacity to give more clarity to applicants and consistency in decision-making. This definition should be linked to the outputs of a functional assessment process that can measure the impact of impairment and allow applicants to be compared to their peers (norm-referenced assessments). The definition could then be operationalised through measuring standard deviations from the mean.

Existing functional capacity assessments should be transparently tested with the groups and disability types they have been validated for to inform the design of the new access process. Where appropriate functional capacity assessment instruments do not exist or are not fit for this specific purpose, these should be designed and validated with the groups for whom they will be used. This should build on existing work that has already established a clear need for a new assessment of functioning for some groups and disability types.

Any assessment should cover a broad range of domains in order to be strongly considered for use (e.g. cognitive, language, social-emotional, motor and adaptive behaviour). There should be an accepted basis for comparing results from two or more acceptable instruments that might be used to assess function in a given domain. Any assessment considered should take into account that disability can fluctuate over time, and based on the environments in which a person is in. The assessment should be able to be undertaken by the applicant's treating professional and should be funded by government. Additional evidence required by the National Disability Insurance Agency to inform complex access decisions should also be funded by government.

Once a participant has met access requirements through the new approach, following a functional capacity assessment, they would not be required to be reassessed unless there are exceptional circumstances.

Existing access lists should be removed and automatic access replaced with streamlined evidence requirements to ensure only essential information is collected for all people seeking access. These changes must be designed transparently with people with disability and other relevant experts (see Action 3.8).

^The terminology relating to functional assessment, assessment of functioning and assessment of functional capacity have been used to be consistent with the existing legislation.

#### Action 3.2

The <u>National Disability Insurance Agency</u> should introduce a new Access Request and Supporting Evidence Form and accompanying guidance to make the process of applying for NDIS access more transparent and simple.

This should include a new, dynamic online form. The form and guidance should update as details are entered by the applicant, nominee or treating professional, making it clearer what information is required and why. It should also give real-time guidance where additional evidence is needed or there are issues with information entered. This should offer a more guided experience for applicants and allow for evidence from the applicant as experts in their own lives and needs, alongside evidence from treating professionals. There should also be additional guidance for treating professionals on what evidence is required and why, to improve the consistency of evidence and equity of access outcomes. This should be in addition to enhancements to existing verbal or printed access request options to give applicants more choice in how they apply for NDIS access.

#### Action 3.3\*

The <u>National Disability Insurance Agency</u> should change the basis for setting a budget to a whole-of-person level, rather than for individual support items.

This would require Australian governments agreeing to redefine reasonable and necessary in the *National Disability Insurance Scheme Act 2013* and NDIS Rules as the total amount of funding determined to meet the support needs of a participant. The whole-of-person reasonable and necessary budget should be based primarily on supports needs and intensity, rather than functional impairments. Focusing on support needs is intrinsically more person-centred and strengths based than the functional assessments used currently. Focusing on the whole person, their circumstances and their support needs would also end the current unhelpful and inappropriate focus on establishing a primary or secondary disability. A whole-of-person budget should be sufficient to cover the amount and type of support needed to enable the participant to participate in an inclusive life. This should be determined through a structured needs assessment (see Action 3.4).

#### Action 3.4\*

The <u>National Disability Insurance Agency</u> should introduce new needs assessment processes to more consistently determine the level of need for each participant and set budgets on this basis.

This should support the allocation of a reasonable and necessary budget at a whole-of-person level (see Action 3.3). This would require structured, reliable and valid assessment processes to enable Needs Assessors to accurately identify support needs and intensity. This should also include an assessment of what risks might be present in the participant's life and what safeguards could be put in place in response.

The assessment should enable the Needs Assessor to identify types of support needed, frequency, and any one-off or time limited support required. The Needs Assessor should be able to understand how different support types combine to create a package that makes sense for and meets the needs of a person. The Needs Assessor should be a representative of the National Disability Insurance Agency (staff member or contractor). To deliver this, a significant investment should be made in the time spent on each person's assessment and the experience, training and qualifications of the Needs Assessor.

The total cost of supports recommended by the Needs Assessor should be translated into a budget that can be used more flexibly by the participant to meet their needs (see Action 3.5). Budgets should be able to be multi-year where the Needs Assessor has determined with the participant that this is appropriate. Re-assessments should ideally be scheduled to align with key life transition points where relevant. The budget would be indexed at 1 July each year following price reviews. Existing support needs assessments should be tested with the groups and disability types they have been validated for to inform the design of the new budget setting process.

These changes must be designed transparently with people with disability and other relevant experts (see Action 3.8).

#### Action 3.5\*

The <u>National Disability Insurance Agency</u> should allow greater flexibility in how participants can spend their budget, with minimal exceptions.

The budget should consist of a flexible budget, a housing and living budget, and stated supports for assistive technology, equipment, or other one-off capital costs. The flexible budget should include funding for supports formerly known as core and capacity building supports.

The housing and living budget should include Specialist Disability Accommodation, home modifications, medium-term accommodation and 24/7 living supports. A participant should be allowed to use their flexible budget for housing and living supports, but not vice-versa. This is consistent with the increased focus on a needs-based approach.

Participants should be supported by their Navigator (see Recommendation 4) to decide how to best use their funding and develop a plan of action in line with the objects of the National Disability Insurance Scheme Act 2013. Aligned to more flexible budgets, NDIS Rules would also be developed to better define what 'ordinary living expenses' are.

#### Action 3.6\*

The <u>National Disability Insurance Agency</u> should adopt a trust-based approach to oversight of how participants spend their budget, with a focus on providing guidance and support.

All interactions with participants should be based on trust that they are using funding to improve their lives. The Navigator should be trained to support participants to make best use of their funding and make it easy for them to comply with rules through a clear plan of action and regular check-ins (see Recommendation 4).

The Navigator should also offer gradually increasing guidance and support where risks or minor issues are identified. Plans of action should be recorded in the same system as the needs assessment output (see Action 3.4), and fully electronic payments data (see Action 10.3) to equip Navigators with data to proactively identify risks and respond to issues. Where risks or issues are identified, the Navigator should have tools for mitigation and a clear escalation pathway.

As a last resort where a person has chosen not to comply with the rules or extreme risks of non-compliance have been identified, the NDIA should have transparent processes to implement proportional controls over a participant's budget. These should be codified in the NDIS Rules. This should be complemented by measures to better empower and support people with disability to make decisions about their lives (see Recommendation 5).

#### Action 3.7\*

The <u>National Disability Insurance Agency</u> should reform the NDIS early intervention pathway to provide supports to individuals where there is good evidence the intervention is safe, cost effective and significantly improves outcomes.

The pathway should include a distinct access and needs assessment process to identify applicants who are likely to benefit from early intervention supports in the NDIS. This should include an agreed definition of 'likely to benefit' and clarification of when need can be appropriately met through the reformed foundational supports system. These should be clarified in the NDIS Rules. This should be linked to the outputs of a needs assessment that can allow applicants to be compared to their peers and identify appropriate service responses. Budget setting should be based on evidence of the frequency and type of early intervention support appropriate for the participant.

Early intervention participants should receive tailored support from a Navigator or Specialist Navigator. This Navigator should schedule check-ins and use mechanisms such as case conferencing to discuss progress, ensure service delivery is based on best-practice evidence and principles and adjust the approach where expected benefits are not being achieved.

Reassessments should be conducted biennially or at a frequency determined by the Needs Assessor to determine if there continues to be a need for and benefit from early intervention supports. These changes must be designed transparently with people with disability and other relevant experts (see Action 3.8).

#### Action 3.8

The <u>National Disability Insurance Agency</u> should implement reforms to the participant pathway using an iterative, inclusive approach to design and testing, and ensure participants experience a smooth transition to the new arrangements.

Reforms to the pathway (see Actions 3.1 to 3.7) should be designed through agile projects commissioned by the NDIS Experience Design Office (see Action 24.3). Design, testing and implementation should be undertaken with people with disability and should be aligned with the principles and implementation considerations set out in the Co-Group Feedback to the NDIS Review Panel, developed as part of the Review's participatory engagement process (for further details on the Co-Group's work see Appendix C), as well as the Australian Government Digital Service Standard. Inclusive and proportional user testing should be conducted to allow priority reforms to be phased in and start delivering benefits as soon as they are validated and approved by Disability Reform Ministers for implementation. Assessment

processes in particular require highly transparent, rigorous and inclusive design and testing prior to implementation. Implementation of the changes to the pathway should adhere to a principle that ensure all current participants experience a smooth and fair transition to the new arrangements (see Action 26.2).

#### Action 3.9\*

The <u>Australian Government</u> should update and clarify legislation to support a more effective approach to determining access.

This should include updating the *National Disability Insurance Scheme Act 2013* and NDIS Rules to support the implementation of the changes described in Actions 3.1, 3.2 and 3.7. This should also consider the need for legislative changes to strengthen the operation of the permanence criteria while ensuring availability and affordability of supports for people with disability outside the NDIS (following the Federal Court decision known as *National Disability Insurance Agency v Davis*).

# Support for all people with disability to better navigate mainstream and disability supports

### Finding the right supports can be complex, costly and time consuming

We have heard about the complexity people with disability and their families face navigating poorly integrated service systems every day. This includes services across different levels of government and different departments and programs.

Complexity acts as a barrier to social and economic participation. Despite being highlighted multiple times by previous reviews and inquiries, change has been slow, complexity persists and little help has been provided to help people navigate the system.<sup>94</sup>

Most people with disability have multiple interactions with other government service systems. Participants and providers alike find the interfaces between the NDIS and other systems confusing.

The NDIS currently has multiple functions to help participants navigate in and outside the NDIS. However, these roles are split, and sometimes unintentionally duplicated, across Partners in the Community, Support Coordinators, Specialist Support Coordinators and Community Connectors, as well as Plan Managers. National Disability Insurance Agency (NDIA) Health and Justice Liaison Officers also play a role working with hospital and correctional service systems.

"I think what makes that particularly worse for the person with a disability is it's complex and there is no single service or someone that can represent their views other than an advocate to navigate those complexities. So be it, you know, NDIS and SDA, social housing, access to the private rental and those processes, so you are pretty much on your own navigating all of that, unless you get a good advocate."

- Person with disability 95

Splitting these roles into so many pieces has added unnecessary complexity and resulted in considerable variation in the type and quality of navigation support. The level of access or availability of these functions is also inconsistent. Some participants are not funded to access Support Coordinators and Partners in the Community are constrained

by significant caseloads and aren't present in all locations. This means there is often no single point of contact to help people access supports.

"Not having a consistent contact point means that I feel like I have
to repeat my story on multiple occasions, and that I am just a random
client, not a family and a human with a story, cause and knowledge that
I bring, and a plan."

- Carer 96

We have heard from participants and their families that additional external support is required to successfully navigate the NDIS and interfaces with other service systems.

"Support Coordination isn't just an option for NDIS participants, it's a must have thing. Participants need an advocate on their side who knows the system, how to interact with providers and to book services. Not having this is wasting the NDIS's money, as participants who don't have these services are left spending their funding without guidance and are open to exploitation."

There are issues with the implementation of the Partners in the Community program

Issues with the implementation of the Partners in Community program have been raised in previous reviews. 98 We have heard the same issues from participants, families and other technical experts. Partners in the Community are community based organisations that work with the NDIA to deliver the NDIS. They include Local Area Coordinators who assist people 9 years and older and early childhood partners who assist children under the age of 9 and their families.

The Productivity Commission originally envisaged the local area coordination model as having a key role as 'the scheme's case managers'. Their purpose was to provide "broad services, including individual or family-focused case management and capacity building within a specified geographical area". 99

Funding and staffing constraints in the NDIA have led to Partners in the Community being diverted from their intended role to focus almost entirely on access and planning tasks. This has left people with disability without support to implement their

- Participant 97

plans and prevented community capacity building. Very high caseloads have meant Partners in the Community spend limited time with each person. As a result, relationships have become transactional rather than relational, and people with disability are not being supported to achieve the outcomes that matter to them.

The large-scale contracting of Partners in the Community means they can often lack the deep local knowledge and disability expertise needed to provide people with support that meets their needs.

### Support coordination is not available consistently and not proportional to need

Support coordination is currently funded by the NDIS to assist participants to understand their plan and make the best use of their budget, connect people to supports and build individual capacity. We have heard many participants do not receive enough help to coordinate and implement their plans effectively. Support coordination is only available to some people and there is not a consistent approach to ensure people receive support that is proportional to their needs.

"For many participants there is no, or inadequate, support coordination funding. Families and carers of participants with no, or inadequate

Support Coordination funding, face difficulty navigating the complex

NDIS service market."

- NGO 100

Decisions about the level of support coordination funding can be influenced by how well participants and their supporters — or Support Coordinators — can advocate for funding. There can also be inconsistent application of the concept of reasonable and necessary supports and unclear guidelines to determine what level of support coordination is needed.

"Many Participants who are in desperate need of support coordination funding, either receive no such funding or inadequate funding. The fact that some Participants are reluctant to use their allocated funding, due to being considered as a "burden to society" means that they might leave things until they escalate into a crisis situation. Thus ultimately needing an increase, not decrease in support coordination funding."

- Person with disability 101

There is mixed feedback on the quality of support coordination. We have heard of some providers that are very highly valued by participants and their families, as well as other providers that are not providing support with sufficient care, skill or integrity. There is little consistency in the support coordination market and participants can experience a lottery of whether their provider or specific Support Coordinator is effective or not.

There is also strong concern about conflict of interest and client capture when providers or other NDIS services also provide support coordination to participants. This is of particular concern when participants have limited natural safeguards.

### The Complex Support Needs Pathway is not meeting the specialised needs of some participants

There were approximately 10,400 participants in the NDIS on the Complex Support Needs Pathway as at June 2023. This pathway was designed to provide specialised assistance from the NDIA for participants who have many different challenges in their lives. These may include mental health, incarceration, homelessness, or a higher level of specialised supports required to meet their needs.

People with disability and the broader disability community have told us there are many challenges with the Complex Support Needs Pathway, including that the number of participants eligible is surprisingly low. Limitations on NDIA resources have meant that the additional support isn't available for many participants with higher needs.

There is a support gap to help people with disability with many different challenges meet access requirements. This is because streaming to the Complex Support Needs Pathway happens after access has been granted. Those who are transitioning from hospital or justice are supported by specialist Health and Justice Liaison Officers, but this is not consistently available to support broader access requests.

These challenges are compounded by a lack of coordination between different government service systems to provide a continuum of care outside the NDIS. The people with the most complex needs generally have the most complex support arrangements and require person-centred rather than system-centred support to manage this complexity.

### The Panel's vision

### Proactive navigation support is needed for all people with disability

All people with disability should have access to a Navigator, who acts as their agent. This should be complemented by the proposed changes to foundational supports, and mainstream and community services (see Recommendations 1 and 2). This is needed to avoid people navigating to nothing, or feeling they have to keep using services that do not meet their needs.

Navigators should act on behalf of the person with disability, at their direction, and be incentivised to build capability, help the person meet their goals, facilitate choice and enable inclusion. They should not be an agent of the NDIA to ensure a separation between those who set a budget and those who help a participant to use it. They should be funded outside of individual budgets to ensure participants do not need to choose between a Navigator and other supports.

The Navigators must have realistic caseloads and be able to flex up or down as the needs of participants change. This would overcome a major challenge with individualised support coordination budgets today, which are fixed and do not change as circumstances change. Where appropriate, Navigators should operate out of locally based 'hubs' with other relevant services and be able to share information on support quality and opportunities for greater community inclusion.

Navigators should help all people with disability find and coordinate the support they need and achieve what is important to them. For people who will not access the NDIS, Navigators should support people to determine their own goals, connect with mainstream services, community supports and foundational supports to participate in their community.

For people who may be eligible for the NDIS, Navigators should help people understand what the NDIS is, who it is for and how to make an access request if required. It also includes amplifying the voice of participants with providers, helping them switch providers where existing arrangements aren't working or finding better alternatives in the local community. Though it should not be their responsibility, Navigators would help to make NDIS markets work more effectively.

Specialist Navigators should be available for people with more complex support needs, certain population groups and people at key life transitions, such as preparing for education, employment and independent living. These Navigators should have more experience and smaller caseloads.

Navigators should be delivered locally by people who have genuine local connections, knowledge and links to local services. There should be a national framework to ensure consistent delivery, with local design to capture the unique needs of different locations. Navigators and Specialist Navigators must not be involved in information gathering or budget setting functions and should not deliver other NDIS services to avoid potential conflicts of interest.

The role and functions of Navigators should be scoped and designed with people with disability as well as other sector representatives and others with technical expertise. This should keep features of the current Partners in the Community and Support Coordinator functions that are working well, and reimagine those that are not. It should involve a carefully planned approach to testing the new navigation model and staged transition to mitigate disruption to participants and their families.

The staged approach to transitioning to the new approach should also provide the opportunity for existing Support Coordinators to become Navigators and to allow continuity of support. There is significant capability and expertise for many of the required activities in the new approach already in the market and this should be harnessed as part of the new approach to navigation.

Figure 4
Overview of proposed navigation support

	Navigation support	Plan of action	Specific roles/ competencies	Data gathering and reporting
General navigator Support for all people with disability	Navigation supports (varied caseloads based on need) Support finding and accessing NDIS and non-NDIS supports Help understanding what the NDIS is and who it is for Connect to individualised safeguards, including support for decision making	Supporting participants and nominees to develop a plan of action to implement mainstream, foundational and funded supports Helping to identify supports and providers	Outreach for people with barriers to access Critical life transition points (including education, employment and independent living) Support those who would benefit from early intervention to access and adapt supports that work for them	Collecting data and reporting on demand for services and unmet need for all people with disability  Reporting gaps in local service systems  Information gathering for people with barriers to access  Sharing good practice
Specialist navigator Support for participants with complex needs	Same as general, with higher intensity and more time per participant (lower caseloads (max 1:12)) due to complexity of needs, situations and/or interfaces with multiple services systems	Same as general, with a greater need for a coordinated approach to the range of services needed Work with NDIA Justice and Health Liaison Officers to help with transitions	Higher levels of experience and training Specialist expertise to navigate transition points in the context of complex situations and interaction of multiple services systems	Same as general, with a focus on data for people with complex needs
Additional service offerings				
Psychosocial recovery Support for participants with psychosocial disabilities	Same as general, with varied caseload, depending on need Outreach and assist people with psychosocial disability to connect with non-NDIS services and apply to the NDIS	Assist participants with psychosocial disability to set and achieve goals, identify evidence based supports, and connect with mental health, primary care and housing services	Evidence informed and best practice approaches in mental health and supported decision making	Same as general, with a focus on data for people with psychosocial disability
Housing and living Support for participants with housing and living needs	Advises Navigator when participant is starting to explore housing and living options  Provides time-limited support to participant and their Navigator to identify and negotiate with providers; implement housing and living solutions; trial different housing and living options	Provides advice to either the participant's general or Specialist Navigator in developing a plan of action	Evidence informed and best practice approaches to housing and living Knowledge of the wide range of housing and living supports available across service systems, as well as local housing and living options	Same as general, with a focus on participants with a need for housing and living supports

### Support all people with disability to navigate mainstream, foundational and NDIS service systems

\*Legislative change required

#### Action 4.1

The <u>National Disability Insurance Agency</u>, through the joint commissioning process described in Action 4.3, should be the lead commissioner of a local navigation function to help people with disability find supports in their community and make the best use of their funding.

Significantly greater support should be provided by a Navigator with genuine local connections, knowledge and links to local services. Navigator support should be provided to people with disability, regardless of whether they are a participant or not. This should be aligned to the new Foundational Supports Strategy (see Action 1.2).

The Navigator should act on behalf and at the direction of the person with disability when providing information and supporting access to mainstream, foundational and NDIS services. This should include connecting people with disability to individualised safeguards, including support for decision-making. The Navigator should support participants to develop a plan of action, book and coordinate support where needed, undertake progress check-ins, and provide specific advice on key transition points or key issues. There should be additional service offerings for those with psychosocial disability (see *Action 7.1*) and those with housing and living needs (see *Action 8.2*) as part of the Navigator function.

A carefully planned and staged transition to implement navigation would be essential to mitigate disruption to participants and their families. The staged approach to transitioning to the new approach should also provide the opportunity for existing Support Coordinators to transition to the provision of Navigator supports and allow continuity of support. Implementation should ensure the features of roles that are working well are retained and those that are not are reimagined (see Action 4.4).

#### Action 4.2

The <u>National Disability Insurance Agency</u>, through the joint commissioning process described in Action 4.3, should be the lead commissioner of a Specialist Navigation function for participants who have more complex or specific needs that cannot be reasonably met by general navigation support.

A Specialist Navigator should be available for participants with more complex support needs. This includes those with interactions with acute service systems and where complex situations or significant risks have been identified as part of the access or needs assessments. Opportunities for the National Disability Insurance

Agency (NDIA) to jointly commission these specialist Navigators with other service systems should be explored by the NDIA to improve coordination.

Specialist navigation should be provided locally by staff with lower caseloads than other Navigators and have relevant experience managing complex situations and risks and ideally are qualified in allied health, social work or related fields. They should provide a higher level of support to participants when delivering Navigator functions to help respond to the participant's complex support needs, environmental complexity, or mitigate risk. Specialist Navigators should work closely with (but not duplicate) the role of NDIA Hospital or Justice Liaison Officers to ensure smooth transitions and coordination of supports for those participants who are exiting other service systems.

#### Action 4.3

The <u>National Disability Insurance Agency</u> should ideally adopt a joint commissioning approach to deliver local navigation support within a nationally consistent framework developed in partnership with other relevant Australian government and state and territory government agencies.

Design of the navigation function should balance the need to design services that would be delivered locally to meet the specific needs of a community, while maintaining national consistency. This ideally should be approached through a process of joint commissioning between all Australian governments to ensure a coordinated approach to local service navigation. Local delivery should be underpinned by a nationally consistent approach to governance, branding, online service options, information management, communities of practice, monitoring and evaluation, and capability and training.

Wherever possible, there should be a local physical space or hub for people to interact with Navigators, co-located with existing community service organisations and foundational supports to increase service integration. The footprint for the navigation function should be significantly more local than the current NDIS service areas, and resourcing should allow for appropriate caseloads. This should ensure Navigators have the necessary local knowledge and connections, and can spend time providing genuine support. An alternative approach to delivering Navigators in remote communities should be considered to align with alternative commissioning of supports (see Action 14.1) and the general approach to outreach in the Navigator model.

#### Action 4.4

The <u>National Disability Insurance Agency</u> should design, test and implement the navigation function gradually, prioritising continuity of support for participants and their families and a smooth transition for the workforce and market.

The navigation function should be designed and tested with people with disability and other relevant experts through agile projects commissioned by the NDIS Experience Design Office (see Action 24.3). The design process should be aligned with the principles and implementation considerations set out in the Co-Group Feedback to the NDIS Review Panel, developed as part of the Review's participatory engagement process (for further details on the Co-Group's work see Appendix C). The design should include trial(s) across multiple service areas. Trials should encourage the formation of consortia and allow for multiple organisations (including existing independent support coordination providers) within a local area so that smaller organisations can contribute to genuinely local approaches. Trials should take an iterative and inclusive approach to designing functions with people with disability, as well as sector and technical experts. This should provide an opportunity to test both local approaches and measures to ensure national consistency and quality prior to wider implementation. The function should then be rolled out gradually to ensure continuity of support for existing participants, steward the significant existing capability in the support coordination and Partners in the Community workforce, and minimise impacts on the market.

# Support to empower people with disability to make decisions about their lives

## The majority of participants in the NDIS require support for decision-making

The right to individual autonomy and to make one's own choices are enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Choice and control is also at the heart of the NDIS. People with disability have the right to access the supports they need and to be involved in decision-making about their lives. But without appropriate support, some people with disability are currently not able to exercise this right.

Given the majority of adult participants in the NDIS have a cognitive disability, many would benefit from support for decision-making. In addition, around 50 per cent of participants are children or adolescents and may require additional support, especially as they move towards adulthood. 103

## The NDIS has increased the complexity of decision-making

Prior to the NDIS, people with disability had no choice over the services and supports they received. The introduction of the NDIS brought greater choice of services but also increased the number and complexity of decisions required by people with disability and their families to access supports.

The speed and complexity of the roll-out of the NDIS meant insufficient consideration was given to supporting participants and their families to make decisions. This has led to many participants with cognitive disability and those with complex communication support needs having limited opportunities to be involved in planning or decisions about the services that they receive. It has also resulted in significant growth in both formal and informal substitute decision-making.

"...the advent of the NDIS has resulted in significantly increased use of the adult guardianship system. This is curious because consumer (not substitute decision-maker) "choice and control" is a bedrock principle of the scheme. But ... the scheme results in a greater number of decisions needing to be made by the many NDIS participants and prospective

participants who have impaired decision-making ability... For participants whose disabilities impact on their decision-making, there exists significant potential for them to be assisted to make their own decisions, rather than have others — including adult guardians — appointed to make decisions for them."

- Australia's Public Advocates and Public Guardians 104

We have identified challenges around access to support for decision-making, including lack of accessible information to inform decision-making, limited opportunities for people to develop decision-making skills, lack of appropriate support for decision-making (including independent support and access to trained decision-supporters), and nominees who do not have clarity about their roles and responsibilities or sufficient knowledge to support participants to be involved in decision-making.

### Participants do not have access to high quality information to make informed decisions

A lack of access to tailored information and advice that is proportional to the complexity of the NDIS means many participants struggle to get the information they need to make informed decisions. We have heard repeatedly from participants how difficult it is to navigate the NDIS and access the information they need.

"The information available to participants has not been clear and has not been conducive to decision-making, including: Poor training of NDIA staff at all levels, resulting in inconsistent and unreliable advice being provided by contact centre staff, LACs, planners and other. Absence of information about appropriate terms and conditions applicable to service agreements, resulting in confusing, lengthy and unenforceable contracts terms. Insufficient (and contradictory) publicly available information about how funding can be used, and public claims of participant rorting and "crackdowns" resulting in participants being too afraid to make decisions and plan managers policing spending."

Working together to deliver the NDIS NDIS Review: Final Report

- Disability Legal Rights Service 105

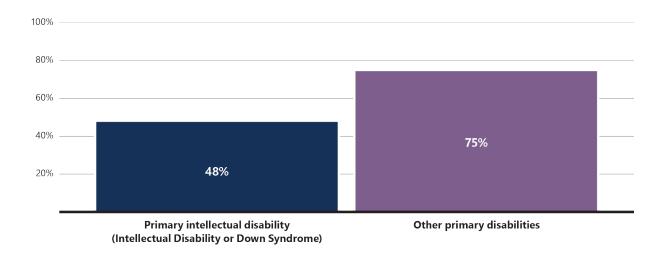
## People with cognitive disabilities have limited opportunities to participate in decisions about their lives

Capacity building supports for decision-making are fragmented and availability varies across jurisdictions. Many of these supports are not appropriate for people with a higher level of support need or for those from diverse groups. This means they are not effective in breaking the cycle of exclusion.

Decisions about children and adolescents are often framed as being made in their best interests, rather than involving the person in decision-making. This can limit opportunities for them to develop and practice decision-making skills and navigate risk. Families are often unsure how to involve them more in decision-making. They are not provided with the information or advice they need on how to support the child or adolescent with decision-making and independence.

Adults with cognitive disabilities experience a similar lack of opportunities to be involved in making decisions about their lives. Decisions are often made for people with cognitive disability with little consideration of their preferences. This can happen for big decisions, such as where to live, or smaller decisions, such as how to spend time during the day (*Figure 5*). Less than half of adult participants aged 25 and over with intellectual disability (including Down syndrome) report that they choose what they do each day. This is significantly lower than the proportion of participants aged 25 and over in the whole scheme who report that they choose what they do each day.

Figure 5
Proportion of participants aged 25 and over who choose what they do each day<sup>106</sup>



There is currently no strategic approach to delivering and coordinating supports for people with cognitive disability to develop their decision-making skills. We have heard from advocates and families about the importance of having access to funded peer-support and self-advocacy initiatives to help people with cognitive disability to build their skills, experience and community connections.

### Support for decision-supporters has not kept pace with the increased demands of the NDIS

People with cognitive disability often rely on family members and other supporters to assist them in making decisions about their lives. These informal decision-supporters are usually well placed to provide this support, given their knowledge about their person and their trusted relationship.

This does not mean it is easy for families. There is significant pressure on family members to take on the role of providing support for decision-making. A recent national survey of carers found that 83 per cent of family carers are providing support with decision-making.<sup>107</sup> Providing decision-support to a family member can be complex. It can be difficult for families to recognise differences between what the person with disability may want and what the carer or family thinks would be best for them.

We have heard that families and other decision-supporters do not have access to the training, information and resources they need. This can lead to substitute decision-making, where people are making decisions on behalf of the person with disability, occurring either informally or formally through a guardianship order.

Support workers or other paid staff also play a role as decision-supporters, even if they are not in a formal decision-support role. Workers will support people to make decisions about what they eat, how they spend their day or what activities to participate in. Many workers have difficulty balancing issues around the person's autonomy and managing risk in their role. These workers are often not provided with the training they need to navigate these issues.<sup>108</sup>

Access to support for decision-making is particularly challenging for people with cognitive disability who have little or no informal supports. They are reliant on providers or Support Coordinators who can have inherent conflicts of interest. The lack of independent support can have significant impacts on choices over services, with limited opportunities to explore options outside of their current providers or housing arrangements.

## There are insufficient checks on nominees' suitability and the supports they receive to execute their duties

Nearly half of participants with intellectual disability (including Down syndrome) have nominees in place who are able to act, or make decisions, on their behalf.<sup>109</sup> In some cases this works well and nominees act according to best practice approaches to supported decision-making. However, the design of the nominee provision leaves it open to misuse and the potential for abuse of participants.

Nominees have significant powers and therefore should be subject to appropriate checks as part of the appointment process. Currently, a participant can request a nominee be appointed and the National Disability Insurance Agency (NDIA) actions this without sufficient consideration of risk and suitability of the nominee. There is also no assessment of what support a nominee might require in their role.

Nominees are given minimal information and support after their appointment. Nominees are not provided with training, support or guidance, beyond the instrument of appointment, about how to execute their duties.

While many nominees are doing the right thing, there is little oversight to identify when nominees are not making decisions in the best interest of participants. In some cases, a nominee may be the only person in the person's life outside of providers, which puts the nominee in a position where they could use their powers to perpetrate abuse or cease needed services.

"I've come across quite a few times this year. I've been supporting someone with an intellectual disability who has a nominee, but their nominee is not listening to their will and preference, and the providers are listening to the nominee over the person who is receiving the supports. I've talked to the NDIS about this... and asked about getting people removed as a nominee, and they've just said it's not up to them; it's so difficult."

- Individual advocate 110

There are also complexities with how the nominee arrangements interact with other government-appointed substitute decision-makers. Under the *National Disability Insurance Scheme Act 2013* there is limited recognition of the role of an appointed guardian or attorney with relevant powers. Unless appointed as nominees, guardians are not recognised under the legislation as being able to make decisions about a participant's plan.

### The Panel's vision

We must do more to support participants to exercise genuine choice and control and to be able to make decisions about their lives

The NDIA should embed a best practice, rights-based approach to supported decision-making. This involves providing accessible information and tailored advice, building decision-making capacity of participants and providing the supports needed for participants to make decisions about their lives.

To achieve this, the NDIA should ensure participants have access to the supports they require. Need for decision-making supports should be assessed as part of the process of determining a budget and the risk assessment and safeguard building process. This should include considerations of the level of informal support available and whether it is reasonable and desirable for the family or others to continue to provide this level of support.

The Navigator should support participants to access the level of support they require, including as their needs fluctuate over time. These supports could include:

- Peer-support networks (foundational support)
- Self-advocacy groups (foundational support)
- Tailored training (foundational support)
- Assistance to explore, set up and maintain networks of supports (NDIS funded support)
- Funded independent decision-support (NDIS funded support).

Participants, families, nominees and other decision-supporters should be provided with access to high quality information and training to support them in their roles as decision-supporters. This would help participants access higher quality support for decision-making and reduce substitute decision-making. This approach would assist in maintaining informal supports. There should also be better support for participants to establish circles of support or Microboards. Nominees should also be provided with better information, support and training about their role, with appropriate oversight in place.

### Provide better support for people with disability to make decisions about their lives

\*Legislative change required

#### Action 5.1

The <u>National Disability Insurance Agency</u> should ensure participants receive accessible information and tailored advice to support informed decision-making.

The Navigator should be responsible for ensuring participants receive accessible information and advice to inform decision-making, including connecting participants to other advice services. In addition, all communications from the National Disability Insurance Agency (NDIA) to participants and families must be provided in accessible formats aligned with participants' communication preferences. This should be supported by ensuring NDIA staff and Navigators have completed appropriate training on accessible communications. These changes should occur in parallel to additional support for decision-making for participants with a cognitive disability or complex communication support needs (see Action 5.2).

#### Action 5.2

The <u>Department of Social Services</u> and <u>National Disability Insurance Agency</u> should both ensure those with cognitive disability or complex communication support needs are connected with capacity building support and other lifelong opportunities to build decision-making skills and experience.

The foundational support system should include funding for programs and initiatives that help to build decision-making capacity and independence for participants with a cognitive disability or complex communication support needs. At a minimum, this should include self-advocacy, peer-support, and training. It should include a disability led mechanism to support a coordinated approach to self-advocacy networks and peer support, as well as training on supported decision-making delivered by disability organisations. Within the NDIS, there should be support for participants to build networks to assist in support for decision-making (such as circles of support and Microboards) as well as informal networks to aid decision-making and increase social connections.

### Action 5.3

The <u>National Disability Insurance Agency</u> should include an assessment of participants' need for independent decision-making support as part of budget setting and ensure participants can use their NDIS budgets to access independent decision-making supports.

Need for decision-making supports should be assessed as part of the process of determining a budget (see Action 3.4) and the risk assessment and safeguard building process (see Action 16.2). This should include supports for participants to build and maintain decision-making support networks and access independent decision-supporters where required. Where participants with little or no informal supports receive funding for decision-making supports, this should be provided independently of other service provision to embed natural safeguards and ensure participants are able to consider different models of support and housing. Information must be available to participants, nominees, and Navigators about options to purchase supports for supported decision-making with NDIS budgets. Participants should be allowed to use their NDIS budgets to fund independent decision-making supports and establish decision-support networks (such as circles of support). Independent decision-supporters should be NDIS providers and required to be registered, consistent with the broader regulatory model (see Recommendation 17).

### Action 5.4

The <u>Department of Social Services</u>, the new <u>National Disability Supports Quality and Safeguards Commission</u> and <u>National Disability Insurance Agency</u> should ensure decision-supporters have access to information, training and resources to assist them in providing best-practice support for decision-making.

Navigators should link decision-supporters to information and training to assist them in their role. They should also guide participants to access decision supports to ensure the participant is involved in decision-making and are supported to access capacity building foundational supports (see Actions 5.1 and 5.2). To enable this, Navigators should have access to a central repository of curated evidenced-based resources and training coordinated by the Department of Social Services

### Action 5.5

The <u>National Disability Insurance Agency</u> should reform the approach to appointing nominees, provide improved training and information to nominees, and increase oversight of nominee decisions.

The NDIS Nominee Rules should be reformed to ensure there is a more rigorous assessment of the need for and suitability of a nominee prior to appointment. Once appointed, the nominee should be provided with information, evidence-based training, and guidance for complex matters or concerns. This should ensure they fully understand their role and responsibilities and are supported to perform their role consistent with the participant's will and preferences.

To improve oversight of decisions, the Navigator should undertake an ongoing monitoring role of nominee appointments, as part of a more structured review process to be conducted by the National Disability Insurance Agency (NDIA), to ensure participants and family are getting the support they need to make decisions about the NDIS.

The Department of Social Services should work with state and territory governments, participants, advocates and nominees to address the conflict between other substitute decision-making schemes and nominee appointments. Consideration should be given to changes to the NDIS Act and NDIS Rules to recognise guardians and attorneys, to the extent and for the period articulated in their appointing instrument, as having the same ability to take actions on behalf of participants as plan nominees (without being appointed as plan nominee). In the event of a conflict between an appointed guardian or attorney and a plan nominee, the NDIA should consider removing the plan nominee, for the duration of the appointment of the guardian or attorney.

# Better support for children and their families inside and outside the NDIS

In Australia, one-in-five children have disability or developmental concerns.<sup>111</sup> The lack of support for parents, limited foundational supports, gaps in mainstream services and the delivery of NDIS funded early intervention supports mainly in clinical settings means that children and families are not getting the supports they need at the optimal time.

The number of children who were developmentally vulnerable on one or more domains by the time they reached school age has remained relatively stable over the 12 years data has been collected. Prevalence rates continue through the schooling years, where 20 per cent of students require an educational adjustment due to disability.

This means that support for children with disability and learning difficulties is a mainstream issue, not a marginal issue and must be addressed systemically.

Many more young children are entering the scheme than was expected.<sup>114</sup> This partly reflects higher than previously identified rates of disability and delay amongst young children. It also reflects a lack of supports for children with developmental concerns or disability in mainstream settings. With so few supports outside the NDIS it is not surprising that families are seeking access to the scheme to get much needed support.

This is illustrated by the growing numbers of children in the scheme, while the proportion of children who are developmentally vulnerable has remained stable. There are currently around 145,000 children aged under 9 who are participants — this is approximately 5 per cent of all children in Australian under 9.<sup>115</sup>

The experience of the last ten years has highlighted the critical need to create an ecosystem of support for children with developmental concerns, delay or disability to ensure they and their families are well supported and have what they need to thrive.

### Children with disability and developmental concerns are not being consistently identified early in life

It is well established that children with disability and developmental concerns need effective supports early in life. Children learn right from birth and their learning is continuous and cumulative. Gaps in development can open at any time and widen progressively without early intervention.<sup>116</sup>

This means children with emerging developmental concerns need to be identified as early as possible. Developmental monitoring needs to occur regularly over the early years to ensure children are identified and supported early.<sup>117</sup> Both the child and their parents need support because children thrive in well-supported families.

Despite this, there are inconsistent approaches to identification in mainstream services across Australia. This means some children are missing out on critical early support.

Even when children are identified early with disability or developmental concerns, it can be hard for families to find evidence-based and accessible supports. This has meant there is every incentive for families to seek access to the NDIS to ensure they can receive supports during this critical period.

### Inclusive education improves outcomes for children, but has a long way to go in Australia

Inclusion in education remains a significant challenge in Australia. Barriers to inclusion in education and exclusion begin early. Children with disability and developmental concerns are less likely to access early childhood education and care, experience difficult transitions to school and often face barriers to accessing and maintaining school enrolments.<sup>118</sup>

"The NDIS will only be able to achieve its full potential if children and young adults with disability get an education that adequately prepares them for later life."

- Children and Young People with Disability Australia 119

We have heard about a number of barriers to inclusion and enrolment for children with developmental concerns and disability. The Australian Government's Inclusion Support Program provides support for eligible mainstream services to "build their capacity and capability to include children with additional needs, alongside their typically developing peers, so all children have genuine opportunities to access, participate and achieve positive learning outcomes". An evaluation of the Program found 1 in 5 parents of a child with additional needs reported having to change childcare providers because of issues with care. This is double the rate of parents of children without disability.

"We spent an incredible amount of time, resources, and funding to try
to fix the school but without legislation that has accountability measures
we were insignificant and throw-aways as far as the school was concerned."

- Case study, Children and Young People with Disability Australia 122

We have heard about the fraught experience in transitioning to school, securing necessary adjustments, and the fragmentation between the NDIS and the education system. Others told us that progress is lost when their child started to attend school. Children with disability or developmental concerns often face suspensions, expulsions and restrictive practices at higher levels compared to other children.<sup>123</sup> The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has also heard about the lack of inclusion and adjustments in mainstream education settings, meaning many children are not experiencing an inclusive education that will lead to positive lifetime outcomes.<sup>124</sup>

## Families feel unsupported and lack information, advice and peer support

When a child has a disability or developmental concerns, families are more likely to experience stress and increased demands on their time that affect their wellbeing. We have heard about the isolation, exhaustion, anxiety and stress which underpins the experiences of families and caregivers of children.

Families currently have limited access to capacity building, peer support, neurodiversity affirming or other disability-specific organisations that promote contemporary models of disability, positive visioning and inclusion.

While all families of children with disability and developmental concerns need early access to information, advice and peer support, it has been notable that it is families of participants who most often reported feeling unsupported. Too many described their experience of the NDIS as stressful and traumatic.

### Access to the NDIS for children is inconsistent, inequitable and not based on need

Many children enter or remain in the NDIS based on an access list. The access lists provide for both automatic access and streamlining of evidence based on disability. These lists can provide simple and transparent access to the scheme for some children. However, they also exacerbate inequity and delay support for children with similar levels of need who may not have a diagnosis on an access list or lack the means to obtain a diagnosis if they don't meet the age criteria for developmental delay. Determining eligibility through a diagnosis-based approach also fails to provide a good understanding of the needs and circumstances of children and their families.

"My son was denied access at 5 years old as he had an adhd diagnosis and didn't meet disability requirements even though his functional capacity was well Below that of his peers in all areas. I spent \$5,000 with money

I didn't have for a ASD diagnosis and 2 months later he got in only because of his autism diagnosis. I was told by the planners to just change the date on the initial access form as everything else was still the same.

How is the right?"

- Carer 125

### The budget setting process for children is complex and inconsistent

We have heard about a myriad of challenges experienced by families during the planning process. This includes difficulties gathering information and a lack of support to navigate the system. We heard that too often outcomes are determined by a family's ability to advocate.

Families have described the planning experience as confusing, overwhelming and opaque. Families need to advocate for their child, often by painting a deficit-based picture of their child in the worst possible light. If families do not have sufficient self-advocacy skills, this leads to inequitable funding outcomes. When combined with being new to the world of disability and having a limited understanding of best practice, families are often unprepared for the planning process.

"Families say it feels like the system skewed outcomes towards those with the best knowledge of the system including how to use the right jargon, those who are lucky enough to be linked in with the right support, and those with the right skills to research the intricacies themselves."

- Child and Family Disability Alliance 126

Families generally tell their experience to an early childhood partner who makes a recommendation for a plan budget. This is usually approved by a separate delegate in the National Disability Insurance Agency (NDIA) — who has more than likely never met the family before. It is confusing and frustrating for families when the approved plan budget is not in line with what the early childhood partner or providers had recommended. This leads to distrust.

It is also challenging for the NDIA to assess competing information, including what providers and early childhood partners recommend, and how these factors might be linked to structured practice guidance and a best practice early intervention approach. The NDIA is heavily reliant on the information and case made by the family and early childhood partners. These factors can lead to subjective and inequitable assessment of

reasonable and necessary supports for children. This is compounded by an inconsistent uptake of family centred planning approaches and a lack of transparency of why decisions were made.

The current use of functional capacity tools such as Pedi-CAT to inform planning has also been criticised in other reviews. Many of the functional capacity tools used by the NDIA during planning have not been developed or validated for use in determining funding. 127

### Best practice is not embedded in supports for children and families

The NDIA early childhood approach was designed based on best practice principles for children with disability or developmental concerns.<sup>128</sup> This involves a family centred, capacity building approach, a collaborative team working together, with support primarily being delivered in natural settings, where children live, play and learn.<sup>129</sup>

Efforts to encourage families and the market to adopt this approach have failed. The inability of the NDIS to effectively inform, support and build the capacity of families has been repeatedly highlighted.

"Recent evidence reviews reaffirm the efficacy of family-centred practice for children with all disability types, including children with ASD [Autism Spectrum Disorder], but family-centred practice in the NDIS is undermined by the lack of attention to supporting families and building their capacity."

- Independent Advisory Council to the NDIS 131

Before the NDIS, best practice was not consistently implemented or available across Australia. Individualised funding models including Helping Children with Autism and Better Start for Children with Disabilities, were often in tension with best practice despite providing increased support to families. These programs incentivised families to select delivery of supports in clinical settings, to maximise face-to-face time with therapists, over supports provided in natural settings.<sup>132</sup>

There has been insufficient attention to shaping the early intervention market, restricting more widespread use of best practice supports. There are limited requirements or incentives to deliver support in natural settings, appoint a key worker or promote collaboration of the team around the child.<sup>133</sup> Providers report that families often feel that use of funding for these purposes is 'reducing the therapy budget' intended for their child.<sup>134</sup> Travel time for therapists is often seen by families as eating

into precious therapy time. Families face an extremely tough decision to choose a service model that may result in fewer hours of therapy being delivered to their child. They need far more support through this decision and greater information of the benefits of best practice.

"There has been a widespread swing back to clinic-based therapy services, even though these are less effective and appropriate with this age group than home-based capacity-building services."

- Professionals and researchers in Early Childhood Intervention 135

### Progress monitoring processes are currently insufficient to improve outcomes

There are few mechanisms within the NDIS to monitor children's development and functioning in a safe, non-judgemental and responsive way, or to assess how a child and their family are responding to supports. Planning and plan reviews have also been identified as inappropriate forums for reviewing a child's progress due to their links to funding decisions.

This is compounded by there often being multiple professionals and therapists working with an individual child and family, often in isolation from each other. Without effective monitoring and evaluation, it is difficult to assess how well the combination of supports is working or what outcomes are due to each intervention.

The fragmentation of supports and lack of monitoring and evaluation mechanisms means opportunities are missed to make adjustments needed to accelerate developmental progress. This also means there isn't an effective way to identify children who are or aren't making good progress as a result of the early intervention. This means supports and budgets aren't as responsive to changes in need as they should.

### The Panel's vision

### The future approach should deliver a continuum of support that serves families and children best

Far more support should be available where children are and reduce the pressure on families having to access the NDIS for support. Implementing a holistic and joined up continuum of supports for children with disability and developmental concerns (see Figure 6) should be an urgent priority for all governments. They are the future of our nation and their needs must be met better as early in life as possible.

Children with developmental concerns and disability should be matched with supports that best meet their needs. This requires more mainstream and foundational supports. This would create a continuum of supports, matched to the needs of children and their families, and also relieve pressure on families to have to access the NDIS to be supported.

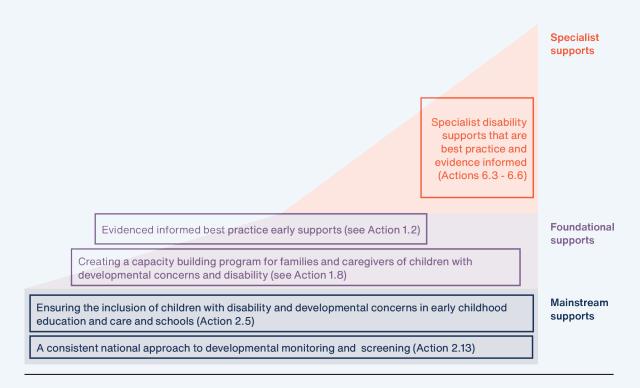
Children with higher support needs should be able to access the NDIS through a more fair and transparent access process. Children who are eligible for the NDIS should receive a budget based on support needs, determined through child centred assessments.

All early intervention supports for children, including those provided through the NDIS and foundational supports, should be based on the best evidence of what works to give children and families their best life. Providers who deliver capacity building supports in the early childhood approach should be required to be registered to ensure the uptake of best practice services. This should be complemented by a consistent approach to ongoing monitoring and evaluation of the effectiveness of early intervention for children.

Government is approaching a critical point for transformative change for children and families. There will be soon be findings and recommendations available from the Early Years Strategy, Autism Strategy, National School Reform Agreement, and Productivity Commission inquiry into the early childhood education and care sector, along with this Review.<sup>136</sup> These provide an opportunity for governments to strengthen the support available to children and families through mainstream and foundational service systems.

Figure 6

Overview of the future continuum of support for children and families



### Create a continuum of support for children under the age of 9 and their families

\*Legislative change required

#### Action 6.1

<u>National Cabinet</u> should agree to jointly invest in a continuum of mainstream, foundational and specialist supports to address the needs of all children with disability and developmental concerns.

Supports provided outside the NDIS should include mainstream supports (including early identification of children with developmental concerns and inclusive education, see Actions 2.5 and 2.13) and foundational supports (including expanded supports for children with emerging developmental concerns and disability and programs, see Action 1.12). Within the NDIS, children under the age of 9 with higher levels of need should receive specialist support through a reformed early intervention pathway (see Action 6.2). Figure 6 illustrates how these related recommendations come together.

#### Action 6.2\*

The <u>National Disability Insurance Agency</u> should reform the pathway for all children under the age of 9 to enter the NDIS under early intervention requirements.

This should include an agreed definition of 'likely to benefit', and clarification of when need can be appropriately met through the reformed foundational supports system (that is, linked to the outputs of a needs assessment - see Action 3.4). These should be clarified in the NDIS Rules. Children with clear lifelong support needs should also enter through the early intervention pathway, but should be provided assurance by the NDIA that their eligibility would continue beyond age 9 under section 24 (disability requirements). Existing access lists should be removed and automatic access replaced with streamlined evidence requirements to ensure only essential information is collected. Additional evidence required by the NDIA to inform complex access decisions should be funded by government.

### Action 6.3\*

The <u>National Disability Insurance Agency</u> should introduce a more consistent and equitable approach to assessing developmental delay.

This should include a precise definition of substantial developmental delay to give more clarity to applicants and consistency in decision-making, replacing the current test of substantially reduced functional capacity. This definition should be linked to the outputs of a developmental assessment that can determine children's

developmental functioning and allow applicants to be compared to their peers (norm-referenced assessments). The definition could then be operationalised through measuring standard deviations from the mean.

This would require a suite of developmental and behavioural evaluation assessments suitable for young children that adhere to best practice methods of child assessment. Existing developmental assessments should be transparently tested to inform the design of the new process. Any assessment should cover a broad range of age appropriate domains in order to be strongly considered for use. Any assessment considered should take into account that delay and disability can fluctuate over time, and based on the environments in which a person is in. There should be an accepted basis for comparing results from two or more acceptable instruments that might be used to assess delay in a given domain.

This assessment should be made universally available through the health system to be completed by a trained specialist who does not have a conflict of interest.

#### Action 6.4\*

The <u>National Disability Insurance Agency</u> should change the basis for setting a budget to a whole-of-person level, and introduce a new needs assessment process to more consistently determine the level of need for each child and set budgets on this basis.

Reasonable and necessary funding for children should be set based on need, including any need to build the capacity of the family to support the child.

This would require reliable and valid assessment processes that provide a structured approach for a Needs Assessor to identify support needs and intensity (similar to the approach described in *Actions 3.3 and 3.4* for all participants). This would require a child-specific assessment(s) that should include observation of the child in natural settings and family feedback. Existing support needs assessments should be tested with the children and disability types they have been validated for to inform the design of the new budget setting process. The assessment should enable the Needs Assessor to distinguish between the type of support, the frequency, and one-off or time limited supports.

Government may choose to link this assessment to an individual budget (see Action 3.4) or develop a number of funding levels that children with similar needs may be allocated to (with an exceptional circumstances provision for children with very high needs).

Delivering this would require an investment by government in ensuring the assessment is delivered by a highly experienced and qualified Needs Assessor (ideally an allied health professional experienced with children) who is able to spend sufficient time to understand a child and family.

#### Action 6.5\*

The <u>National Disability Insurance Agency</u>, in partnership with the Department of Social Services and the National Disability Supports Quality and Safeguards Commission, should require early intervention capacity building supports for children be based on best practice principles and evidence.

This would involve the introduction of a dedicated Lead Practitioner role and a revised regulatory model for providers delivering support to children under the age of 9.

Lead Practitioners and all other providers delivering supports to children should be registered, consistent with the graduated risk-proportionate regulatory model (see Action 17.1) and supported by strengthened Early Childhood Practice Standards. The Lead Practitioner should be an agent of the family and work with families in the best interests of the child to identify and address needs, connect them to foundational and mainstream supports, and provide information, advice and coaching to support their child's development. The Lead Practitioner should be funded from participant budgets, including for the delivery of NDIS supports within their scope of practice. The amount of support available to the child from the Lead Practitioner should be determined through the needs assessment (see Action 6.4). Specific service delivery requirements for the Lead Practitioner will be set by the NDIA through contractual arrangements. There should be sufficient market depth to allow families to have a choice of Lead Practitioner and contestability to incentivise higher performance by Lead Practitioners, including allowing new entrants to enter the market.

These changes should be supported by far greater consumer education and information, support for provider workforce development and other market incentives (such as changes to the pricing and commercial arrangements) to support the increased adoption of capacity building supports based on best practice principles and evidence.

### Action 6.6\*

The <u>National Disability Insurance Agency</u> should develop and implement an approach for ongoing monitoring and evaluation of the effectiveness of early intervention for children.

This should involve the Lead Practitioner working with the family and the Navigator to develop a plan of action to guide the family and the team around the child. The plan of action should be regularly and informally reviewed. This should be reinforced by more formal periodic case conferencing with the team around the child to check in on progress and effectiveness of the interventions, and identify any adjustments that need to be made. Families should be actively involved in these discussions to feel empowered and help them understand their child's progress and how they can best support them.

#### Action 6.7

The <u>National Disability Insurance Agency</u> should implement reforms to support the continuum and pathway for children using an iterative, inclusive approach to design and testing, and ensure participants experience a smooth transition to the new arrangements.

Reforms to the pathway for children (see Action 6.1-6.6) should be designed through agile projects commissioned by the NDIS Experience Design Office (see Action 24.3). Design, testing and implementation should be undertaken in consultation with families of children with disability or delay, and should be aligned with the principles and implementation considerations set out in the Co-Group Feedback to the NDIS Review Panel, developed as part of the Review's participatory engagement process (for further details on the Co-Group's work see Appendix C), as well as the Australian Government Digital Service Standard. Inclusive and proportional user testing should be conducted to allow priority reforms to be phased in and start delivering benefits as soon as they are validated and approved by Disability Reform Ministers for implementation. The assessment processes in particular require highly transparent, rigorous and inclusive design and testing prior to implementation.

The implementation of the changes to the pathway would adhere to a principle that ensures all current participants experience a smooth and fair transition to the new arrangements (see Action 26.2). Implementation of this recommendation should be consistent with broader reforms to the participant pathway (see Recommendation 3), and should be directly linked to implementation and ramp-up in foundational supports for children under the age of 9 and their families (see Actions 1.8 and 1.12).

# Recovery-focused psychosocial supports in the NDIS and the broader mental health system

### Supporting people with the most significant psychosocial disabilities is core business for the NDIS

The NDIS has delivered a significant increase in funding for disability supports for people with severe mental ill-health. There are 62,000 participants (10 per cent of all participants) with a primary psychosocial disability, such as schizophrenia, post-traumatic stress disorder or borderline personality disorder, and an additional 37,000 participants (6 per cent of all participants) with a secondary psychosocial disability, such as anxiety or depression, in the scheme as of June 2023. <sup>137</sup>

The NDIS has made a positive difference for many people. In the June 2023 National Disability Insurance Agency (NDIA) dashboard, 77 per cent of participants with primary psychosocial disability said the NDIS has helped them have more choice and control over their life. 138

"The importance of choice and control, a recovery orientation,
life-long support and the successes that can be achieved through a
well-functioning NDIS cannot be under-estimated for people with
psychosocial disability."

- National Mental Health Consumer and Carer Forum 139

While the NDIS has improved the lives of many, participants with psychosocial disability continue to experience lower community participation, employment and carer employment than other participants in the scheme.<sup>140</sup> We have heard that approaches to eligibility, planning and plan reviews are traumatising, and that the NDIA and partners do not have a good understanding of psychosocial disability.<sup>141</sup>

"Mental health still feels like an afterthought of the NDIS.

- Participant 142

"Attempting to access NDIS supports and services often re-traumatises those with psychosocial disability due to a lack of psychosocial-specific training for frontline staff and assessors, and without having lived experience embedded in the agency to help people navigate the system."

- National Mental Health Consumer and Carer Forum 143

# The NDIS has not structured its processes or stewarded the provider market to support independence and personal recovery

We have also heard from many people with psychosocial disability, family and carers, providers, advocates and researchers that the NDIS is not investing in the right supports to get the best outcomes for participants with psychosocial disability. In particular, the NDIS does not respond sufficiently to the often episodic nature of psychosocial disability and the potential for recovery.

Personal recovery is not primarily about the medical basis of symptoms and cure. Rather, as the World Health Organisation describes: "For many people recovery is about regaining control of their identity and life, having hope for their life, and living a life that has meaning for them whether that be through work, relationships, spirituality, community engagement or some or all of these".<sup>145</sup>

With a lack of diversified services in the market and poor understanding of the need for recovery-focused supports, planning has drifted towards mainly funding ongoing daily living and social and community access supports, similar to the support mix for participants with physical and intellectual disability, rather than focusing on personal recovery and long-term outcomes. Daily living supports remain essential, during an acute mental health episode or on an ongoing basis for participants with ongoing needs. However, best practice psychosocial programs invest in evidence-based supports that rebuild engagement and skills, self-management and optimal independence.

The effectiveness of services like navigation, capacity-building and housing depends on providers who are trauma-informed and have a good understanding of psychosocial supports. However, there are currently too few providers with psychosocial competencies. The NDIS is not stewarding the market to deliver a recovery-focused approach.

"In my experience, good support workers are few and far between, especially within the psychosocial space. Support work needs to be regulated. Anyone can be a support worker and that's dropping the standard. To work within mental health, you should have to have qualifications, experience and supervision."

- Participant 147

The under-emphasis on early intervention supports across the scheme for adults likely to benefit, for example for people with neurological conditions, to improve outcomes and reduce the long-term impacts of disability, also affects people with psychosocial disability. An early intervention approach for psychosocial disability under section 25 of the *National Disability Insurance Scheme Act 2013* has not been developed, despite strong evidence about the effectiveness of early intervention supports. A 2016 literature review by the University of Melbourne found "significant evidence that people with psychosocial disability make significant gains in their capacity to engage in social and economic participation if they are offered early intervention". The lack of an early intervention approach is a missed opportunity to help participants maximise their quality of life.

## For participants with highly complex needs, the NDIS is not providing intensive, coordinated assistance

A smaller number of participants with psychosocial disability have particularly complex support needs. They may be long-stay patients in hospital or have co-occurring conditions or complex behaviour management issues. Some may cycle through hospital, homelessness services or correctional or forensic services.

The NDIS does not have an integrated complex care approach with the public mental health system. This means participants are more likely to experience unnecessarily long stays in hospital, have inadequate supports to transition and live in the community, and are therefore at greater risk of returning to hospital or correctional facilities.

"People with severe mental health issues should never be released from a psychiatric ward without wrap around supports (supported independent living with decreasing intensity over time according to improvement/needs)."

- Participant and carer 149

### The NDIS does not operate effectively with the broader mental health system and there are major gaps in psychosocial supports outside the NDIS

Despite the connection between mental health and disability services, governments have not taken a holistic approach to supports for people with severe mental ill-health. Gaps in mental health services prevent people from being as well as they can be and maximising life outcomes. Gaps also place additional pressure on the NDIS. It is important to acknowledge that while Australia's mental health system is currently being reformed, the NDIS remains disconnected from broader mental health policy reform development.

NDIS expenditure on primary psychosocial disability was approximately \$4.3 billion in 2022-23.<sup>150</sup> In comparison, total funding for mental health, excluding the NDIS, was \$11.6 billion in 2020-21.<sup>151</sup> The significance of the interdependencies between these two large national service systems is not reflected in national policy frameworks or intergovernmental agreements.

A key example of this is the use of acute mental health beds by long stay patients in public hospitals. As at June 2023, there were approximately 443 NDIS participants with psychosocial disability who have been resident in public hospitals for more than twelve months, using an estimated 160,000 bed days (at a cost of \$211 million to the public hospital system).<sup>152</sup> The lack of a joined-up approach across policy and practice results in poorer participant outcomes and reduced productivity in the public hospital system.

There is also a major shortage of psychosocial supports outside the NDIS. In 2020, the Productivity Commission estimated that 154,000 non-participants with severe and persistent mental illness were missing out on the supports they need. This includes services such as assistance participating in the community, finding accommodation, managing daily tasks, and improving connections with family and friends. Other key services include help with financial management and budgeting, help to find and maintain a home, assistance with maintaining physical wellbeing and support accessing alcohol and drug addiction programs. The Productivity Commission estimated that the funding shortfall was approximately \$610 million per annum in 2020.<sup>153</sup>

"Psychosocial supports are very challenging to get assistance with.

This should not be such a challenge for those with these needs to access the support they need."

- Carer 154

While participants with psychosocial disability are among those with the greatest need for mental health services, many participants have difficulty accessing treatment. Availability and affordability are significant barriers to accessing mental health treatments.

There is a shortage of community mental health services and too few clinicians and waitlists in some areas.<sup>155</sup> In addition, rehabilitation for mental illness prior to hospital discharge is not consistently available.

"In the world of psychosocial disability, psychiatry isn't bulk billed and despite Government saying that it's readily available through the state health care system, it's simply not."

- Participant 156

The result is some participants finding themselves in a situation where they can access NDIS funding but cannot afford psychology, psychiatry and some general practice services.<sup>157</sup> These barriers particularly affect people with severe psychosocial disability. A particular gap is care for young people with more complex, severe mental illness, and who are at risk of recurring psychosis.<sup>158</sup> This means some young people do not get access to early intervention within the mental health system and as a result may be more likely to require NDIS supports in the future.

Collectively, these issues mean some people applying for the NDIS have not and will not receive timely mental healthcare.

### The Panel's vision

### A new psychosocial disability approach is needed to focus on personal recovery and better connect the NDIS with the wider ecosystem

Government and the NDIS must do better for people with psychosocial disability. A psychosocial pathway should make access to the NDIS more straightforward for participants with psychosocial disability, improve budget setting processes and deliver better outcomes.

Participants should have access to a Navigator who has expertise in psychosocial supports and is trauma-informed (see Action 4.1). Given many participants have had mental ill-health for a long time and some very negative experiences, Navigators should work with participants to understand their journey and what treatments and supports they have tried. They should help participants identify evidence-based supports to live the life they want to lead, and to connect with mental health services, education and employment.

As part of strengthening early intervention across the scheme, to reduce the long-term impacts of disability, the NDIS should develop an early intervention approach for psychosocial disability. Many new participants, whose psychosocial disability is likely to be permanent, should initially access the NDIS through section 25 early intervention supports. With guidance from the Navigator, participants would be able choose a range of services to learn to live with and without the symptoms of mental ill-health. These services would provide more targeted and effective evidence-based supports, to re-build participants' functional abilities and improve lifetime management of their psychosocial disabilities and wellbeing.

An early intervention approach for this group with psychosocial disabilities is likely to give them the best opportunity for personal recovery while early in the scheme. If participants require lifetime supports following a period of early intervention, Navigators could assist with shifting to access under section 24 to provide ongoing support. Supports should be able to step-up and step-down depending on the health and circumstances of the participant and whether they are accessing the NDIS through section 24 or section 25.

The NDIA should better use and increase the supply of providers with psychosocial expertise, particularly for early intervention, capacity-building and housing supports. The NDIS should continue to fund daily living supports, but participants should be supported to access providers and therapists who have the competencies to help people build their independence. This should significantly improve outcomes for participants with psychosocial disability.

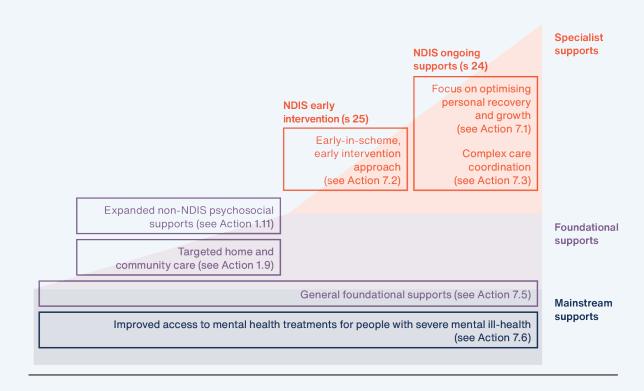
Navigators should assist people before they access the NDIS, through proactive outreach and support. There should be more psychosocial supports outside the NDIS, delivered by the mental health system. Mental health services should take a more preventative approach, including for young people at risk of recurring psychosis.

Navigators should also help participants access mental health services. Participants should have access to affordable clinical mental health services, through a more joined up approach between the NDIA and mental health systems, supported by strengthened intergovernmental agreements.

Taken as a holistic package, our reforms should reduce the gap between those in the scheme and those outside, enable better coordination with the broader health system, and improve outcomes for participants in the NDIS.

Figure 7

Overview of the continuum of mental health and psychosocial support



Introduce a new approach to NDIS supports for psychosocial disability, focused on personal recovery, and develop mental health reforms to better support people with severe mental illness

\*Legislative change required

#### Action 7.1\*

The <u>National Disability Insurance Agency</u> should introduce a new approach to psychosocial disability in the NDIS based on personal recovery and optimising independence.

The approach should implement and build upon the NDIS Psychosocial Disability Recovery-Oriented Framework, including strengthening integration and working arrangements with the mental health system. Access and assessment processes should be tailored to the specific needs of participants with psychosocial disability and be delivered more consistently and equitably, including through an uplift in the capability of NDIA staff. Navigators should have competencies in psychosocial supports to assist people to access evidence-based NDIS, mainstream and foundational services (see Action 4.1).

#### Action 7.2\*

The National Disability Insurance Agency should establish an early intervention pathway for the majority of new participants with psychosocial disability under section 25 of the *National Disability Insurance Scheme Act 2013*.

This should provide structured and targeted time-limited supports for a defined period. It should deliver evidence-based psychosocial early interventions including supports such as supported employment, supports to find and maintain housing, illness self-management, cognitive remediation, family psychosocial education and social skills training. Participants should be able to choose from a range of providers, which have entered into a service agreement with the National Disability Insurance Agency that sets specific service delivery requirements. Following the early intervention period, Navigators should assist people who no longer need NDIS supports to transition to mainstream or foundational services, or if ongoing NDIS supports are required, transition to supports under section 24 of the NDIS Act.

#### Action 7.3

The <u>National Disability Insurance Agency</u> should establish an integrated complex care coordination approach with public mental health systems for participants with complex needs.

The integrated complex care approach should be a joint initiative between the NDIS and public mental health systems for participants with complex support needs and active mental health management issues. This should aim to facilitate effective and timely coordinated care to best meet the needs of participants and reduce lifetime support costs within the NDIS and mental health system. The approach should prioritise participants who have been long-stay patients in hospital, have co-occurring conditions, been released from prison and forensic services, and/or with complex behavioural management issues that require an integrated treatment and disability support approach (see Action 2.7).

#### Action 7.4

The new National Disability Supports Quality and Safeguards Commission should require providers delivering psychosocial supports to be registered, including demonstrating compliance with a new support-specific Practice Standard.

This Practice Standard should set out additional responsibilities of providers when delivering psychosocial disability-specific supports, including workforce competencies (see Action 17.1). These requirements would apply to Navigation, early intervention, 24/7 living supports and capacity-building supports for participants with psychosocial disability. This should be complemented by National Disability Insurance Agency, Department of Social Services and National Disability Supports Quality and Safeguards Commission market stewardship, including investing in training in psychosocial supports. As part of a broader proposed role in advising on pricing (see Action 11.3), the Independent Health and Aged Care Pricing Authority should also develop updated payment approaches and advise on price caps for psychosocial disability-specific supports.

#### Action 7.5

<u>All Australian governments</u> should prioritise supports for people with psychosocial disability as part of general foundational supports.

This should fund a range of initiatives providing information, individual and family capacity-building. Priority areas for investment include mutual peer support; recovery colleges where people can learn about mental health; and family psychosocial education to assist families in their roles of supporting people with severe mental ill-health. In addition, as a targeted foundational support, governments should commit to increasing supply of psychosocial supports outside the NDIS (see Action 1.11).

#### Action 7.6

<u>All Australian governments</u> should improve access to mental health services for people with severe mental illness and strengthen the interface between mental health systems and NDIS.

Governments should update the National Mental Health and Suicide Prevention Agreements to set out an overarching approach to psychosocial disability supports to improve the integration and co-ordination of the NDIS and mental health systems. This should include: reforms to prioritise treatment for participants with psychosocial disability; early interventions to prevent and reduce the disability impacts of serious mental illness; and improving access to mental health services for participants more broadly. The NDIS and state and territory governments should develop Memoranda of Understanding to operationalise the approach to psychosocial disability supports (see Action 2.7), such as those agreed in the National Mental Health and Suicide Prevention Agreements.

# Housing and living supports that are fair, consistent and promote choice

# Housing and living supports for participants who require 24/7 support are a key feature of the NDIS

Achieving better housing and living outcomes for participants is critical to the scheme delivering on its promise of greater inclusion for people with disability in the economic and social life of the community. Given a home is foundational to genuine inclusion and participation, participants must have choice and control over where, how and with whom they live. Genuine choice is also fundamental to realising the rights outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>159</sup>

Participants can access a range of housing and living supports depending on their needs and circumstances — from home-related assistive technology and home modifications to more intensive and ongoing accommodation and independent living support.

These supports are particularly critical for participants who have high support needs and require a significant amount of assistance throughout the day as well as overnight supports. There are close to 41,000 participants receiving 24/7 living supports. This includes around 31,500 participants with Supported Independent Living (SIL) funding and close to 9,500 participants receiving an equivalent high level of Assistance with Daily Life (ADL) supports.<sup>160</sup>

We define 24/7 living supports as participants who require at least eight hours of active support and/or supervision with activities of daily living and some level of support for the remaining hours of the day while at home, including overnight assistance (whether active or passive).

Housing and living supports account for a large share of overall scheme costs. In the year to 30 June 2023, SIL payments alone were \$8.8 billion, representing a quarter of total scheme payments.<sup>161</sup>

# Housing and living funding decisions are inconsistent, inequitable and opaque

Many participants with housing and living supports in their plans still have limited choice in where, how or with whom they live. Participants with similar levels of need and circumstance do not always receive similar levels of funding.

"My friend and I submitted our applications for SDA and SIL supports for our boys in September both have very similar needs. We worked on this together, had the same support coordinator, submitted them on the same day. We included proof that our boys have spent their entire lives together in the form of a pictorial history. My son was approved for both SDA and SIL supports and mention of pieces of information in the reports were included in the reasons why decision was made. A week or so later my friend received a rejection for SIL, SDA and in fact supports were reduced. There were also massive errors in the plan. Remembering this young man is the child of a 73 year old woman who needs to make plans for her son's future. My friend was totally devastated."

- Carer 162

Individualised support for people with very intensive support needs was provided before the NDIS was introduced, and will continue. Single living arrangements with no sharing of living supports (or only sharing overnight supports) for some participants with 24/7 needs are appropriate to be funded in specified circumstances. However, currently there is no clear guidance for participants or providers on when participants should have access to these arrangements. This poses risks to the financial sustainability of the scheme and creates uncertainty for participants.

Too many participants and families are left to seek clarity through the Administrative Appeals Tribunal (AAT). While less than one in twenty participants had Specialist Disability Accommodation (SDA) in their plan, one in ten planning-related AAT applications in 2022-23 had SDA in dispute.<sup>163</sup>

While single living arrangements with no sharing of supports are needed in specified circumstances, they can lead to isolation and poor outcomes for participants.

We have heard participants often do not have access to the information, advice and support they need to make genuine informed choice on where and with whom they live, in line with a human rights framework.<sup>164</sup> Planning conversations are often disjointed and focused on short term issues.<sup>165</sup> Many participants are not supported to prepare for housing and living solutions early. When considering their options, they cannot easily access the information and support that would enable them to explore and compare different housing and living solutions, both within and outside the scheme.

"Housing conversations need to happen early on in the planning process to allow people who have a housing need to properly consider their housing and living arrangements. Support coordinators need to be upskilled to have proper housing related housing conversations with people with disability or there needs to be dedicated housing support coordinators."

- Carer 166

There are also very limited opportunities to trial alternative housing and living solutions. It is very difficult to make informed choices when you have not had the opportunity to experience different options. This particularly affects those with cognitive disability and people with limited informal support networks.

#### The Panel's vision

Participants should receive housing and living support funding in a clear, fair and consistent way, in line with their needs and circumstances

There should be a new budget setting pathway for participants with 24/7 housing and living support needs that is focused on exploring options early (*Figure 8*).

Participants (including those with cognitive disability or limited support from family and friends) should be supported by an independent Housing and Living Navigator at key life stages to articulate their goals, explore their options and secure a housing and living budget. Housing and Living Navigators will require in-depth knowledge of local housing and living options and should build on the expertise of existing organisations in this area including, for example, through partnerships.

Participants with similar levels of need, in similar circumstances, should have access to similar levels of funding. For those requiring 24/7 living supports, funding should be on the basis that supports are shared, except in specified circumstances (this could include, but not necessarily be limited to, where there is a risk to self or others from living in a shared arrangement, participants with dependent children, and those with very complex needs). In general, reasonable and necessary funding should be based on an average shared support ratio of one support worker to three participants (1:3), consistent with an assessment of need that determines the maximum support intensity and level of overnight support that a participant is eligible to receive. It is important to note that the calculation of shared funding does not necessarily equate to living with others. Rather, it is about having access to a more diverse range of innovative and individualised housing solutions that enable some sharing of supports. Participants would be able to choose from a diverse range of innovative housing arrangements (see Recommendation 9).

Participants should have greater flexibility and more choice in their housing and living arrangements within the budget that has been allocated to them. But because of the centrality of living arrangements to a person's social and economic participation, health and wellbeing, housing and living budgets will be stated in a participant's overall budget. Participants will be able to add funds from their flexible budget to increase the amount spent on housing and living supports, but not vice versa.

At the heart of a new housing and living approach should be a more urgent shift away from group home settings with little choice and control to one where participants can choose their living arrangements and the supports they receive. No one should be forced to enter a living arrangement that is not of their choosing. Capacity building supports should start from an early age and continue throughout their life, with a focus on independent living skills. This would reduce the need for future high intensity living supports for some participants.

Participants requiring 24/7 living supports should receive funding to trial new living arrangements before they commit to them and vacancy management arrangements should allow more time for residents to choose who they live with.

"The co-tenant matching process is vital for a harmonious
living situation. This needs to be a process not just one-night sleep
over and then the decision to push that person into the SIL vacancy.
It is vital to consider behaviours of the prospective co-tenant and
whether these are compatible with the other person e.g. noise level,
annoying behaviours, bullying behaviours, aggressive behaviours,
tactile issues."

- Carer 167

Finally, participants sharing supports should be assisted by a Shared Support Facilitator to have a say in the governance of their shared living arrangements, irrespective of their level of access to informal supports, and in who fills a vacancy in a shared living arrangement.

Transition to these new arrangements should be graduated. Participants should be supported to explore shared support arrangements but should not need to move from their current home unless they choose to do so. New participants, and those who choose to move, will access the new budget setting process and be allocated a Housing and Living Navigator to support them through the process.

#### Figure 8

#### Budget setting pathway for participants with 24/7 living support needs

## Pre-budget setting

**New participants** with 24/7 living support needs will, initially, follow the same pathway as all other people with disability (Recomendation 3).

**Existing participants** would, at key life stages, be supported by navigators to explore alternative living arrangements and go through a change of circumstance process.

#### Needs assessment and budget setting

#### Holistic assessment to understand needs

A comprehensive assessment of need is undertaken by a skilled Assessor. Participants will have as long as they need to ensure they are understood and will be able to view the assessment before the budget is set.

Depending on the participant's needs, circumstance and life stage the housing and living budget may include: SDA, home modifications, medium term accommodation, housing related assistive technology and/or 24/7 living supports. These supports will all be stated.

#### Provisional housing and living budget set

Where the holistic assessment reveals a need for 24/7 living supports, the participant receives a provisional budget based on their maximum support intensity and individual overnight support needs. Assessors and participants have clear guidance on exceptions where 1:1 living supports, with no or limited sharing, is reasonable and necessary.

#### Exploring and securing supports

## Navigation to support participant to explore and evaluate different living arrangements

Options explored must not exceed the participant's provisional budget amount. Participants with different overnight support needs can share with each other, opening a wider range of options.

### Participant chooses preferred living arrangement and provider advises actual cost

Living support provider working with navigator or shared support facilitator advises actual cost of providing services based on individual participant support needs, model chosen and, in shared arrangements, how supports will be pooled and shared across participants. The actual cost for a participant cannot exceed their provisional budget.

## Housing and living budget adjusted to reflect the actual cost of the preferred arrangement

The NDIA adjusts the value of the participant's living support budget to reflect the actual costs of the arrangement.

#### Maintaining supports

Participant accesses supports with ongoing check-in on progress from navigator and support from shared support facilitator.

Fund housing and living supports that are fair and consistent, and support participants to exercise genuine choice and control over their living arrangement

\*Legislative change required

#### Action 8.1\*

The <u>National Disability Insurance Agency</u> should change the budget setting process to ensure that housing and living budgets are consistent and sustainable.

The budget setting process for housing and living supports should ensure housing and living budgets are consistently based on an assessment of need and are considered at a whole of-person level (see Action 3.3).

Funding for participants requiring 24/7 living supports should typically be on the basis of those supports being shared. In general, reasonable and necessary funding should be based on an average shared support ratio of 1:3, consistent with an assessment of need that determines the maximum support intensity and level of overnight support that a participant is eligible to receive. This should create a provisional budget amount that is the maximum participants can use in considering different living arrangements, with the support of their General Navigator (see Actions 3.3, 4.1 and 8.2).

Participants should have flexibility to choose a living arrangement. The provisional budget should be individualised and not restrict choice of living arrangements to sharing supports with other participants with the same level of overnight support needs. Once a participant has decided on their preferred living arrangement, the provider should determine the actual cost of delivering supports for the participant. In shared living arrangements, the actual cost should reflect how supports will be pooled and shared. Actual costs should not exceed any individual participant's maximum provisional budget and must comply with the price caps.

Individualised 1:1 (or higher intensity) living supports with no shared component or only sharing of onsite overnight support, and any associated single-resident Specialist Disability Accommodation (SDA) funding, should only be considered reasonable and necessary in specified circumstances. This could include, but not necessarily be limited to, where there is evidence of risk to self or others from living in a shared arrangement, participants with dependent children, and those with very complex needs. The specified circumstances criteria for 1:1 living supports and associated SDA funding should be set out in NDIS Rules.

Transition to new budget setting arrangements for 24/7 living supports should be graduated. Participants should be supported to explore shared support arrangements but should not need to move from their current home unless they choose to do so (see Action 26.2).

#### Action 8.2

As part of the local navigation function (see Action 4.1) the National Disability Insurance Agency should commission Housing and Living Navigators to provide advice on participants' housing and living options.

Participants and Navigators (see Action 4.1) should have access to advice from an independent Housing and Living Navigator with specialist expertise in the range of local housing and living supports. The Housing and Living Navigator should work with the General Navigator (or this could be the same person) to support a participant to explore the range of housing and living options available and understand what options align with their preferences and provisional NDIS budget. They should also help participants connect with suitable providers to identify new living opportunities or those with vacancies. This approach should ensure any change in housing and living arrangements at key life stages is explored, designed and planned well in advance of a change.

#### Action 8.3

The National Disability Insurance Agency should design, fund and implement a process for participants to try new living arrangements at key life stages, before they commit to them.

A process for participants to try new living arrangements should be designed to help participants feel more comfortable with any move into a new arrangement. This should encourage participants to try diverse, innovative options that are more inclusive and contemporary and reduce the cost of poor matching and housing outcomes. The process should be designed and trialled with people with disability and the sector before being rolled out. Priority for taking up this opportunity to trial new arrangements should be given to those living with ageing carers and in ageing Specialist Disability Accommodation (Legacy and Basic) dwellings.

#### Action 8.4

The National Disability Insurance Agency should commission a shared support facilitation function to empower participants sharing supports to exercise joint decision-making.

A shared support facilitation function should be introduced for participant groups sharing supports, as well as their families and/or other representatives, to embed participant-led household governance in shared arrangements. This should involve designing, negotiating, monitoring and implementing an agreed model for shared support delivery for the group. This function should be independent of the support provider and property manager.

# A more diverse and innovative range of inclusive housing and living supports

# Too few housing and living arrangements are fostering more inclusive and connected lives

There has been little innovation in housing and living supports, and increases in supply of Specialist Disability Accommodation (SDA) have been slow and have not always met the needs of participants.

Outdated group homes still dominate the system and, despite pockets of innovation, service models appear relatively unchanged — leaving participants with little choice. At the end of June 2023, over half (55 per cent) of SDA enrolled places were in either group homes with four to five residents or legacy stock (dwellings designed for six or more long-term residents).<sup>168</sup>

A decade into the scheme, many participants who transitioned from previous disability service systems have not been given the same opportunities for more contemporary housing and living support arrangements as new participants. Close to four out of five participants receiving 24/7 living supports transitioned into the scheme from previous disability systems. These transitioned participants were almost twice as likely to have funding amounts equivalent to sharing support with more than two others (22 per cent compared to 13 per cent). For participants funded for 24/7 living supports residing in SDA, indicatively, more than two in five (44 per cent) transitioned participants lived in ageing SDA, compared with fewer than one in five (17 per cent) new participants.<sup>169</sup>

While there are pockets of innovative dwelling design, we have found there are barriers to greater diversity and innovation in the delivery of housing and living supports.

Providers have incomplete and inadequate information on best practice housing and living supports, and there is limited understanding and knowledge translation of alternative, contemporary housing and living support models. Constant reforms over the last decade have diverted providers from investing time and focus in improving their service models.

We have heard individualised funding and payment approaches do not always align with the shared nature of delivery of housing and living supports, or give incentives for providers that align with good outcomes for participants and a sustainable scheme.

"The NDIS' individualised pricing structure works poorly in shared

living arrangements. It prevents providers from investing in shared

costs to support safety, as spending must be tied to an individual's plan.

It makes funding for supported living unpredictable, as one participant's withdrawal from a provider can undermine the viability of supports of other residents they live with. It leads to unstable rosters that impact the ability to recruit and retain staff, and as a result, staff vacancy rates have never been higher."

- Health Services Union<sup>170</sup>

We have also found current rules and procedures have led to unintended consequences. For example, we have heard about the challenges with getting home modifications for private rentals. In determining value for money for home modifications, the National Disability Insurance Agency (NDIA) takes into account whether tenure is secure and there is written approval from their landlord. We have heard that even when landlords are amenable to a tenant making modifications, obtaining support for modifications through the NDIS can be difficult.

"Members have consistently reported struggles with lengthy wait times, overpriced quotes on housing modifications as well as modifications not being approved to stay where they are, which again, leads to a lack of choice and control in their living situations, not to mention safety issues and difficulty with completing everyday essential tasks. It creates housing insecurity, without a long-term view of modifications that can change over time as people's needs change."

- Queenslanders with Disability Network<sup>171</sup>

We have also heard about unintended consequences of current rules within Supported Independent Living (SIL) arrangements. Currently, a participant can voluntarily exit a shared SIL arrangement with 14 days' notice. But SIL providers cannot claim vacancy payment. This can lead to an overall reduction in the amount of support offered to the remaining participants for the duration of the vacancy and create perverse incentives for providers to fill the vacancy quickly, without regard to the preferences of the existing residents.

"Filling a vacancy successfully can take some time and organisations work through a carefully considered framework which can often take months."

- Anonymous <sup>172</sup>

The SDA market is still maturing, but has achieved much to date, attracting a large amount of private investment and increasing the supply of specialist accommodation. Nevertheless, there is a mismatch in demand and supply. Utilisation of SDA funding is also low, and at the same time, many SDA dwellings sit vacant. As a result, the SDA market is not yet delivering the right homes in the right locations.

## Participants not eligible for SDA face difficulties accessing accommodation

Access to suitable and affordable accommodation is particularly difficult for participants sharing living supports and who do not have access to SDA.<sup>173</sup> They get little support to locate accommodation appropriate for sharing supports.<sup>174</sup> Despite recommendations from numerous reviews and inquiries, there remains concern about 'client capture' where housing and support continue to be provided by one provider.<sup>175</sup> Closed system 'SIL homes' have emerged leading to more, rather than less, integration of housing providers and living support providers.<sup>176</sup>

"In our region new unregistered providers are starting up businesses, renting private homes that are not modified or fit a person's needs and taking in SIL participants with high plan funds. What happens when the rental agreement finishes, where are these people to live in this housing crisis? These providers will cease supports and they will have nowhere to live."

- Parent 177

More broadly outside the NDIS, there is a lack of accessible and affordable housing in Australia. This has a disproportionate impact on people with disability, particularly those with high support needs, who are more likely to have fixed or low incomes.

Most general and social housing stock is not fit-for-purpose for people with accessibility needs. There are inconsistent residential tenancy rights for participants across different dwelling types. Widespread adoption of the Livable Housing Design Standard in the National Construction Code would improve accessibility of the general housing stock. But roll-out will take time and not all states have signed up.

#### The Panel's vision

#### Participants should be able to choose from a range of diverse and innovative housing and living options to find what best suits their particular needs and circumstances

Ensuring greater choice for participants would require changes to how the NDIA and the new National Disability Supports Quality and Safeguards Commission (National Disability Supports Commission) set the rules and procedures for how housing and living supports are delivered. More frequent and detailed information would also support providers in delivering diverse and innovative housing and living supports.

Consistent with the findings of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, there should be increased focus on promoting safe and effective support for participants with 24/7 support needs. A new specific Practice Standard for 24/7 living supports should be developed. The SDA Practice Standard should also be strengthened to mandate a formal separation between SDA and living support providers.

Better outcomes for participants sharing living supports could be achieved through living support providers being funded to deliver a mix (or bundle) of supports that can be appropriately shared, and being held accountable for participant outcomes. The bundle could include living supports and related supports such as assistance with shopping for household essentials.

This approach should not 'lock' people into shared living arrangements. Rather, it should recognise those supports that are shared at the household level and better reflect the nature of service delivery in these settings.

To ensure these arrangements work as effectively as possible, Shared Support Facilitators should assist participants to set up a service agreement, and check-in with participants to ensure the agreed service standards are being met. This would enhance participant say and choice in the operation of support in their home and improve outcomes.

Access to a new low-cost category of SDA should also be introduced for participants sharing living supports who do not require the specialist design features of other SDA categories. This will stop the expansion of closed system SIL homes operated by support providers.

The Improved Liveability category of SDA should be removed as it does not represent value for money. Following the 2022-23 review of SDA prices, the price of Improved Liveability SDA is now only marginally cheaper than Fully Accessible SDA, despite the latter having more specialised design features that can support a wider range of participants.<sup>178</sup> In implementing this change, there should be no change to the living

arrangements for those currently living in Improved Liveability SDA. Those living in ageing (legacy and basic) stock, as well as new participants to the scheme, should be assessed according to their level of need and be funded for an alternative category of SDA (which could include the new shared support SDA category).

Given that reasonable and necessary funding would typically be based on an average shared support ratio of one support worker to three participants (while ensuring flexibility in line with a needs-based assessment process), there is therefore no longer a need for new SDA dwellings of four bedrooms or above, other than where this is the choice of participants.

There is also an opportunity for the disability sector to continue to work with the Australian Building Codes Board to ensure that the National Construction Code Building Classifications align with the SDA Design Standards. This would resolve the current confusion around how to classify SDA dwellings. These efforts should be encouraged and supported by governments and the NDIA.

To ensure participants are not restricted in their choice of providers, SDA providers should be separately owned and operated from living support providers. Together with broader reforms to quality and safeguarding arrangements (see Recommendation 17) and the new independent Shared Support Facilitators to support and check-in with participants, separation of SDA ownership and provision from living supports would help to address issues with client capture.

Better outcomes for participants in SDA would also be achieved through:

- More flexible pricing of SDA, which would help to support more accommodation in locations where participants can build and maintain their informal support networks, such as friends, family and connections to neighbours. This would enrich lives and, over time, build opportunities for increased independence in activities.
- SDA providers having better information to respond to the needs of participants.
- An intergovernmental strategy for upgrading and repurposing ageing SDA stock owned by states and territories and supporting participants into appropriate housing in line with their needs and preferences.

As the NDIA and the National Disability Supports Commission implement these changes to housing and living supports, priority should be given to working with participants who have transitioned into the scheme from previous disability service systems who have never had a full assessment of their housing and living needs, goals and eligibility. Priority should also be given to those participants living with ageing carers.

Secure and affordable housing is foundational to the lives of all Australians. The NDIS alone cannot deliver this. All governments have a role to play. Intergovernmental cooperation is essential to ensure that scheme participants who are not eligible for SDA (the vast majority of participants) are supported in accessing better mainstream housing options.

## Deliver a diverse and innovative range of inclusive housing and living supports

\*Legislative change required

#### Action 9.1

The <u>National Disability Insurance Agency</u>, in collaboration with the new National Disability Supports Quality and Safeguards Commission, should invest in the collection and dissemination of housing and living data and analysis.

Detailed, disaggregated and tailored data, analysis and information on housing and living supports should be collected and disseminated. A more robust evidence base should inform better diversity and innovation in housing and living supports offerings and underpin more effective market stewardship arrangements.

#### Action 9.2

The <u>National Disability Insurance Agency</u> should implement a new funding approach for participants sharing living supports to strengthen the focus on service quality and outcomes.

The new funding approach should be designed with participants, families and the sector. The approach should outline a set or 'bundle' of shared supports that should be the responsibility of the living support provider and that would ensure the provider is adequately funded and held accountable for participant outcomes, in line with the broader quality and safeguarding arrangements (see *Recommendation 17*).

As part of this funding approach, participants' funding should be pooled to cover this 'bundle' of shared supports. To better enable pooling and to ensure adequate ongoing funding for shared supports, reviews should also be aligned for participants sharing supports and when there is a significant change in the circumstance to the group sharing, such as, one participant vacating the arrangement. Shared Support Facilitators (see Action 8.4) should work with participants to develop a service agreement with their chosen living support provider.

Shared living providers should be paid an enrolment payment, which in time could include an outcome-based payment, for the agreed period set out in the service agreement. The enrolment payment, together with regular check-in from the Shared Support Facilitator to ensure service expectations are being met, would reward providers for investing in building the capabilities of participants and their connection to community that contribute to more open settings, improve natural safeguards and could reduce the need for formal supports. With greater certainty of demand, providers might also have more stable workforces who know and understand the needs of residents and invest more in active support and assistive technology.

#### Action 9.3:

The <u>National Disability Insurance Agency</u> should release more detailed and frequent information on participant demand for 24/7 living supports and Specialist Disability Accommodation (both medium and longer term needs).

Data and information should be published quarterly and include current and projected Specialist Disability Accommodation (SDA) demand, current vacancies, and the features and characteristics of SDA dwellings both completed and in the pipeline. This should be complemented by information on participant preferences and best practice shared living arrangements gathered by Housing and Living Navigators (see Action 8.2) from interactions with participants. Frequent publication of detailed data should ensure the SDA market can respond by building the right types of dwellings in the right locations.

#### Action 9.4\*

The <u>National Disability Insurance Agency</u> should remove the Improved Liveability category for new Specialist Disability Accommodation (SDA) developments, and review the remaining SDA categories and associated Design Standards to evaluate their effectiveness.

The Improved Liveability category should be replaced by alternate Specialist Disability Accommodation (SDA) design categories which meet the assessed needs of participants. The review should be conducted in consultation with participants, the SDA sector and disability community. It should examine whether the High Physical Support, Fully Accessible and Robust categories are fit-for-purpose and enable delivery of best practice and cost-effective living supports for the diversity of SDA participants. It should also consider how the building classification system of the National Construction Code and the SDA Design Standards could be better aligned.

#### Action 9.5\*

The <u>Australian Government</u> should transition responsibility for advising on Specialist Disability Accommodation pricing to the Independent Health and Aged Care Pricing Authority and introduce more flexibility to the way prices are set.

The remit of the Independent Health and Aged Care Pricing Authority (IHACPA) should be expanded to advise on pricing and costing matters for Specialist Disability Accommodation (SDA) to strengthen transparency and independence in the pricing of SDA, and align with the recommended pricing arrangements for other NDIS supports (see Action 11.3). IHACPA should promote investment in the right

types of dwellings in the right location. The SDA pricing framework should also be revised to allow flexibility for IHACPA to price certain dwellings above the price cap by exception. Relevant exceptions could include dwellings in higher cost locations to maintain a participant's connection to their community, or to allow for multi-category needs.

#### Action 9.6

The <u>National Disability Insurance Agency</u>, in consultation with state and territory governments, should commission Specialist Disability Accommodation where needs are not adequately met by the private investor model.

Specialist Disability Accommodation should be commissioned for participants living in remote locations, and for participants with very specialist or complex needs (such as those requiring forensic housing). The National Disability Insurance Agency should work in partnership with communities (see Recommendation 14) and state and territory governments, who deliver both public housing and specialist disability housing, to design, deliver and evaluate a pilot approach to assess how a commissioned model can deliver better supply and outcomes for participants before implementing at scale.

#### Action 9.7\*

The new National Disability Supports Quality and Safeguards Commission should strengthen Specialist Disability Accommodation (SDA) regulation to ensure dwellings are managed in accordance with the needs of participants and mandate the separation of SDA and living support providers.

Monitoring and enforcement of compliance with Specialist Disability Accommodation (SDA) practice standards should be strengthened. The legal and practical separation of SDA and living support providers should also be mandated, with limited exceptions, and monitoring and enforcement of compliance arrangements put in place (see Action 17.1). Any exceptions to the requirement should be clearly specified, for example, in remote areas where separation is not feasible.

#### Action 9.8

<u>All Australian governments</u> should agree and implement an intergovernmental strategy for upgrading or repurposing ageing Specialist Disability Accommodation stock owned by states and territories.

The strategy should be embedded within the new Disability Intergovernmental Agreement (see Action 20.1) as part of the targeted action plan for Housing in Australia's Disability Strategy (see Action 9.11). The strategy should set out timetables for upgrading or repurposing ageing (Legacy and Basic) Specialist Disability Accommodation stock and transitioning participants to appropriate housing in line with their needs and preferences. The strategy should include sensitively responding to preferences of residents and should be designed in collaboration with residents and their supporters and advocates.

#### Action 9.9\*

The <u>National Disability Insurance Agency</u> should amend its change of circumstance and Specialist Disability Accommodation (SDA) policies to reduce the bedroom count of ageing SDA dwellings.

National Disability Insurance Agency policies should be amended to reflect that when a participant exits ageing (Legacy and Basic categories) Specialist Disability Accommodation stock that houses more than three participants, the dwelling is able to be re-enrolled at a lower resident count — down to three residents — and funding for remaining participants is adjusted to reflect revised support ratios. This should reduce the incidence where participants are being encouraged to choose housing that does not meet contemporary standards.

#### Action 9.10\*

The <u>National Disability Insurance Agency</u> should introduce a new Specialist Disability Accommodation (SDA) category for participants funded for shared living supports but not eligible for existing categories of SDA.

A new shared-living category should be designed with participants and the sector to enable the delivery of best-practice and cost-effective supports for participants funded for shared housing and living supports. Funding of the new category should only cover the additional capital costs associated with providing shared supports safely and effectively. This should be offset by a decrease in any implicit capital subsidies in Supported Independent Living (SIL) packages. This should enable broader reforms for delivery of best-practice housing settings for shared living and reduce the cost of living supports over time. This would also ensure a more

transparent allocation of funding for the capital component of shared living supports, strengthen safeguarding and secure a transition away from closed-system SIL only housing arrangements.

#### Action 9.11

<u>All Australian governments</u> should agree and publish a targeted action plan for housing under Australia's Disability Strategy.

The action plan should be developed by jurisdictions and include measurable actions from each state and territory government for improving the suitability of social housing stock for people with disability. This should include a requirement to build all new social housing to gold level Livable Housing Design Guidelines or equivalent. The action plan should ensure consistency in residential tenancy and occupancy rights for participants in Specialist Disability Accommodation and include a commitment for all remaining jurisdictions to sign up to the Livable Housing Design Standards in the National Construction Code. It should also be linked to the National Housing and Homelessness Agreement and the National Housing Plan.

#### Part two

# Markets and support systems that empower people with disability

"... carers [are] often put in difficult situation of trying to navigate

and find services. This is a hit and miss lucky dip scenario, where one

has no idea of the quality of service."

- Anonymous 179

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# Accessible, timely and reliable information to improve market functioning and scheme integrity

# Participants, providers and governments don't have the information they need

We've heard from participants that NDIS markets are not yet working as intended. Current information on what supports can be purchased, what supports are available, and the prices and quality of supports is often hard to find or understand. This affects their ability to exercise informed choice and control over their supports.

"[There is an] overwhelming amount of information on website. Not easy to try to understand if you are able to purchase something ... there often seems to be conflicting information and I don't want to live in fear of being audited and having to repay or have self-managed revoked which is what some people are claiming."

- Carer 180

Understanding complex information across different sources requires significant time and effort from participants, their families, carers, and their intermediaries (such as, Support Coordinators and Plan Managers). Working out how NDIS funding can be used is too confusing and complicated.

"How confusing it is ... it baffles me that it is so hard for us to use and access because we have troubles with the things we need to do to get help.

No one informs you what things are ... [including] what you can use those allocated things for."

- Participant 181

It takes a lot of time and effort for participants to find providers.

"[It is] too clumsy for participants and too hard to find providers easily all the info is dumped into complicated documents and [Australia] wide rather than State based and sector based. How are disabled people and their stressed carers supposed to navigate this?"

- Carer 182

The current NDIS Provider Finder tool only provides basic information on available, registered providers in a participant's local area. However, this information can be unreliable and is often not enough for participants to find and choose suitable service providers. Many participants and their decision supporters rely on word-of-mouth information and advice from other participants, especially people they know and trust, or help from an intermediary (such as, a Local Area Coordinator or Support Coordinator) with varying outcomes.

Providers also lack sufficiently detailed, accurate or timely information on what supports and services participants need and where.

This means there are very significant information gaps which undermine the effectiveness of NDIS markets.

# Current NDIS digital systems make it difficult for many participants to make informed purchasing decisions when managing their funding

While the National Disability Insurance Agency (NDIA) has made efforts to improve its processes and systems, managing and monitoring spending is still challenging and administratively burdensome for many participants. Paying providers can take a lot of work, and can be slow. Tracking how much funding participants have and in what budgets, as well as how much funding has been used, can be difficult.

More than half of all participants are choosing to use a Plan Manager where they get more choice over providers (compared to agency-management) and it can be administratively easier (compared to self-management).

"Being plan managed means [I] can choose my providers without the hassle of self-management."

- Participant 183

However, there is significant confusion about who should be doing what in helping participants to understand, use and manage funding. As at 30 June 2023, over 65 per cent of all active participants have access to two or more intermediaries, with over half of these participants having funding for support coordination and plan management.

"The person who is helping a participant to understand and decide how to use their funding is often the support coordinator, not the plan manager. Confusion in responsibilities has led to variability in what plan managers do and help participants with. There can often be a lack of shared understanding of how funding can be used, delays in payments being made to service providers, and risks to the integrity of the scheme. "It is evident and widely reported that a proportion of intermediaries fail to properly understand their roles and responsibilities, and this is adversely impacting quality and safety."

- SDA Alliance 184

"When there is not enough education or support for people who do not have the benefit of having a support coordinator — organizations, plan managers and support workers end up doing the job for them — this is unpaid work and it is also dangerous as they may not have the correct information and often think they are helping people by saying something like 'you can get XYZ because I know someone who got it paid for by their plan'."

- Provider 185

#### Current NDIS processes and systems could better enable market stewardship, monitoring and protect the scheme from non-compliance, sharp practice and fraud

Current NDIS processes and systems don't provide governments with sufficient information to protect the integrity of the scheme and allow governments to monitor and steward the market.

Governments can only see part of the market based on NDIA and plan managed transactions. Data about whether supports meet participants' needs and are effective in delivering outcomes is not collected in a coordinated way, to know how the market is working and what support approaches work best. Incomplete data and limited market visibility also make it difficult to understand the nature and scale of non-compliance, sharp practice and fraud occurring across the scheme.

"Providers can claim payment from NDIA or Plan Managers without confirmation from participants that the services were provided. Similarly, self-managed participants can submit claims for payment without providing evidence of services provided (although they are expected to retain evidence). These payment arrangements pose a high risk of fraud"

- ANAO Report on 'Effectiveness of the National Disability

Insurance Agency's Management of Assistance with Daily

Life Supports', 2023 186

Without sufficient market visibility, it is difficult for governments to send timely and appropriate market signals to service providers about potential opportunities and supply gaps in the market, or protect scheme integrity.

#### The Panel's vision

# Investment is needed in the digital and data infrastructure of the NDIS

Improving digital and data infrastructure of the NDIS, including making it easier and faster for participants to pay providers, would improve the experience of the scheme for both participants and providers (*Figure 9*). These reforms are essential to improve scheme integrity and for the market to function well.

#### Figure 9

Investing in the digital and information infrastructure of the NDIS will make it easier for participants and providers to navigate and interact with the scheme

Easier for providers to set up to deliver supports

Providers enrol or register under the risk-proportionate regulatory model.

- Once enrolment or registration is complete, providers are listed on the centralised online platform.
- Providers can also choose to use other platforms for participants to find them, with application programming interfaces (APIs) used to streamline the process of signing up to use other platforms.

Easier for participants and providers to connect with each other Participants (and their navigators) can use the centralised online platform or other platforms to search for providers by location and support. Where needed, participants receive help from their navigator to choose and engage providers. This includes:

- Supporting participants to make informed spending decisions.
- Helping participants to manage funding and spending against their budget.

Easier for participants to pay providers and manage their budgets Participants, or their nominees, pay providers electronically through multiple channels. It is easier and faster to pay all providers using different channels. Navigators may help participants use these payment channels, which may involve checking and verifying if invoiced supports have been delivered.

- Digital payment system has improved checks and controls to protect scheme integrity, while minimising delays in paying providers after supports are delivered.
- The NDIA has the resources and capability to do random payment checks and investigate potential anomalies in transaction patterns along with other scheme integrity measures.

These investments would help participants and their Navigator have access to timely, reliable information, empowering them to act as informed consumers in the market.

It would also give providers more timely market signals. Better information could improve provider responsiveness and encourage greater innovation in delivering supports to meet the diverse needs of participants. Providers would also have more market information to benchmark their performance and prices.

A range of technologies and channels would improve digital inclusion for participants. This would deliver a digital experience tailored to the diverse needs of people with disability, including people with an intellectual disability.

Participants and service providers would be supported to communicate more easily with each other through faster digital transactions. At the same time, safeguards for participants and the integrity of the scheme would be strengthened.

Governments should have more comprehensive and timely information. This would drive more evidence-based market monitoring (see Recommendation 13), support more effective stewardship of the market (including setting price caps) and better protect the integrity of the scheme.

There should be changes to the ways in which participants and, if applicable, their nominees can manage funding:

- All participants (with help from their Navigator where needed) should be able to pay their providers — whether they are enrolled or registered — through the NDIS payment system.
- Participants can still self-manage all their funding, and this should be easier and more accessible. Paying for supports would also be faster and easier through the new system. Participants would no longer have to pay for some supports first before being reimbursed by the scheme.
- Where participants need more help, Navigators should help participants with understanding and using their funding. Navigators would also be responsible for helping participants to monitor and manage their funding to remove confusion about who should be doing what.

Over time, digital payment systems and the increased support of Navigators in helping participants manage their budgets will reduce the demand for some functions of plan management. Enabling participants to pay all providers — both enrolled and registered providers — through the NDIS payment system should mean Plan Managers no longer "pay the bills".

The transition to the digital payment system will however take time. In the interim, Plan Managers still have an important role to play in supporting prevention, detection and response to non-compliance, sharp practice and fraud. In the longer term, as the digital capabilities of the NDIS grow, plan management is likely to need to change significantly. Improvements to the NDIS digital landscape should not happen overnight, and should be coordinated well and communicated clearly and early.

Invest in digital infrastructure for the NDIS to enable accessible, timely and reliable information and streamlined processes that strengthen NDIS market functioning and scheme integrity

\*Legislative change required

#### Action 10.1

The <u>Australian Government</u> should develop and fund an easy-to-use centralised online platform that provides information on all locally available supports and services for participants and Navigators

An online registry should provide participants and Navigators with essential, accessible, timely and reliable information to search for providers by location and service type. This should cover all available, local NDIS providers, including registered and enrolled providers (see Action 17.1). Information on how much supports cost and provider performance (see Action 12.3) should be centralised to make it easier for participants and Navigators to compare providers based on price, safety and quality of their service. The centralised online platform should also include information about available foundational supports (see Actions 1.3 and 1.4).

#### Action 10.2

The National Disability Insurance Agency and the new National Disability Supports

Quality and Safeguards Commission should enable better two-way information sharing with third party online platforms to encourage digital innovation that builds on the centralised online platform

The National Disability Insurance Agency's current application programming interface (API) functionality should be expanded to enable better two-way information sharing. This should build on what is offered by the centralised online platform (see Action 10.1) and provide participants with a more tailored digital experience. Information sharing arrangements should comply with relevant privacy, information handling and data security requirements.

Information sharing arrangements could also be designed to enable third party online platforms to help connect participants with service providers to share information collected on participants' experiences with providers, and governments to share consistent, reliable provider information across platforms. This could improve governments' market monitoring capability and enable more timely response to quality and safety concerns.

#### Action 10.3

The <u>National Disability Insurance Agency</u> should transition to fully electronic payments and improve visibility of NDIS payments.

This should give governments the information required to be effective market stewards, understand what works and deliver outcomes, and strengthen scheme integrity. Investments should be made in a multi-channel digital payments approach, including near real-time claims and payment technologies. The design of a multi-channel digital payments approach should make it easier and faster for participants to pay for supports, improve information captured on all NDIS payments, and enable participants and Navigators to better monitor spending (see Action 3.6). Participants should be able to continue to pay upfront and seek reimbursements in the short term, but reimbursements should be phased out over time.

#### Action 10.4

The <u>Australian Government</u> should invest in the underpinning digital infrastructure and capability needed to protect the integrity of the NDIS.

Investments in information technology, capacity and capability should be made to improve prevention, detection and responses to non-compliance, sharp practices and fraud in the scheme. Where possible, existing fit-for-purpose government technologies, such as myGov, should be used or built upon. Investments should align with the Australian Government's future Data and Digital Government Strategy, and form part of a holistic approach in protecting the integrity of the scheme and the broader NDIS digital transformation strategy and roadmap (see Action 10.6).

#### Action 10.5\*

The <u>Australian Government</u> should develop and implement a clear transition path for existing Plan Managers.

The future electronic payment system (see Action 10.3) would enable participants to pay all registered and enrolled providers. A strategy to steward the plan management market should be developed in transitioning to fully electronic payments. Work to clarify Plan Managers' current responsibility in protecting scheme integrity should start now and should be refined as the NDIS digital infrastructure and capability evolves (see Action 10.4). Where needed, support for participants to monitor and manage their funding should transition to Navigators (see Recommendation 4).

#### Action 10.6

The <u>Australian Government</u> should design and roll out an NDIS digital transformation strategy and roadmap to bring together and sequence all initiatives in the NDIS digital landscape.

This should guide improvements to the NDIS digital landscape, support a more risk-proportionate regulation of providers, and enable a seamless user experience for participants, providers and workers. The strategy and roadmap should link with and leverage digital transformation efforts across the Australian Government. This should ensure investments in the NDIS digital landscape support interoperability and data sharing with other Australian Government systems (such as, aged care and veterans' care) to minimise the burden placed on participants, workers and providers.

# Payment and pricing frameworks to improve incentives for the delivery of quality supports

NDIS markets are not like other markets. They are social markets. Finding and buying NDIS supports is different to going to the supermarket or choosing a service like an internet provider. This means the role of government in stewarding NDIS markets must also be different.

#### There are opportunities to improve how price caps are set

Most NDIS supports have a maximum price or price cap. In 2022-23, around 83 per cent of payments were subject to a price cap.<sup>187</sup> Price caps aim to prevent large providers from using their market power to drive up prices and help ensure services are value for money. However, the way price caps are set is creating issues in the NDIS market:

- The blunt and non-transparent way price caps are set is not helping providers respond to the needs of participants or encouraging market confidence or innovation.
   We've heard from some providers this also makes it hard to invest in the capability of workers.
- While price caps are slightly higher for participants with complex needs, past reviews
  have heard that the current price caps don't do a good job at supporting access for
  participants with complex needs.

We know that providers often charge participants at the maximum price. In the NDIA's 2021-22 Financial Benchmarking Survey, over four in five providers (83 per cent) reported always setting prices at the price cap. A small share of providers (16 per cent) said that they 'sometimes' set prices below the price limit.<sup>188</sup>

We also heard from participants, families and carers that it is difficult to find supports that are below the price cap.

"NDIA staff have a misinformed perception that participants

(especially those who self-manage) hold significant power to

negotiate with providers in relation to fees charged. Providers simply

refuse to provide service and move on to the next participant."

- Carer<sup>189</sup>

Providers respond to incentives embedded within pricing and payment rules. For example, when participants purchase low cost assistive technology (that is, assistive technology under \$1,500) they do not require a quote and only require written advice from an assistive technology advisor for 'higher risk' items. We see a spike in transactions at the \$1,500 threshold. Between July 2020 and June 2023, 62 per cent more transactions were made just below the threshold — that is, between \$1,401 and \$1,500 — compared with transactions made between \$1,301 and \$1,400.

We also know participants may not change their provider when prices change. So, there is little reason for providers to compete by lowering the price or improving the quality of supports.

We have heard from the sector about the National Disability Insurance Agency's (NDIA) inherent conflict of interest in setting price caps when it is also responsible for the sustainability of the scheme. Providers have also long expressed concern about the lack of transparency in the way prices are set.

"The current price setting mechanism, which is an annual review undertaken by the NDIA, is perceived as being a fast and incomplete review mechanism that does not fully utilise stakeholder feedback or undertake a full analysis of the factors that are currently influencing the NDIS market and delivery of NDIS services. There is also a perception that NDIA's Annual Pricing Review is impacted by overall NDIA budget constraints in its final decision making. While budgetary impacts must be a key consideration, it should be transparently accounted for as an element of overall decision making, which does not occur currently."

- Occupational Therapy Australia<sup>191</sup>

#### Providers are incentivised for quantity rather than quality

For most NDIS supports, providers get paid for each support they provide. For example, they get paid a certain amount for an hour of support. We call this 'fee-for-service'.

Fee-for-service is an easy way to pay providers. However, it means providers benefit when they increase the number of supports to participants — even if these extra supports do not improve outcomes. Providers may not benefit when they help a participant to be more connected to community and need fewer supports. This way of paying providers can place pressure on the total cost of the scheme.

"Currently providers are paid based on the services they provide, rather the benefits of those services to participants. Providers should be rewarded for helping to achieve participant goals. This would benefit the providers who provide high-quality services, and it increases the focus for Government, the NDIS and providers on building the long-term capabilities of participants."

- Get Skilled Access 192

"Fee-for-service arrangements may also contribute to a lack of investment in provider and workforce capability and quality assurance. Where providers are incentivised to prioritise more services over and above quality assurance, people with disability bear the consequences. This includes funding consequences (through over-servicing) and safety and quality consequences (as providers are incentivised to limit resources)."

- Women with Disabilities Australia 193

#### The Panel's vision

# A new pricing and payments approach is needed to improve incentives for providers to deliver quality supports to participants

Price caps should continue to help ensure the NDIS market is sustainable, not drive up prices, and that services are value for money. But, the way price caps are set should be improved.

The process for setting price caps should be clear, transparent and be based on the market price for delivering supports, including any costs associated with regulation (see Recommendation 17), with robust information on the cost and amount participants are being charged. This would help ensure quality providers remain viable in the NDIS market.

Price caps should also better reflect the differences in the costs for delivering supports to participants with more complex needs and in different regions and in group-based settings. Further differentiations of price caps, as long as they are well understood and are accessible through the centralised online platform (see Action 10.1), would help ensure participants can access quality supports, and help providers to respond to the needs of participants and invest in the capability of their workers.

Over time, changing how prices are set and providers are paid — or the 'pricing and payments framework' — would help the NDIS market work better.

Providers should be paid in different ways to reflect the differences in the types of supports provided. Using a mix of payment approaches would better reward providers for helping participants to achieve their goals and to be more connected to community. This will improve outcomes for participants and reduce cost pressure on the scheme over time.

The Department of Social Services (DSS) and the NDIA would actively monitor and evaluate changes in payments to providers to ensure these new payment approaches are improving outcomes for participants. They would also work closely with the Independent Health and Aged Care Pricing Authority, who would independently advise on NDIS pricing to ensure greater alignment of pricing across the care and support sector.

Opportunities to shift away from the current fee-for-service approach, where providers are paid for each hour of support delivered, should be carefully explored and tested. Instead, there may be opportunities to reduce incentives for providers to 'over-service' — that is, to deliver more supports than needed. This could include looking at ways to better define pathways of support and to pay providers for delivering a group of supports or a range of activities rather than individual hours of support. We call this an 'activity-based payment'.

One-off and irregular supports — including assistive technology and other capital supports — should continue to be paid on a fee-for-service basis.

For shared living supports, where participants and their chosen provider have an ongoing relationship and the level of support needs are more well known, providers should be paid an enrolment payment (see Action 9.2). The enrolment payment should be designed with participants and could incorporate a small outcome-based payment, which could initially reflect a simple measure of a participant's satisfaction with their provider.

Following the development of an outcomes framework, outcome-based payments should be more widely designed, tested and evaluated to reward providers for achieving participant outcomes. If successful, outcome based payments could be 'mixed' or 'blended' with other payment models and be applied across a range of supports.

Participants should get a better deal for capital supports (such as assistive technology), through 'preferred provider' arrangements, where the NDIA would negotiate with providers about how much these supports cost and the services the providers would deliver. DSS and the NDIA should also look for opportunities to work across government agencies to align prices across the care and support sector and better leverage government buying power.

Taken together, the improvements in how prices are set and providers are paid should, over time, more clearly reward the best outcomes for participants, as well as helping participants truly exercise informed choice and control.

## Reform pricing and payments frameworks to improve incentives for providers to deliver quality supports to participants

\*Legislative change required

#### Action 11.1\*

The <u>Department of Social Services</u> should develop a new NDIS pricing and payments framework to be administered by the National Disability Insurance Agency and the Independent Health and Aged Care Pricing Authority, including better ways to pay providers to promote the delivery of efficient and quality supports and continuity of supply.

The new framework should enable price caps to reflect the market price for delivering supports, including for participants with more complex needs, in different regions, in group-based settings, costs associated with training, workers compensation, liability insurances and other indirect labour costs. The implementation of the framework should be data-driven with strengthened requirements for providers, with appropriate exemptions for smaller and enrolled only providers, to disclose relevant financial information and the prices they charge. The framework should also enable payment approaches that strengthen incentives for providers to deliver 'value-based' supports that help participants to achieve outcomes. As part of the new framework, fully self-managed participants or their nominees who are capable of and choose to manage their own funding should not be subject to price caps.

#### Action 11.2

The <u>National Disability Insurance Agency</u> should progressively roll-out preferred provider arrangements for capital supports to better leverage its buying power and streamline access for participants.

This should include home modifications, assistive technology and consumables. Preferred providers should be paid a fee-for-service payment negotiated by the National Disability Insurance Agency (NDIA), reflecting the one-off, irregular and more transactional nature of capital supports. The NDIA should consider opportunities to work with other government agencies to further increase buying power across government-funded programs. Preferred provider arrangements should also include, where relevant, published, user-friendly, and standardised service agreements covering maintenance and servicing, as well as loan arrangements for assistive technology required for short periods.

#### Action 11.3\*

The <u>Australian Government</u> should transition responsibility for advising on NDIS pricing to the Independent Health and Aged Care Pricing Authority to strengthen transparency, predictability and alignment.

The Independent Health and Aged Care Pricing Authority (IHACPA) should be responsible for advising on suitable indicators of the market price and price caps for relevant NDIS supports. IHACPA should consult with the Department of Social Services, the NDIA, the National Disability Supports Quality and Safeguards Commission, state and territory governments, and the broader sector when advising the Australian Government on prices.

Expanding the remit of IHACPA to include NDIS pricing would support greater alignment across the care and support sector and ensure government does not compete with itself and makes better use of its buying power across sectors.

#### Action 11.4

The <u>Australian Government</u> should review and refine the pricing and payments framework once underpinning reforms have been implemented

This should consider the suitability of the framework based on changes in the NDIS market that result from implementing reforms to participant budget setting, dedicated and graduated assistance with navigating the NDIS, information including quality and safety measures, and improved incentives for providers. It should also evaluate the outcomes and functioning of the self-managed market, with improved data and market visibility through fully electronic payments (see Action 10.3).

#### Continuous quality improvement

#### Better regulatory focus on improving the quality of NDIS supports is needed to achieve the best outcomes for participants

In addition to changes to pricing and payments, there is an opportunity to enhance the role of the new National Disability Supports Quality and Safeguards Commission (National Disability Supports Commission; see Action 19.2) in improving quality.

Quality is the extent to which supports meet or exceed a person's needs and expectations. 194 Quality may look different for different people, but key aspects of quality typically include the satisfaction of consumers, the efficacy of support delivery and outcomes achieved, as well as a provider's responsiveness in addressing issues.

Safe support is the bedrock of quality support. But quality support clearly goes far beyond safety. Quality support is key to both good outcomes for people with disability, but also importantly to preventing harm and safeguarding people with disability. This is why we believe quality is best driven by an integrated approach with safeguarding. This is supported by literature on best practice regulation and the approach taken in similar human services regulation — for example, the Aged Care Quality and Safety Commission in Australia and the Care Quality Commission in England. 195

Despite this best practice approach, since its conception, the NDIS Quality and Safeguards Commission (NDIS Commission) has needed to focus largely on establishing and operating its regulatory functions and processes, with limited efforts to improve quality. The NDIS Commission's constrained resources have been prioritised to the significant task of transitioning to a national regulatory approach to safeguard participants. As a result, we have seen quality improvement take second place.

"...the focus needs to be on quality and outcomes, rather than simply price... Quality should be the bottom line for eligibility to provide services."

- ANZACATA 196

## There is an opportunity to provide more support for providers and workers to engage in quality improvement

More recently, the NDIS Commission has begun to implement a number of positive quality improvement initiatives. These have been focused on provider and workforce capability building, including a Workforce Capability Framework setting out the expected attitudes, skills and knowledge for all workers, a new online repository of resources regarding behaviour support, and practice alerts on best practice support delivery.<sup>197</sup>

We have heard from many workers and providers, however, who feel there is still not enough targeted and focused information, training and resources to help them understand what good quality support delivery looks like and how they can implement this in practice.

"Capability building is more than just a website article but instead requires training, education among the sector and building information awareness through a proactive means."

- The CEO Collaboration 198

Providers have also told us their efforts to improve quality would be assisted by the NDIS Commission sharing insights from the data it collects about what is working well and where change is needed.

"Greater use, interrogation and interpretation of data ... could allow for deep and authoritative insights into the state of quality and safeguarding across the country."

- National Disability Services 199

## Incentives for providers to engage in quality improvement are limited

Registered NDIS providers must undergo an external third party quality audit to assess performance against relevant NDIS Practice Standards and associated Quality Indicators. While this is intended to support quality improvement, we have heard that there is too much focus on paperwork, procedures and policies and not enough focus on the quality of support delivery and the experience of participants.

"Audits are too preoccupied with items that relate to administration,

policy compliance and reporting requirements that reveal little association

to factors that influence the actual quality of service."

- Family Advocacy <sup>200</sup>

A lack of transparency about quality and performance means providers have no way of understanding how they are performing relative to other providers.

"...a single source of truth for publishing provider performance data is required to better build provider capability, monitor performance and improve the supply of high-quality supports."

- Anonymous <sup>201</sup>

This lack of visibility of provider performance and inadequate guidance for choosing supports and providers also means participants face challenges in understanding what quality looks like and how their provider's performance stacks up. This further undermines incentives for providers to maintain good performance or improve when performance is poor.

"... carers [are] often put in difficult situation of trying to navigate and find services. This is a hit and miss lucky dip scenario, where one has no idea of the quality of service."

- Anonymous 202

#### The Panel's vision

#### A stronger focus on quality embedded in the regulator would better support and incentivise providers and workers to deliver supports of the highest quality

Safe supports are essential for all people with disability. However, they must be accompanied by a renewed and sharper focus on improving quality. This should start with a stronger and more prominent emphasis on quality in the new National Disability Supports Quality and Safeguards Commission (National Disability Supports Commission). A dedicated quality function led by a Deputy Commissioner for Quality should be established to embed a focus on quality across the breadth of the National Disability Supports Commission's work.

An appropriately resourced National Disability Supports Commission should prioritise improving quality and outcomes across key areas we have identified throughout this Review, including behaviour support, navigation, early intervention, psychosocial supports, housing and living supports, and supports for children, families and First Nations people. Expanded capacity-building, industry outreach and data and insights sharing initiatives would help providers and workers understand best practice and engage in genuine and continuous quality improvement.

In addition, providers should be rewarded for achieving good outcomes for participants. Whether that be community connection, greater inclusion, or employment outcomes, the system must be reformed to incentivise providers to help participants achieve the fundamental aims of the NDIS: to become more independent and connected.

These efforts should be complemented by more robust auditing with a sharper focus on quality, including the voice and experience of people with disability. In addition, the performance of providers against quality and safety metrics should be measured and made public in a transparent and accessible manner. This would make providers more accountable for the supports they provide, improve competition on the basis of quality, and empower people with disability to exercise informed choice to ensure they receive fit-for-purpose, quality supports delivered by the best providers and workers.

#### Recommendation 12

Embed, promote and incentivise continuous quality improvement in the market, supported by a dedicated quality function in the new National Disability Supports Quality and Safeguards Commission

\*Legislative change required

#### Action 12.1

The <u>Australian Government</u> should establish and appropriately resource a quality function within the new National Disability Supports Quality and Safeguards Commission led by a dedicated Deputy Commissioner for Quality.

This function should be adequately resourced to deliver on quality improvements. It should drive a range of initiatives to promote quality improvement through capacity-building, improved auditing and greater transparency (see Actions 12.2 and 12.3), and should provide leadership and coordination across the new National Disability Supports Quality and Safeguards Commission to deliver a focus on driving quality improvement in the market.

#### Action 12.2\*

The new National Disability Supports Quality and Safeguards Commission should make quality improvement a priority in capacity-building initiatives and audit processes.

Initiatives should better support providers and workers to understand and focus on quality improvement. Efforts should be directed to more effective and targeted capacity-building initiatives and outreach with providers. The audit process should also be refocused on the quality of support delivery and the voice of people with disability, to support efforts to improve quality and build a continuous quality relationship in regulatory processes.

#### Action 12.3\*

The new National Disability Supports Quality and Safeguards Commission, working with the Department of Social Services, should design, test and implement an approach to measure and publish metrics of registered provider performance.

This should include an initial focus on quality and safety and be designed to incentivise improvements by providers and drive greater competition on quality. It should be supported by accessible and useful information to support people with disability in making choices about providers. Over time, this should incorporate measurement of outcomes, and be accompanied by consequences for good and poor performance.

## Market monitoring and coordinating NDIS markets

#### NDIS markets are not yet working for all participants

The NDIS has transformed the way disability supports are delivered. Shifting from a government, block-funded model to a market-based model with individualised funding — where funding follows the participant and not the provider — has enabled participants to have more choice and control over the providers they work with and what supports they access.

With this shift came a significant increase in scale and diversity of demand for services and significant market development. Over 390,000 participants are now receiving disability supports for the first time.<sup>203</sup> But this growth has not been sufficient to secure access to quality services for all participants, across all locations. Past reviews of the NDIS indicate a range of ongoing market challenges that reflect more than just transition issues (*Figure 10*).

Moving from block funded arrangements removed governments' responsibility for coordinating access to support. The shift relied on participants, their families, providers and intermediaries having the capacity and capability to co-ordinate supports in an already complex environment, with limited (or at least unclear) protection for participants where markets fail.

For some NDIS supports, it has often been difficult for participants to find suitable service providers, and for providers to achieve economies of scale and to ensure continuity of supply.

"There is a lack of options and choices, I'm struggling to find options near us that will help build independence towards future employment, build connect to community, friendships etc. Everything is far away."

- Carer and person with disability 204

For these supports, competition between multiple service providers has not been able to effectively ensure access to supports for all participants and in all locations.

Sometimes the number of providers or participants in the market is too small for competition between multiple service providers to work well or at all. We call this a 'thin market'.

Thin markets have left some participants with limited, or no, access to supports or certain types of supports. As far back as 2017, the Productivity Commission found thin

markets have been, and will continue to be, a persistent feature of the disability support sector. In the absence of government intervention there will be greater shortages, less competition, and ultimately poorer outcomes for participants.<sup>205</sup>

#### Figure 10

Past reviews of the NDIS indicate a range of ongoing market challenges that reflect more than just transition issues<sup>206</sup>

## Limited access to supports in remote and very remote areas

"An issue for participants in rural and remote areas is a lack of service providers to provide the supports that participants are funded for in their plans, leading to low plan utilisation rates and the possibility of a decrease in funding in participants' subsequent plans. As a result, service providers that do exist in rural and remote areas may feature long wait times and long waiting lists for services."

Joint Standing Committee on the NDIS (JSC) Inquiry into NDIS Planning (2020), Chapter 9

## Shortages of some supports in non-remote communities

"The key issues with the NDIS in my experience is that regional areas are poorly serviced by a market-based approach, especially when services are specialised. It does not matter if you have the funds if nobody will provide the service."

Participant quote from Tune Review (2019), p.122

## **Limited capability of NDIA to identify thin markets**

"Existing mechanisms to solve thin markets rely on participant complaints to the NDIA and/or NDIA monitoring of participant utilisation — which trigger thin market initiatives"

Queensland Productivity Commission Inquiry into the NDIS Market in Queensland (2021), p.256

## Lack of culturally appropriate care for First Nations communities

"Aboriginal and Torres Strait Islander participants in the NDIS faced significant difficulty in accessing services, which witnesses and submitters observed could be largely attributed to the lack of culturally appropriate and affordable services available, particularly in rural and remote areas."

JSC Inquiry into NDIS Workforce (2022), Chapter 5

## Some participants are being left behind

"[The] NDIS pricing framework is not working for participants with high and complex needs ... some service providers are 'cherry picking' clients and potentially leaving some of the most vulnerable NDIS participants with no access to adequate services."

JSC Inquiry into Market Readiness (2018), Chapter 5

# Unclear protection of participants against market failure

"The NDIS should address thin markets by ... publicly releasing its Provider of Last Resort (POLR) policy and Market Intervention Framework discussed in the NDIS Market Approach: Statement of Opportunity and Intent as a matter of urgency."

Productivity Commission Review into NDIS Costs (2017), Recommendation 7.1

#### Attempts to steward the market have been limited

The National Disability insurance agency (NDIA) has tried different ways to improve access to supports. This includes testing in a small number of areas:

- sharing information for participants and providers to find and connect with each other; and
- ways to help participants find and buy supports as a group.

To date these efforts have been too narrow. The NDIA's own evaluation of their thin market trials suggests providing better information alone is not sufficient to overcome challenges. Rather, governments must be more active and flexible to help ensure markets work for everyone.

Ensuring NDIS markets work for everyone is hindered by an incomplete picture of those markets. There is a lack of comprehensive, accurate and timely information about who is delivering supports and services and what supports are being delivered due to the current NDIS payment system. Coupled with fragmented feedback on service safety and quality, it is challenging for governments to understand what the markets look like and how they are working.

In addition to the challenges around access in remote and First Nations communities (discussed below), we've heard from participants about the continuing issues in accessing allied health supports in regional and rural parts of Australia. Over 33 per cent of participants — who have been in the scheme for at least one year — are not accessing any therapy supports in small and medium rural towns, despite having funding for these supports.<sup>207</sup>

"I am in a regional area of 60,000. It is almost impossible to get services here for things such as OT's or speech pathologists — given these people are also required for approval of any spending — it is becoming quite unworkable."

- Extracted Participant Quote from Australian Association of Psychologists Inc<sup>208</sup>

Governments need to do more than just set the rules of engagement or act as a funding body. As market stewards, governments should also oversee these markets and intervene when necessary. These are social markets where governments need to monitor outcomes and carefully balance considerations of efficiency, effectiveness and equity.<sup>209</sup>

#### The Panel's vision

#### Governments, as market stewards, should be more active and flexible to help ensure NDIS markets work for everyone, everywhere

NDIS markets, with guidance and active intervention from governments where necessary, should function better for all participants.

To achieve this, governments need to do more in their role as stewards of the NDIS market. This includes:

- informed participant choice (see Recommendation 10 on information sharing)
- continuous improvement in service quality and effectiveness –
   (see Recommendations 10, 11 and 12 on improving quality of services)
- access to quality supports (see Recommendations 13, 14 and 15 on better access to supports)
- appropriate regulation and safeguards for people with disability (see Recommendations 16 to 19 on regulation and safeguards for people with disability).

Agencies across the Australian Government have different functions and roles as market stewards. While the Department of Social Services stewards the market by setting market policy, other agencies – including the NDIA and National Disability Supports Commission – have a role in providing information and guidance to the market, operationalising policy, monitoring the market and taking action where the market is not functioning well or as intended (*Figure 11*).

#### Recommended NDIS market stewardship functions for Australian Government agencies

#### Stewards the market by

### Setting market policy

#### **Department of Social Services**

- •Oversees changes to primary legislation and the broad policy of the scheme
- •Coordinates actions across Australian Government and state and territory government agencies to steward the NDIS market
- •Works with government agencies to coordinate workforce planning and development across the care and support sector

#### Service delivery

#### Quality and safeguards

#### Pricing and payments

#### Scheme integrity

# Stewards the market by providing information and guidance operationalising policy through systems and processes

taking action or intervening where the market is not functioning well, or as intended

#### NDIA

- Informs and educates about the scheme and market (including information to support participant decisionmaking).
- •Shares public data and intelligence to the market (including on opportunities and gaps in the market).
- Enable connections between participants and providers (e.g. through matching tools).
- Sets access and funding approaches for NDIS supports to ensure access to effective, quality supports.
- Works across government to leverage buying power for better access to supports.
- Builds partnerships with community to design and roll out service delivery approaches (including alternative commissioning).
- •Coordinates actions to ensure continuity of access to critical supports where markets fail.

#### National Disability Supports Quality and Safeguards Commission

- Controls market entry and sets requirements such as provider registration and enrolment, worker screening (with states and territories), behaviour support and restrictive practices (with states and territories).
- Informs and educates providers and workers (e.g. about their regulatory obligations) and participants (e.g. their rights and how to raise issues).
- Identifies, investigates and responds to complaints, incidents and issues of noncompliance and takes corrective action (e.g. conditions, enforceable undertakings, bans, penalties).
- -Drives quality through capacity-building of providers, outreach, performance measurement (e.g. communities of practice, good practice guidance).
- Works with other regulators and law enforcement to ensure safety and improve market quality.
- Supports actions to ensure continuity of access to critical supports where markets fail.

#### **IHACPA**

advises on the maximum amounts providers can be paid for delivering supports

#### **NDIA**

- •Oversees enabling payment infrastructure.
- -Administers payment system (including multiple payment channels), price cap and claiming 'rules'.

## NDIA and National Disability Supports Quality and Safeguards Commission

Shared responsibility

- Refines risk management strategies on an ongoing basis.
- Sets and refines risk treatments and controls to prevent, detect and respond to noncompliance, fraud and sharp practice (e.g. identity verification, payment controls).
- •Enforces compliance with scheme integrity 'rules'.

#### Monitors the market (by gathering and sharing data and intelligence) to inform market actions and interventions

- Monitors market demand and supply using participant data, payment data and local intelligence (including navigators).
- •Proactively monitors and responds to risks and emerging changes in the market through provider reporting, complaints and other regulatory intelligence
- Monitors and enforces pricing and payment 'rules'
- Monitors market responses to price settings.
- Assists providers with information to compare and benchmark their performance.
- Monitors payments, transactions and other intelligence to detect non-compliance, fraud and sharp practice.

Strengthening access to quality supports for all participants will require more active market monitoring and using a range of responses flexibly to address identified market challenges.

Government, with the assistance of Navigators and improved visibility of all payments, should be able to better identify where participants are facing persistent challenges accessing supports.

Government should also be more active in providing tools that can help participants who have similar needs connect with each other and with providers to get the supports they collectively need. New matching tools should be available to participants and Navigators to connect and pool their funding to access supports that meet their needs as a group and on their terms. These tools should be scalable so that, when needed, they can be used widely by participants for a range of supports and across different locations.

Where competition between multiple service providers is limited or not possible, other tools should be used to ensure participants have access to supports where they live.

One such tool includes setting up a group of providers to deliver certain supports and in specified locations. We call this a 'provider panel'.

Where market gaps persist, setting up provider panels would ensure participants have access to supports where they live. This should start with provider panels for allied health supports in small and medium rural towns. Provider panels should leverage good providers already operating in these areas and be regularly monitored and re-tested to ensure participants and the scheme benefit from improved access and investment in communities. In remote communities and for First Nation communities across Australia, we need a different way to deliver supports that is place-based and community-driven and built on the strengths of these communities (see Recommendation 14). Supports need to be coordinated and purchased across the whole community.

There should be a clear, publicly available, policy on what actions would be taken by the NDIA, the new National Disability Supports Quality and Safeguards Commission and state and territory governments when a provider fails or no provider — which is not owned or run by government — is willing or able to provide supports.

#### Recommendation 13

## Strengthen market monitoring and responses to challenges in coordinating the NDIS market

\*Legislative change required

#### Action 13.1

The <u>Australian Government</u> should undertake more active, evidence driven market monitoring to identify issues with access to quality supports early and take more timely and appropriate action.

Market monitoring should draw on improved data collected from the transition to fully electronic payments (see Action 10.3) and information on service access issues reported by Navigators (see Recommendation 4). The National Disability Insurance Agency, in consultation with other government agencies, should use this information to take action to address market challenges and persistent and emerging supply gaps. This should include regularly releasing local market monitoring information to Navigators and providers (including, for instance, the NDIS Demand Map).

#### Action 13.2

The <u>National Disability Insurance Agency</u> should progressively roll-out provider panel arrangements for allied health supports in small and medium rural towns or where participants face persistent supply gaps.

Provider panels should leverage good providers already operating in these areas and be retested at least every three years (or earlier where the panel is not meeting agreed service standards and outcomes). This would ensure panels are lowering the cost of service delivery through greater coordination of travel and sharing costs and resources among providers, and increasing certainty of demand for providers to encourage investment in communities. Provider panels should be progressively rolled-out in small- and medium-sized rural towns (Modified Monash Model categories 4 and 5), and used flexibly in other areas where supply gaps persist. Initial pilots should be evaluated to ensure settings are fit for purpose ahead of any wider roll-out of panels.

#### Recommendation 13

#### Action 13.3

The <u>National Disability Insurance Agency</u> should develop matching tools to support participants and Navigators to pool demand for supports.

New matching tools should assist participants and Navigators to connect with other participants where there is a joint benefit from pooling their budgets to find and purchase supports. This may apply to group-based and other innovative supports. These tools should build on the lessons from the National Disability Insurance Agency's use of Coordinated Funding Proposals to provide more scalable online matching tools. Participants and Navigators should be able to easily access these tools, including via the centralised online platform (see Action 10.1). These tools should allow participants and Navigators to collectively broadcast opportunities for existing and new providers to respond to their support needs and preferences.

#### Action 13.4

All Australian governments through the Disability Reform Ministerial Council should agree and publish a provider of last resort policy to ensure participants have continued access to supports where markets fail.

Provider of last resort arrangements should be evidence-driven and underpinned by market monitoring (see Action 13.1), and reviewed every five years to ensure governments' market responses remain timely, effective and fit for-purpose. These arrangements should be part of a broader approach in how governments maintain access to critical supports for participants, including where services cannot be delivered as a result of natural disasters. The policy should address the needs of very complex clients and the need for the NDIA and National Disability Supports Commission to work together to ensure quality service continuity.

# Access to supports for First Nations communities and all participants in remote communities

There is limited access to supports for remote and First Nations participants

For all participants living in remote communities who have been in the scheme for at least one year:

- around two in five participants are not getting daily activity supports
- over one in three participants are not getting therapy services.<sup>210</sup>

Even in towns and cities, many NDIS services are not culturally appropriate for First Nations people with disability. As a result, First Nations participants may need to choose between supports that are not culturally safe or not getting funded supports at all.

Funding for individuals also does not consider the strength of communities that participants live in.

"Aboriginal Health as ... Not just the physical wellbeing of an individual, but the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their community.

It is a whole of life view and includes the cyclical concept of life-death-life."

- Jenny Bedford and Cassie Atchison, Disability Royal Commission

Public Hearing <sup>211</sup>

"A narrow focus on the individual, without an understanding of the importance of family and community, conflicts with the Anangu way of living...

To help the individual, you often have to support and build the capacity of the family and community... if the NDIS continues to operate without any flexibility to work with families, the scheme will limit individual choice and control for Anangu."

- Kim McCrae, Disability Royal Commission Public Hearing <sup>212</sup>

Increases in loadings to remote and very remote price limits and greater flexibility in pricing arrangements have helped, but not enough. Past reviews have repeatedly called for different ways to deliver supports. We have found the NDIS cannot rely on 'competition' alone to deliver supports to remote communities and First Nations communities.

# Governments should better coordinate and purchase supports in remote communities and First Nations communities

The National Disability insurance Agency (NDIA), First Nations communities, remote communities, other Australian Government agencies and state and territory governments should work together as partners to buy or 'commission' supports for people in the community to improve access. We call this 'alternative commissioning'.

One way which communities may want to coordinate supports is by joining up (or integrating) funding for different supports and community initiatives across government programs. We call this 'integrated commissioning'.

Integrated commissioning approaches would make it clearer and easier for communities, particularly in remote areas — to understand what services they can access, from who and when. Taking a whole-of-community approach can also minimise duplication and gaps in supports.

Over time, communities should be supported to buy and coordinate supports for themselves. We call this 'community commissioning'.

## Governments must share power with First Nations communities

The National Agreement for Closing the Gap commits all Australian governments to work in full and genuine partnership with First Nations people in making policies. It emphasises the importance of four key priority reforms:

- shared decision-making
- community controlled delivery
- transforming government organisations to be more accountable and responsive
- providing shared access to data and information at a regional level.

These key priority reforms are central to ensuring progress and delivering fundamental change. These apply to all government activities involving First Nations communities.

The Disability Sector Strengthening Plan was developed under the National Agreement for Closing the Gap to support achievement of the priority reform regarding community controlled delivery within the disability sector.<sup>213</sup> It also tells governments how they should engage with and respond to the needs of First Nations people with disability. Designing and rolling out alternative commissioning approaches should be no exception.

#### The Panel's vision

## Working in partnership, local communities and governments should design what alternative commissioning looks like

Ongoing on-the-ground partnerships with First Nations representatives, communities and participants is key. When place-based and driven by communities, alternative commissioning arrangements would mean:

- First Nations communities would have more access to culturally safe supports, even in towns and cities. They would choose and control how disability services work for their community.
- All people in remote communities would access more supports where they live.
   More supports would be delivered by people who are part of their community instead of having to rely on people who travel in and out of the community.

This roll out should start as soon as possible with interested communities. It should enable communities and governments to:

- build skills and confidence to design and roll out alternative commissioning approaches
- learn what approaches and options would work best
- understand how joining up different supports such as, foundational supports, navigation supports or aged care — might work best for different communities.

Design and roll out of alternative commissioning approaches should be done in full and genuine partnership with communities, and should build on the strengths and capabilities already in communities. Governments should ensure they meet their commitments under the National Agreement on Closing the Gap when working in partnership with communities. When place-based and led by communities, these approaches can contribute to Closing the Gap by strengthening the community-controlled sector and creating a more sustainable, localised workforce.

These principles, practices and outcomes would come together in an 'alternative commissioning cycle'.

#### Figure 12

#### Alternative commissioning cycle

#### Monitor, evaluate and improve

using a **practical and community-driven approach**, considering Indigenous data sovereignty, with best practice Indigenous evaluation and inclusion in the National Disability Data Asset (NDDA).

#### **Understand community needs**

through strengths-based assessment and analysis of community's needs.

#### Implement approach

through culturally appropriate, relational approaches to commissioning and contracting fit for purpose enablers, such as:

- Access points and pathways into services
- Regulation, workforce and infrastructure
- Funding arrangements and assistance with coordinating and navigating supports

#### **Explore and design solutions**

including how community and NDIA decides if, and what, alternative commissioning approaches are needed.

Examples of alternative commissioning approaches

- Direct commissioning
- Community commissioning
- Integrated commissioning

**Effective governance is required for alternative commissioning to succeed.** In First Nations communities this includes:

- Share decision-making with First Nations communities.
- Community-led design and implementation that builds on the communities strengths and addresses unmet needs
- Sustainable and embedded place-based governance arrangements.
- Accountability to national, overarching governance structures (see Action 21.3).

#### Recommendation 14

Improve access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements

\*Legislative change required

#### Action 14.1

The National Disability Insurance Agency, in partnership with First Nations representatives, communities, participants and relevant government agencies should progressively roll-out alternative commissioning arrangements for both First Nations communities and remote communities, starting as soon as possible.

The alternative commissioning approaches should be designed in partnership with First Nations representatives, communities and participants, and should be underpinned by governance structures that share decision-making power with communities (see Action 2.10), including First Nations representatives in non-remote communities as well as remote community representatives (which also encompasses the non-Indigenous local population). Alternative commissioning approaches should be based on a commissioning cycle that:

- Is underpinned by an understanding of, and builds on, community strengths and preferences
- Explores and designs commissioning approaches on a case-by-case basis
  with communities. This could include models of direct and community-led
  commissioning approaches as well as integrated commissioning (where a
  provider is commissioned to provide supports across multiple service types)
- Provides culturally appropriate, outcome-based commissioning processes, and
- Uses practical and community-driven processes to collect data and evaluate outcomes.

# A responsive workforce that delivers quality supports

#### Workforce challenges are well known and widespread

In 2021-22 there were around 325,000 workers supporting NDIS participants, their families and carers.<sup>214</sup> The supports these workers provide are essential for people with disability to live their lives.

Participants, families and carers told us of the difference good support workers can make in their lives.

"I have been linked with the most amazing support workers. People who work for me in their own time to fill the many, many gaps left by an inadequate plan. if it were not for the wonderful humans who support me so well, I guarantee you I would have checked out."

– Participant <sup>215</sup>

As the NDIS grows, more workers will be needed to support people with disability. About 128,000 more workers are likely to be needed by June 2025 to fully meet demand. But service providers, participants, families and carers told us that finding and keeping disability workers with the right skills, values and attitudes is already hard today.<sup>216</sup>

"Finding good support workers has been very difficult for us. I have often gone unsupported due to [being] unable to find good workers for our daughter."

- Carer 217

The disability sector is also trying to build its workforce at the same time as there is strong demand for new workers right across the care and support sector.

#### Figure 13

The NDIS workforce is diverse, covering disability support workers, allied health workers and other workers working across a variety of settings<sup>218</sup>

# Disability support workers 280,000 workers in 2021-22 385,000 workers needed by June 2025 8 in 10 work part-time 7 in 10 are female 6 in 10 aged 44 or under

#### Allied health workers

**36,000** workers in 2021-22

**51,000 workers** required to fully meet demand by June 2025

This group includes both allied health professionals and allied health assistants. In the year to 20 September 2022, allied health services accounted for around 13% of NDIS payments.

#### Across the broader care and support workforce



4 in 5 hold a Certificate III qualification or higher, compared with 66% of the broader labour market. Enrolments in relevant VET qualifications increased by around 6.5% between 2015 and 2019, however, completions declined by 4.6%.



Almost **4 in 10 were born overseas**, compared to 32% of the overall workforce.

#### Other workers

**9,000 workers** in 2021-22 **17,000 workers** required to fully

meet demand by June 2025

These workers provide a diverse range of supports and include, for example, support coordinators, interpreters, gardeners and cleaners.

#### **Emerging platform workers**



The number of workers supporting NDIS participants through online platforms is small, but growing.

In 2021-22, around 16,000 NDIS agency and plan managed participants had used a platform provider.

#### **Informal carers**

In 2018, there were an estimated 2.65 million informal carers of people with disability and older people.

Around 1 in 3 (861,000) were primary carers.\*

In 2020, it was estimated that informal carers delivered nearly **2.2 billion hours of care** which would cost **\$77.9 billion** if delivered by formal carers (i.e. paid workers).

\*Primary carer refers to someone who supports a person of any age with a disability. Informal carers includes those who support people of all ages with disability and older people (aged 65 years and over) without disability.

Despite strong workforce growth since the NDIS commenced, large and persistent workforce shortages remain in the NDIS under current policy settings. This limits access to suitable supports for some participants and places pressure on existing workers, particularly in regional and remote areas and for some participant groups.

We've heard that many NDIS workers are feeling burnt out. A recent workforce retention survey found more than two in five (43 per cent) of NDIS workers felt burned out at least half the time in their job.<sup>219</sup>

Jobs can be short term with poor conditions and many workers aren't staying. Each year, indicatively between 17 per cent and 25 per cent of NDIS workers leave their job. Unless this high level of turnover can be addressed, between 198,000 and 292,000 NDIS workers are expected to leave their job in the three years to June 2025.<sup>220</sup>

Many workers say they can't access the training they need and some feel they have limited career opportunities.

"There is a vicious cycle in this sector. People want to make a career as a disability worker. They know that they need to be trained to do the sort of specialised work that is needed. They want to do that training.

But they cannot do it [training] because they are employed only on a casual basis with short contracts and so must work for several organisations just to make ends meet. This means that they cannot refuse a shift because they cannot risk losing that job. If they cannot get time off, they cannot do training. If they do not do training, they cannot get more shifts - because they do not have the specialised training needed for the work.

How do they win?"

- Disability Support Worker, quoted in Australian Services Union<sup>221</sup>

Some workers report not getting enough supervision.

"Supervision is few and far between, that's if it does happen.

We aren't debriefed after extreme major incidents. We're constantly questioned about doing overtime when we're understaffed. We haven't had a staff meeting since 2022."

- Disability Support Worker, quoted in Health Services Union<sup>222</sup>

We also know that three out of four NDIS workers are employed either part-time or casually. Workers with disability — or 'peer workers' — are not well represented in the NDIS workforce. The operationalisation of worker screening can also create barriers to workers joining the NDIS workforce (see Recommendation 17).

Many of the challenges facing NDIS workers are similar for those working in aged care and veterans' care. Some NDIS workers also work across these two other areas. When we talk about these sectors together, we call this the 'care and support sector'.

The care and support sector is also growing. By 2049-50, almost one in 20 jobs in Australia are expected to be in the care and support sector.<sup>223</sup>

But we've also heard that if things don't change there won't be enough workers to provide the care and support all Australians need.

Past reviews looked at ways to grow and sustain the workforce for disability, aged care and veterans' care services. However, they have often not looked at the care and support sector as a whole. Past workforce strategies have also lacked performance measures, making it difficult to tell if government actions have had any impact.

"While monitoring and evaluation of the [NDIS Workforce] plan is expected throughout its life, the plan itself does not set out measurable outcomes that might be used to assess whether the plan is effective in supporting sustainable growth in the NDIS workforce. ... The committee therefore remains concerned that, without adequate attention from the Commonwealth Government in this plan, many of the issues experienced by the NDIS workforce ... will continue to persist."

- Joint Standing Committee on the National Disability
Insurance Scheme <sup>224</sup>

Meeting future needs will need joint and ongoing action across the care and support sector.

#### The Panel's vision

# New ways to attract, keep and train workers across the care and support sector to ensure a capable and sufficient disability workforce

To meet the future needs of the disability sector — the NDIS and foundational supports — we need to look at new ways to attract, keep and train workers across the care and support sector.

Most care and support workers do not work in traditional full-time jobs. Many work more than one job. For these workers, training and other systems are not always helping them to build their skills and careers. Employers are not encouraged to invest in training these workers.

One way to change this is to put in place new ways for workers to build up training and leave balances across the care and support sector. We call this 'portable' leave or training, when it is recognised across the care and support sector and not just with a single employer. Making it easier for workers to move across the care and support sector can open up more career options and encourage them to stay in the sector.

High turnover not only lowers the quality of supports but also increases the cost of delivering supports. The Australian Services Union highlighted two case studies where service providers estimated the direct costs of on-boarding a new disability support worker was between \$2,130 and \$3,320, with one provider noting that "it generally takes a full month of working before they reach acceptable competence." Improving worker retention and helping workers to build their skills in the sector would, therefore, improve outcomes for participants and reduce pressure on scheme sustainability.

There may also be ways to better use technology to upskill workers. For example, in remote communities where providers do not currently have access to relevant technology, such as telehealth, alternative commissioning approaches (see Recommendation 14) could look at ways to invest in training and equipment that can be used by the whole community.

In remote communities there are also opportunities to leverage off changes to other government programs, such as the Community Development Program.

More generally, initiatives to improve workforce training in the care and support sector should be complemented by other government training initiatives, including the progression of micro-credentials (short courses or competencies), a digital skills passport and growing the use of traineeships.

#### More focus on peer workers will improve the quality of support provided

Governments also need to recognise the critical role of peer workers — and do more to build the number of peer workers in the disability sector. This will not only improve outcomes for people with disability but also improve the quality of support provided.

There is much the disability sector could and should learn from the mental health sector, where peer workers are much more widespread. Any barriers to the employment of peer workers with disability should be considered as part of a future joint action plan for disability employment (see Action 1.7).

Building the peer workforce should start with increased support for individual and family capacity building being delivered by peer workers as part of the increased investment in foundational supports (see Recommendation 1).

#### Overseas workers can be part of the solution to acute workforce shortages

Together with action to better attract, keep and train workers, migration can help fill short-term acute workforce gaps. But it can be hard for some overseas care and support workers to come to Australia.

More targeted and flexible approaches to attract overseas workers across the care and support sector should be explored. Importantly, these approaches should not replace efforts to invest in building a sustainable local workforce.

#### Governments need to get better at planning for future workforce needs

This would help governments to better understand current gaps and to better plan for future workforce needs. Ongoing timely and reliable forecasts are needed.

Governments need to work together to better identify and address workforce issues and drive continuous improvement. They also need to be accountable for their plans and actions.

## Complementary reforms to scheme rules and procedures will support a responsive and capable workforce

How, and how much, providers are paid has important flow on effects for attracting and retaining a quality workforce.

Some providers argue they are unable to invest in the capability of their workforce under current pricing arrangements. This exacerbates workforce retention challenges. Uncertainty in participant demand, at least throughout scheme transition, may have contributed to a greater use of casual work in the scheme. Casualisation increased from 36 per cent of all NDIS workers in 2016 to a high of 40 per cent in 2019.

Reform to the pricing and payment regulatory framework would help ensure that the cost of maintaining a capable workforce, with appropriate supervision, is well captured in future price caps. This includes:

- shifts to more transparent processes for setting price caps that reflect the market price for delivering supports (including any costs associated with regulation) with more robust information on the actual cost of delivering support and how much participants are being charged
- price caps that better reflect differences in the costs including, where appropriate, the cost of higher skilled workers delivering supports to participants with more complex needs or in higher cost locations
- shifting away from fee-for-service to other payment models that better focus providers on outcomes rather than outputs (see Recommendation 11). Under the proposed enrolment payment approach for 24/7 shared living supports, providers would have greater stability of funding, supporting a more stable workforce that is familiar with the needs and preferences of the people they support. This flexibility would support investment in improved quality of life and productivity enhancing equipment.

Improved worker screening requirements and minimum online training would also ensure workers understand their obligations and do not pose an unacceptable risk of harm to participants. This should not result in an undue burden on workers. Early in the Review we recommended practical reforms to make worker screening faster, smoother and better harmonised across sectors and jurisdictions (see Action 17.4). Longer term, workers could potentially showcase their skills and qualifications through the worker screening database.

These reforms combined with reforms to focus on continuous quality improvement and information on provider performance (see Recommendation 12), would encourage providers to maintain a workforce capable of delivering safe and quality supports. Participants would benefit from improved access to quality supports.

More broadly, a focus on early intervention supports (see Action 3.7) and improved uptake in assistive technology and home modification supports (including home modifications for participants living in social housing, see Recommendation 9) would support participants to be more connected to their community and safer, and also reduce reliance on ongoing formal supports delivered by workers. This in turn would reduce future workforce pressure in the scheme. The preliminary results of a recent study of 15 people with disability with complex support needs, for example, found that after 6 to 24 months of living in Specialist Disability Accommodation with appropriate assistive technology, there was an average decrease of 2.4 support hours per participant per day 6 to 24 months following their move to the new arrangements.<sup>227</sup>

#### Recommendation 15

## Attract, retain and train a workforce that is responsive to participant needs and delivers quality supports

\*Legislative change required

#### Action 15.1

## The <u>Australian Government</u> should design and trial workforce attraction and retention initiatives.

The Australian Government should work with state and territory governments to design and trial initiatives for the care and support sector to better understand what works. These initiatives should include designing and trialling a portable training scheme and a portable sick and carer's leave scheme, in close consultation with unions, disability and other care and support workers, employers and participants/clients. The trial of the portable training scheme should commence urgently and could initially focus on disability support workers. Both trials should give consideration to the system infrastructure, eligibility criteria and funding approach that would ensure benefits exceed costs and the scheme would be widely adopted. Complementary initiatives — to develop micro credentials, a digital skills passport (potentially through the worker screening database, see *Action 17.4*) and support to grow the use of traineeships for entry-level workers — that have already been agreed for the NDIS should be progressed as a priority across the care and support sector.

#### Action 15.2

## The <u>Australian Government</u> should develop targeted and flexible migration pathways for care and support workers.

Skilled migration programs should be complemented by more specific, targeted and flexible measures to encourage migration of care and support workers. Government should consider implementing an industry labour agreement targeted at workers who would not otherwise qualify for skilled migration. The agreement should be developed in consultation with industry, relevant employer associations and unions.

#### Recommendation 15

#### Action 15.3

The <u>Australian Government</u> should develop an integrated approach to workforce development for the care and support sector.

An ongoing governance function should be established to coordinate workforce planning and ensure the development of a sustainable care and support workforce. This function should work across the Australian Government and state and territory governments and have responsibility for:

- developing and overseeing a data strategy which incorporates data collection and demand and supply projections (which should be shared with industry to support providers, training organisations and workers to be responsive to changing market conditions)
- identifying workforce gaps and work across governments to develop targeted policy responses
- monitoring and evaluating actions and disseminating ongoing learnings.

# Safeguarding that is empowering and tailored to individuals, their service needs and environments

#### Role clarity and coordination in the safeguarding system is poor

The National Disability Insurance Agency (NDIA) and the NDIS Quality and Safeguards Commission (NDIS Commission) both have responsibilities to participants, including helping them take appropriate risks and supporting them with effective safeguards. Both agencies have developed a range of strategies, policies and approaches to support participants and meet Australia's international obligations. Among these are the NDIA's recent Participant Safeguarding and Supported Decision-Making Policies, and a joint approach to identifying and supporting participants at risk.<sup>228</sup>

Nevertheless, poor coordination has resulted in both overlapping initiatives and gaps. Each agency has tended to focus on what it can do, instead of considering how the system as a whole can better support participants. As a result, it is not always clear what options participants have to seek support, and who is best placed to provide that support.

"Many roles under the NDIS can be confusing for participants, supporters and providers alike. For instance, the difference between the roles and functions of the National Disability Insurance Agency (NDIA) and the NDIS Commission is not well understood."

- People with Disability Australia<sup>229</sup>

The development of the 2016 NDIS Quality and Safeguarding Framework (the Framework) was intended to provide an overarching strategy and clear roles for safeguarding across the NDIS.<sup>230</sup> It envisioned that government agencies, providers, workers and natural supports (such as families, carers and communities) would provide a range of safeguards.

Safeguards are "actions designed to protect the rights of people to be safe from the risk of harm, abuse and neglect, while maximising the choice and control they have over their lives". Safeguards can be formal (rules and actions taken by organisations with formal responsibility for the safety of people with disability) and natural (features of people's day to day lives, like support from friends and family). The Framework envisioned three categories of safeguards:

 Developmental safeguards: Measures that strengthen the capability of people with disability, their families and supporters, workers and providers to reduce the risk of harm and promote quality (for example, education, training and information).

- Preventative safeguards: Measures that proactively regulate providers and workers to reduce the risk of harm and promote quality (for example, provider registration and worker screening).
- Corrective safeguards: Measures that resolve problems, enable improvements to be identified and avoid the same problems recurring (for example, complaints processes and compliance actions).

However, the Framework has not successfully promoted coordination amongst the multiple agencies and governments involved in the NDIS and their respective policies and initiatives, as well as the wider ecosystem of safeguarding initiatives. We have heard participants continue to struggle to identify the best service or agency to help them with the risks they face. The Framework also focuses on quality and safeguarding for NDIS supports without addressing the broader disability support ecosystem. It was also developed to cover the period of transition to the full NDIS and so is out of date.

# Current approaches to safeguarding do not effectively engage with participants to understand and address the risks they face

Risk and safety look different for everyone, and safeguarding must be tailored to the individual to be most effective. We have found that NDIS agencies do not always do enough to recognise the different ways people experience and engage with risks or effectively engage with participants about their experiences and needs. Further, sometimes participants may experience risks that are not well recognised by NDIS agencies as a risk to their safety, like the sudden absence of suitable services for participants to use to meet their day to day needs.

The NDIS has a range of mechanisms in place to monitor and respond to the safeguarding needs of participants. These mechanisms include the NDIA's participant risk assessment, NDIA check-in calls with participants; the NDIS Commission's complaints and investigation processes; information sharing between agencies, including state and territory agencies involved in safeguarding; and protocols developed in response to the Robertson Review into the circumstances relating to the death of Ms Ann-Marie Smith.<sup>233</sup>

These mechanisms are typically reactive, relying on participants and supporters raising issues. We have also heard participants are often unaware of risk assessment processes or have found the risk assessment and check-in calls confronting.<sup>234</sup>

"It is not up to individuals and their supports to enforce those safeguards.

Despite all those supposedly existing safeguards, people like me are experiencing poor quality and unsafe services. And I worry a lot about what people with higher needs, not able to communicate for themselves, etc are experiencing."

- Participant <sup>235</sup>

## Options to support and build capacity for participants to manage risk are limited

A range of safeguards are available to participants in their own communities as well as through the NDIS Commission and other government agencies. However, they often do not address the specific problems or risks participants may face when accessing supports, and do not do enough to build their capacity and natural safeguards to manage risks. For example, previous reports describing these issues have highlighted the complexity of existing safeguards and the need for more support for participants to build connections in their community. <sup>236</sup>

Given the majority of adult participants in the NDIS have a cognitive disability, many would benefit from support for decision-making. In addition, 50 per cent of participants are children and may require additional support, especially as they move through the adolescent years towards adulthood.<sup>237</sup>

To meet these needs, the NDIS must offer a range of capacity building safeguards to support participants to make decisions and manage risks. The Framework envisioned a mix of developmental, preventative and corrective safeguards. However, in the rush to roll out the NDIS, the focus has almost exclusively been on regulatory arrangements — and there has been insufficient attention given to developmental supports such as capacity building and support to strengthen natural safeguards. As a result, these supports have been slow to emerge.<sup>238</sup>

"Information about people's rights and entitlements, skills and confidence in advocating need to be considered as life skills. For some people support in exercising choice and decision is also essential, as are building the capacity of carers, families and friends, and supporting people".

- Participant<sup>239</sup>

# States and territories have an important role to play in safeguarding, but their services are inconsistent and their role in the NDIS is unclear

The NDIS is not the only context in which people with disability may experience risk, or the only opportunity to support people in managing risk. Existing state and territory programs can help people experiencing higher risks get the support they need but are not nationally consistent or well-integrated with the NDIS.

Community Visitor Schemes (CVS) offer proactive, outreach-based safeguarding focused on supporting the wellbeing and upholding the rights of people with disability. However, inconsistent arrangements across the country cause confusion and gaps in support for participants, with only six states and territories delivering CVS that provide outreach to people with disability.<sup>240</sup> The legislation for some CVS has not been updated to allow visits to sites in which disability supports are now more commonly delivered, such as home and community settings.<sup>241</sup> It is also sometimes unclear what distinct role CVS play relative to the role of the NDIS Commission.<sup>242</sup> There have also been reports of difficulties for CVS in collaborating with the NDIS Commission and identifying all of the participants whom they should be visiting, because of incomplete information sharing. This has limited their ability to effectively identify and respond to issues for participants.<sup>243</sup>

Adult Safeguarding Agencies (ASAs), as recommended by the Australian Law Reform Commission, are an emerging service offering that can deliver holistic, person-centred support for safety across programs and service systems (comparable to existing child protection systems).<sup>244</sup> States and territories are at various stages in developing ASAs, with New South Wales and South Australia the furthest progressed towards implementing them.<sup>245</sup> However, even in these jurisdictions, their roles, responsibilities and authority in the context of the NDIS remain unclear.

#### The Panel's vision

Safeguarding in the disability ecosystem – the NDIS and foundational supports – should be more complete, personalised and tailored to the different needs of people with disability and their supporters

A joined-up safeguarding system, in which information is shared on a timely basis, should ensure bad outcomes are prevented and participants are actively supported to make decisions about what they need to be safe, manage risks and achieve good outcomes.

The NDIA, along with other government and non-government actors, should take an individualised and participant-led approach to assessing and responding to risk. Based on this, participants should have access to a suite of general and targeted safeguards to support them to manage the risks they face and build their capacity. For example, this should include improved accessible information resources about risk, safety and quality supports, developed by the new National Disability Supports Quality and Safeguards Commission (National Disability Supports Commission); and support to access organisations that help build community connections such as circles of support and Microboards. Navigators should help connect participants to access such programs. Where appropriate, payment may be through funding in individual reasonable and necessary budgets.

Governments should take a more coordinated and collaborative approach to safeguarding. This should be described in a clear strategy that defines and holds governments to account for their responsibilities. As part of this, state and territory governments should step up their efforts to support people with disability at risk of harm through CVS and ASAs. Information between these agencies and the National Disability Supports Commission should flow seamlessly, so they can prioritise the safeguarding of people with disability.

This more personalised and coordinated approach to safeguarding would better support people with disability to be safe and manage any risks or challenges they face, both inside and outside of the NDIS.

#### Recommendation 16

## Deliver safeguarding that is empowering and tailored to individuals, their service needs and environments

\*Legislative change required

#### Action 16.1

The <u>Disability Reform Ministerial Council</u> should agree a Disability Support Ecosystem Safeguarding Strategy to coordinate activities to support the safeguarding of people with disability.

This should ensure clarity about strategy, coordination and responsibilities across government agencies, and connections with broader safeguarding arrangements (see Actions 16.4. and 16.5). It should sit under the new Disability Supports Quality and Safeguarding Framework (see Action 19.1) and operationalise a more coordinated approach to safeguarding across the disability support ecosystem (including foundational supports), with strong connections to safeguarding in and regulators of mainstream services.

#### Action 16.2\*

The <u>National Disability Insurance Agency</u> should design, pilot and implement a new individual risk assessment and safeguard building process.

This process should be participant-led and focus on their strengths and ways in which their capacity can be built. It should be integrated into needs assessment processes to more consistently determine a level of need for each participant (see Action 3.4). This process should connect participants (with the help of Navigators) to a range of individualised safeguards (see Action 16.3) including support for decision-making (see Action 5.3), funded through both foundational supports and individual reasonable and necessary budgets. This process could also address the potential need for a Behaviour Support Plan (see Action 18.2). The process should be designed with participants and families through the NDIS Experience Design Office (see Action 24.3) as part of reforms to the broader participant pathway (see Recommendation 3).

#### Action 16.3

The <u>Department of Social Services</u>, working with the National Disability Insurance Agency, the new National Disability Supports Quality and Safeguards Commission and other agencies where relevant, should ensure participants can consider and access a wider range of safeguarding supports.

Safeguards offered should include a range of developmental, preventative and corrective safeguards. Safeguards should prioritise capacity building, natural safeguards and community connections where possible, with more intensive support for participants facing higher risks. Safeguards should be funded through

both foundational supports and individual reasonable and necessary budgets, depending on the level of need for different safeguards and optimal arrangements for ensuring access.

#### Action 16.4\*

<u>State and territory governments</u>, with support from the Department of Social Services, should ensure participants can access high-quality, nationally consistent Community Visitor Scheme offerings that interface with the NDIS.

State and territory-operated schemes should be focused on supporting the wellbeing of the people they visit, including developing capacity and supporting individuals to manage risks, raise issues and resolve problems. Community Visitor Schemes should also play an enhanced role in sharing insights with regulators to support regulatory activity. State and territory roles should be supported by the Department of Social Services through a new National Community of Practice, with leadership from the new National Disability Supports Quality and Safeguards Commission on relevant operational reforms, including improved information sharing protocols.

#### Action 16.5\*

<u>State and territory governments</u> should establish or improve adult safeguarding agencies to deliver a universal service offering for the safeguarding of all people at risk of harm, including people with disability.

Adult safeguarding agencies (as recommended by the Australian Law Reform Commission and complementary to established child protection agencies) should provide holistic, person-centred safeguarding for anyone who needs them and a one-stop-shop to raise concerns about risks of harm. These agencies should work closely with and complement disability support ecosystem safeguarding bodies through information sharing and collaboration. These agencies should address the need for support across different service systems and with a variety of different risks, within and outside the NDIS. This should include establishing a single national phone number for raising concerns regarding the safety of a person with disability at risk of harm and taking a 'no wrong door' approach on safeguarding issues.

# A new risk-proportionate model for regulation of providers and workers

## There are gaps in oversight of providers, particularly when delivering high-risk supports

In the NDIS, the registration process aims to ensure that providers and their workers are reputable and have the skills and knowledge to deliver supports. While registration is not a guarantee of either safety or quality, it ensures visibility and does indicate a provider has taken steps to deliver supports professionally and competently, and is an important way of holding providers to account.

However, most providers can opt-out of registration. Registration is only mandatory for a limited number of high-risk support types, and the market of unregistered providers is larger than originally expected. This growth in unregistered providers has been driven by a large number of self-managing and plan-managing participants — 29 per cent of participants self-manage all or part of their plan and around 60 per cent use a Plan Manager, and both can access unregistered providers. <sup>246</sup> Similarly, the ability to access unregistered providers has driven demand for self-management and plan-management.

In April to June of 2022-23, over 154,000 unregistered providers received a payment from a Plan Manager.<sup>247</sup> This compares to a total of around 16,000 registered providers currently in the market.<sup>248</sup> The total number of unregistered providers is even higher. Limited visibility of payments made by self-managing participants to unregistered providers (including who payments are made to and for what purpose) means the total number of unregistered providers is actually unknown.

"[Unregistered] providers do not have to show compliance with NDIS safety, quality and workforce regulations. The lack of transparent control on quality standards and supervision would cause harm to NDIS participants...the lack of registration means there would be operations with unregulated quality standards, unaccountable operators, and little visibility on who receives payments, opening the door to fraud and scams as well as risks of violence, abuse, neglect and exploitation."

Unregistered providers are not required to meet any specific standards beyond the basic expectations in the NDIS Code of Conduct, which describes broad community

- NDIS provider <sup>249</sup>

expectations of expected behaviours for providers and workers involved in support delivery.<sup>250</sup> This means that there are many providers 'flying below the radar' with limited regulatory oversight. This leaves participants potentially exposed to risk — particularly those who have complex needs or circumstances.

Some participants may not fully understand the risks they are engaging with, how to manage them or what their rights are, or may have more limited capacity to advocate for themselves. This is a particular concern for the majority of adult participants who have a cognitive disability. Many would benefit from support for decision-making, as would the around 50 per cent of participants aged 18 years or below who may require additional support, especially as they move through the adolescent years towards adulthood.<sup>251</sup>

The NDIS Quality and Safeguards Commission (NDIS Commission) does not have visibility of the significant unregistered provider market. This means the NDIS Commission cannot effectively monitor the market or proactively intervene to prevent harm and promote quality improvement, and has fewer options for taking action against providers if something goes wrong.

## There are also excessive and duplicative regulatory burdens for providers delivering lower risk supports

Registration was designed to be proportionate to the risk and complexity of different support types and providers.<sup>252</sup> This is reflected in the NDIS Practice Standards for providers and varying intensity of compliance auditing.

However, the application of proportionality in registration is variable. The scope, coverage and intensity of standards and audits are not necessarily linked to a provider's size or the risk and complexity of support delivery.

"We ... recently underwent a mid-term audit even though the previous re-registration audit showed no corrective actions were required...

The audit and registration process does not seem to include assessment

of the relative risks for different service delivery types".

- SDN Children's Services <sup>253</sup>

"As a small, independent business offering Support Coordination only, we are unfairly burdened by being treated the same as a large organisation/business offering multiple supports."

- Provider <sup>254</sup>

NDIS providers who work across the wider care and support sector have expressed particular concerns about undue regulatory burdens. Meeting requirements across the wider sector can be duplicative and costly for providers. We have heard of specific issues, including overlap with Aged Care Quality and Safety Commission standards, National Regulatory System for Community Housing reporting requirements, Australian Health Practitioner Regulation Agency requirements and some Australian Commission on Safety and Quality in Health Care standards.

"For some providers, the absence of NDIS registration doesn't mean absence of regulation."

- Australian Physiotherapy Association <sup>255</sup>

There is also a lack of clarity about the expectations and obligations of providers. The NDIS Practice Standards set expectations for providers on their role and outcomes, in addition to supporting participants to understand what they can expect from providers. However, there are a range of support types that do not have specific NDIS Practice Standards, including current Support Coordination and the proposed Navigator function, and Supported Independent Living or 24/7 living supports. The Practice Standards have also not been updated to reflect new supports and delivery models.

"Greater clarity is required on the roles and responsibilities of all the key actors including that of intermediaries (e.g. Support Coordinator) and the wider community."

- Life Without Barriers<sup>256</sup>

# Worker screening is not consistently ensuring the NDIS workforce has the skills and knowledge to deliver safe and quality supports

Workers are critical to safety and quality, yet there are limited preventative safeguards that apply to all NDIS workers. Worker screening can help identify workers who may pose unacceptable risks to participants. However, its effectiveness is limited by only being mandatory for those working for registered providers.

We have heard of instances of workers — who may otherwise be considered to pose an unacceptable risk of harm to people with disability and therefore be excluded from an NDIS Worker Screening Check — establishing themselves as unregistered providers or working for unregistered providers to avoid NDIS worker screening requirements.

"There is no governance or accountability over independent (non-registered) workers... How can the government allow untrained workers to be able to manipulate and work within a system where there is no accountability for them — unless they are caught doing something against the code of conduct — so we then have to wait till a PWD is either taken advantage of, abused, neglected and worse case die before action is taken."

- Provider<sup>257</sup>

Unregistered providers can opt-in for worker screening, and self-managing and plan-managing participants can request their workers undergo worker screening. Despite this, only 6,467 of more than 154,000 unregistered providers have any workers with an NDIS Worker Screening Check as of 30 June 2023.<sup>258</sup>

Worker screening is not sufficient to guarantee all NDIS workers can deliver safe and quality supports. We have heard concerns about whether workers have the necessary skills, competencies and qualifications.

"Currently the role of a support worker/support coordinator does not require anyone to have previous experience, education or training."

- Provider <sup>259</sup>

Worker screening is also inconsistently operationalised across states and territories, can be a slow process, and can be duplicative with other worker screening requirements. Taken together, this can lead to delays for employers in sourcing workers, including creating barriers for workers from other sectors to join the NDIS workforce.

#### Regulatory settings have not reflected changes in the market

Regulatory settings have not been updated to reflect changes in the market, including the introduction of new supports such as platform providers. This has caused uncertainty for providers and workers about what they are expected to do, and how to comply with requirements or manage issues as they arise. This can impact the safety and quality of supports that participants receive, and also acts as a barrier to innovation.

A number of long-standing and emerging quality and safeguards issues would benefit from a more active approach by the NDIS Commission. This includes issues related to conflicts of interest and client capture, sharp practices (including unfair service agreements), transparency and duties of care.

#### The Panel's vision

#### A more graduated and risk-proportionate regulatory model will better prevent harm while continuing to support choice and control and enable a thriving market

We recognise choice and control as a central principle of the NDIS and that the safety of people with disability is paramount. Currently regulatory and registration requirements are largely determined by the way in which a plan is financially managed, which is leading to high-risk supports being delivered with little regulatory oversight. A better balance is required to ensure the effective prevention of harm, while also supporting people with disability to purchase supports of their choosing and have control over the way in which these supports are delivered. We are proposing greater use of preventative measures applied to all providers and participants to make the system work better for everyone and prevent harm to those most at risk. We need to strike a better balance between preventing harm, supporting choice and control, encouraging innovation and enabling the market to thrive.

To prevent harm and better ensure the delivery of safe and quality supports, the new National Disability Supports Quality and Safeguards Commission (National Disability Supports Commission) should apply a risk-proportionate and graduated approach to the regulation of the whole provider market, including foundational supports. This would ensure the National Disability Supports Commission can be more proactive in preventing harm, while also supporting efforts to strengthen scheme integrity.

Our proposed model (*Figure 14*) for the regulation of providers is based around four broad categories related to the risk associated with different types of supports and providers, with corresponding mandatory registration or enrolment requirements:

- Advanced registration for all high-risk supports, applying more intensive regulatory requirements and oversight where supports may pose an inherently high-risk or require high-level technical competence.
  - For example: Supports delivered in high-risk settings, such as daily living supports delivered in formal closed settings like group homes.
- General registration for all medium-risk supports, applying graduated approaches to regulatory requirements and oversight, depending on factors impacting the level of risk.
  - For example: High intensity supports (such as high intensity daily personal activities), supports that require additional skill and training (such as complex bowel care or injections), and supports involving significant 1:1 contact with people with disability.
- Basic registration for all lower-risk supports, applying lighter-touch registration requirements, while still allowing for regulatory oversight against Practice Standards, when required.

- For example: Sole traders and smaller organisations, supports such as social and community participation, and supports involving more limited 1:1 contact with people with disability.
- Enrolment of all providers of lowest-risk supports, providing full visibility of the market and applying lightest-touch requirements through a simple online process.
  - For example: Supports where general protections available under Australian Consumer Law are sufficient, such as consumables, equipment, technology, and home and vehicle modifications.

This approach to preventing harm should promote safe and effective support delivery, without imposing undue barriers, burdens or duplication. Providers should be required to meet requirements that are commensurate to the risk of their activities and operations. These processes should be integrated with other government systems and recognise similar compliance of providers operating in other parts of the care and support sector. This will guard against regulatory creep, ensure proportionality, and minimise unnecessary burdens.

A critical component of this model is ensuring registration requirements and processes are proportionate to the risk and complexity of a provider's activities and operations. This is necessary to address existing issues of burden and duplication, and ensure that the right balance is struck between appropriate regulation to prevent harm without imposing excessive burdens and costs on the market. Proportionality and streamlining could be introduced through simplifying Practice Standards where possible, recognising compliance in other similar regulatory systems (such as aged care), using risk-based auditing and assessment approaches (with a combination of observational audits, desktop audits and self-assessments), and targeting the scope of audits on the most relevant and important issues.

In addition, minimum safeguards through broader requirements for worker screening and basic online training are required to ensure workers understand their obligations and do not pose an unacceptable risk of harm to people with disability. Worker screening should also be faster, smoother and better harmonised across systems and jurisdictions.

In its regulation of providers and workers, the new National Disability Supports
Commission should be more proactive, responsive to change, engage with innovation
in the market and address quality and safeguards issues as they emerge. As an
immediate priority, efforts should be focused on communicating expectations and
taking appropriate compliance action in relation to conflicts of interest and client
capture, sharp practices and service agreements, transparency and open disclosure,
and duties of care. The new National Disability Supports Commission should
also proactively engage with innovative providers, for example through trialling
collaborative models to observe and consider the regulatory approach for innovative
support types or delivery models.

Figure 14

Graduated and risk-proportionate provider registration and enrolment

	<b>A. Advanced registration</b> In-depth registration for high-risk supports	<b>B. General</b> registration Graduated registration for medium-risk supports	C. Basic registration Light-touch registration for lower-risk supports	<b>D. Enrolment</b> Basic visibility and requirements for lowest-ris supports
Code of Conduct	YES	YES	YES	YES
Worker screening (Action 17.4)	YES  Workers in risk-assessed roles.	YES  Workers in risk-assessed roles.	YES  Workers in risk-assessed roles.	YES  Workers directly delivering specified supports or services, or who have more than incidental contact with people with disability.
Subject to complaints process	YES	YES	YES	YES
Report incidents	YES	YES	YES	NO
Practice Standards	YES  General standards and support-specific standards for all support types.	YES  General standards for all support types and support-specific standards where needed.	YES  • Simplified general standards for all support types.	NO
Performance measurement (Action 12.3)	YES	YES	YES	NO
Processes				
Application, identity verification and	and 10.3) to provide the NDIA and new data on payments. Application form collects bas details, support types delivered). Business identity is verified le	plication form, integrated with cer National Disability Supports Qual ic information (e.g. business name everaging existing government sys ding obligations under code of co	ity and Safeguards Commission ve, ABN or Digital ID, bank account	with visibility of all providers and the details, location, contact around the details.
Application, identity verification and Code of Coduct and worker screening	Provider completes online ap and 10.3) to provide the NDIA and new data on payments. Application form collects bas details, support types delivered). Business identity is verified le	National Disability Supports Qualic information (e.g. business name	ity and Safeguards Commission ve, ABN or Digital ID, bank account	with visibility of all providers and the details, location, contact around the details.
Application, identity verification and Code of Coduct and worker screening attestation	Provider completes online ap and 10.3) to provide the NDIA and new data on payments.     Application form collects bas details, support types delivered).     Business identity is verified le	National Disability Supports Qualic information (e.g. business name everaging existing government systims obligations under code of co	ity and Safeguards Commission ve, ABN or Digital ID, bank account stems and processes (such as my nduct and worker screening requ	with visibility of all providers are the details, location, contact of GovID). irements.
Application, identity verification and Code of Coduct and worker screening attestation  Audit of compliance with Practice	Provider completes online ap and 10.3) to provide the NDIA and new data on payments. Application form collects bas details, support types delivered). Business identity is verified le. Provider attests to understan  YES In-depth observational audit of compliance with relevant practice standard. Streamlining where appropriate based on risk, such as the use of desktop auditing, self-assessment and attestation, and mutual recognition of compliance in other	National Disability Supports Qualic information (e.g. business name everaging existing government systems of the systems of th	ity and Safeguards Commission versions. ABN or Digital ID, bank account stems and processes (such as my nduct and worker screening required NO  But includes a self-assessment and attestation of compliance with Practice Standards,	with visibility of all providers are the details, location, contact of GovID). irements.

Develop and deliver a risk-proportionate model for the visibility and regulation of all providers and workers, and strengthen the regulatory response to long-standing and emerging quality and safeguards issues

\*Legislative change required

#### Action 17.1\*

The Department of Social Services and the new National Disability Supports Quality and Safeguards Commission should design and implement a graduated risk-proportionate regulatory model for the whole provider market.

This should be developed in consultation with people with disability, providers and other regulators. The model should include mandatory registration or enrolment of all providers, with requirements proportionate to the risks of a provider's activities and operations. This should provide full visibility of the market, incorporate requirements that are more finely tuned to risk, and address gaps, excessive burdens and duplication in current requirements. New supports and functions proposed in other recommendations (including Navigators, Lead Practitioners and foundational support providers) should be regulated under this model to ensure appropriate safeguarding of people with disability and avoid creating gaps in regulation. The implementation of this model should be informed by the development of a provider risk framework that identifies and evaluates the risk profile of different types of supports and providers.

#### Action 17.2\*

The Department of Social Services and the new National Disability Supports Quality and Safeguards Commission should develop a staged implementation approach to transition to the new graduated risk-proportionate regulatory model.

Transition of providers to the new regulatory model (see Action 17.1) should be sequenced and staged, allowing the new National Disability Supports Quality and Safeguards Commission to learn from implementation and make necessary changes and adjustments to support an ongoing smooth transition of the market. Transition should be completed over five years, prioritising some changes early to improve regulatory oversight of high-risk supports and providers, while legislative and systems changes — including integration with the centralised online platform (see Action 10.1) and payments systems (see Action 10.3) — are developed to support full implementation. It should be accompanied by actions to support providers to transition to new regulatory requirements.

#### Action 17.3\*

The <u>Australian Government</u> should amend the *National Disability Insurance Scheme*Act 2013 to remove the link between a participant's financial management of their plan and the regulatory status of their support providers.

The requirement for a provider to either be enrolled or registered, and the intensity of any regulatory requirements, should be determined by the risk and complexity of different supports and providers.

#### **Action 17.4\***

The <u>Department of Social Services</u>, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should expand the coverage of worker screening requirements.

Worker screening should be mandatory for all individuals working in risk assessed roles for registered providers, and all individuals working for enrolled providers in roles where normal duties include the direct delivery of specified supports or services to people with disability or are likely to require more than incidental contact with people with disability. Expanding worker screening requirements to these roles would support a more risk-proportionate approach to regulation, ensuring workers do not pose an unacceptable risk to people with disability. Expanded worker screening requirements should be informed by engagement with people with disability, providers, workers and unions and adopted as part of the new regulatory model (see Action 17.1). This should be accompanied by mandatory basic online training for workers to understand their obligations.

#### Action 17.5\*

The Department of Finance and the Department of Social Services, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should improve, streamline and harmonise worker screening processes for care and support workers.

Expanding worker screening requirements to more NDIS workers (see Action 17.4) should be supported by efforts to improve the operation of the worker screening process. This should include urgent work to reduce timeframes, improve consistency across jurisdictions and streamline and harmonise checks across the care and support sector.

#### Action 17.6

The new National Disability Supports Quality and Safeguards Commission should be resourced to strengthen compliance activities and communications to respond to emerging and longstanding quality and safeguards issues, and market developments and innovation.

Immediate priorities should include improving communication of expectations and good practices for providers, as well as strengthening compliance activities, relating to conflicts of interest and client capture, sharp practices and service agreements, transparency and open disclosure, and duties of care. On an ongoing basis, a more proactive approach should be taken to ensure innovation and change in the market is appropriately considered and incorporated into regulatory settings, including to support beneficial innovation. This should include trialling collaborative models to observe and consider the regulatory approach for innovative support types or delivery models.

# Reduction and elimination in the use of restrictive practices

**A warning to readers**: This section contains discussion of restrictive practices and abuse and violence experienced by people with disability. The content is upsetting for all but may also be triggering for some. There are contact details to access support at the beginning of this report.

# Efforts across governments have not made sufficient progress in reducing and eliminating the use of restrictive practices

Restrictive practices are practices or interventions that restrict the freedom of movement or rights of a person with disability. Restrictive practices are often used in response to behaviours displayed by a person with disability that others interpret as posing a risk, either to the person with disability or other people around them. There is a long history of people with disability — particularly people with Autism, intellectual disability and psychosocial disability — being subject to restrictive practices, with little regard for the rights and dignity of the person against whom they are being used. We have heard that these practices have become entrenched in some settings and that providers often use restrictive practices out of convenience or habit.

"Restrictive practices are at odds with the human rights of people with disability and represent a significant form of violence and coercion"

- Disability Royal Commission Research Report 264

"While there is nothing wrong with the idea of being safe, if approaches to safety are not undertaken in the context of good life chances, those safety measures can serve to hold the person back, or even actively diminish their chances of a good life. This happens a lot for people who are labelled as having 'behaviours of concern' resulting

in 'restrictive practices' being a feature of their support arrangements."

- JFA Purple Orange <sup>265</sup>

Data collected gives a picture of the widespread routine use of restrictive practices. In the 2021-22 financial year alone, over 1.4 million individual instances of unauthorised restrictive practices were reported.<sup>266</sup> This is a shocking and unacceptable statistic.

In addition, the number of participants subjected to regulated restrictive practices overall continues to grow, with 12,717 participants reported in April to June 2023 (around 2.1 per cent of all participants).<sup>267</sup>

There are several types of restrictive practices reflected in this data, with chemical restraint and environmental restraint the most commonly used.

Figure 15

Types of regulated restrictive practices<sup>268</sup>

Туре	Definition	Number of participants associated with regulated restrictive practice notifications (April to June 2023)
Seclusion	The sole confinement of a person with disability in a room or a physical space at any hour of the day or night where voluntary exit is prevented, or not facilitated, or it is implied that voluntary exit is not permitted.	585
Chemical restraint	The use of medication or chemical substance for the primary purpose of influencing a person's behaviour. It does not include the use of medication prescribed by a medical practitioner to treat, or to enable the treatment of, a diagnosed mental disorder, physical illness or physical condition.	7,930
Mechanical restraint	The use of a device to prevent, restrict, or subdue a person's movement for the primary purpose of influencing a person's behaviour. Mechanical restraint does not include the use of devices for therapeutic or non-behavioural purposes.	1,718
Physical restraint	The use or action of physical force to prevent, restrict or subdue movement of a person's body, or part of their body, for the primary purpose of influencing their behaviour. Physical restraint does not include the use of a hands-on technique in a reflexive way to guide or redirect a person away from potential harm/injury, consistent with what could reasonable be considered the exercise of care towards a person.	1,817
Environmental restraint	The restriction of a person's free access to all parts of their environment, including items or activities.	7,659

All Australian governments have agreed to principles and strategies to encourage the reduction and elimination of these practices, in line with their obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>269</sup> This includes the 2014 National Framework for Reducing and Eliminating Restrictive Practices in the Disability Service Sector and the 2020 Principles for Nationally

Consistent Authorisation of Restrictive Practices.<sup>270</sup> In addition, all Australian governments have also agreed on a national list of prohibited practices, which are types of restrictive practices that are harmful and should never be used against a person (including specific forms of physical restraint, as well as punitive and aversive strategies).<sup>271</sup>

In the NDIS, efforts have been led by the NDIS Quality and Safeguards Commission (NDIS Commission) in partnership with state and territory authorities. The key regulatory strategy for reducing and eliminating restrictive practices in the NDIS is the requirement for providers to have all use of restrictive practices authorised in accordance with state and territory requirements and documented in a behaviour support plan produced by an approved behaviour support practitioner and lodged with the NDIS Commission. The intention of this approach is to focus efforts on the development of non-restrictive approaches to understanding, preventing and responding to behaviours of concern.<sup>272</sup>

More data has been made available on the use of these practices than ever before, and guidance and resources to improve the delivery of behaviour support that reduces or eliminates the use of restrictive practices have been created.

Despite these efforts, the use of restrictive practices, and particularly unauthorised use, remains persistently and disturbingly high. This persistent use of restrictive practices represents continued breaches of human rights for people with disability and is unacceptable. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) has also emphasised the need for action to reduce and eliminate restrictive practices, including by improving the legal framework for authorising these practices and improving access to behaviour support planning.<sup>273</sup> We agree and feel additional steps can be taken to meaningfully reduce the use of these practices.

All governments have responsibilities for regulating and monitoring restrictive practices. In practice, however, there remains limited consistency, coordination and collaboration in the system. For example, state and territory agencies have raised concerns about insufficient sharing of information from the NDIS Commission.<sup>274</sup> Providers have also identified challenges with duplicative reporting requirements.

"Differences across states/territories both within the Framework and then relationships between the Framework and state/territory based authorising bodies leading to inconsistency and confusion, which can mean vulnerable people 'fall through the cracks'".

- NGO 275

In addition, some jurisdictions have failed to implement nationally agreed approaches. For example, the Principles for Nationally Consistent Authorisation of Restrictive Practices (the Principles) set out the respective functions of the NDIS Commission and state and territory authorities in the authorisation and monitoring of restrictive practices. Principles have not yet been fully implemented by states and territories and the authorisation practices of each state and territory continue to differ and are not always aligned to best practice. Turrently, authorisation processes in only four states and territories are considered to be fully aligned with the Principles. Furthermore, while the Senior Practitioner model is recognised as the best practice approach for the authorisation of restrictive practices, this approach has only been implemented (or is in the process of being implemented) in four states and territories.

This inconsistency and slow progress on implementation create further risks for people with disability already at significant risk of violence, abuse, neglect, exploitation and poorer quality of life. It has also led to confusion for providers and behaviour support practitioners.

Similarly, since the Disability Reform Council agreed a national list of prohibited practices in December 2019,<sup>280</sup> states and territories have made varying progress towards prohibiting these practices.<sup>281</sup> This has left too many participants unprotected against practices that are recognised as harmful.

Corrective actions are focused too heavily on reporting compliance over deterrence. The NDIS Commission has developed reporting mechanisms for the use of restrictive practices by registered NDIS providers. However, regulatory action has focused on raising awareness and collecting reports of unauthorised restrictive practice use, rather than taking compliance action against the ongoing use of restrictive practices.

We have also heard particular concerns about certain interventions and practices that may be harmful to people with disability or have significant risks of unintended consequences (such as some interventions and practices under Applied Behavioural Analysis). We have heard concerns that these interventions and practices may not be neurodiversity affirming, strengths based or consistent with the human rights principles underpinning the NDIS; and that there is a limited evidence base for their safety and cost effectiveness. We note some of these interventions and practices may already be considered prohibited practices (for example, punitive strategies involving punishment) — reinforcing the need for rapid action to legislatively prohibit these practices, consistent with the existing agreement.

# There are ongoing concerns about the low quality of many behaviour support plans

A behaviour support plan (BSP) is a document prepared in consultation with a person with disability, their family, carers, and other support people to address the needs of a person identified as having complex behaviours of concern. The aim of behaviour support is to reduce and eliminate restrictive practices.

We have heard consistent concerns around the quality of BSPs for NDIS participants. In 2022, the NDIS Commission undertook a review of 2,744 BSPs submitted between 1 July 2020 and 31 December 2021. <sup>282</sup> This found 80 per cent of BSPs were scored as "underdeveloped" or "weak" overall. The national median score fell in the weak range. BSPs scored particularly poorly in domains related to building a participant's capacity to proactively prevent the behaviour from emerging. We have also heard significant concerns that many BSPs are not being written in a way that supports their implementation.

"There are very poor quality plans coming through with a 'cookie cutter approach'."

- Provider <sup>283</sup>

A good quality BSP is associated with improved outcomes, better quality of life and reduced use of restrictive practices. A poor quality BSP can perpetuate poor outcomes, low quality of life and greater use of restrictive practices.

Inadequate funding for BSP development and implementation is also contributing to poor outcomes, and ultimately a lack of progress in reducing and eliminating restrictive practices. The current funding approach for the development and implementation of BSPs involves participants being allocated funding as part of their NDIS plans. However, this approach is not timely or responsive to urgent safeguarding issues, as a full plan review is needed to enable access to funding for a BSP (if one is not already in place). This does not reflect the regulatory obligations on a provider to seek the development of a BSP regardless of whether it has been funded in the participant's plan. We have heard that there is a high degree of variability in terms of funding allocated in plans for behaviour support, and that there is often insufficient funding available to train staff on how to implement BSPs. We have also heard concerns that the process of developing a BSP is outside the control of providers, and so unauthorised restrictive practices may be employed while waiting for a participant to receive behaviour support funding or for a behaviour support practitioner to be available.

In addition, both BSPs and other actions must take into account environmental factors that impact the need for restrictive practices to be used. For example, inappropriate

dwelling design or residents in a shared house who have needs for very different living arrangements can add to the need for more intensive restrictive practices and behaviour support. These situations point to the need for more appropriate housing and so form part of our recommendations on home and living (see Recommendations 8 and 9).

# Providers continue to use restrictive practices for a range of reasons, and need more support to shift their approach

Participants, families and carers have told us a continued overreliance on restrictive practices by NDIS providers and workers leaves people with disability at significant risk of harm. By normalising the violation of participants' rights, this can undermine the ability of both people with disability and workers to recognise and respond to violence.<sup>285</sup>

We have heard particular concern around restrictive practices becoming entrenched in congregate care settings, such as group homes.<sup>286</sup> There is a perception that providers often use restrictive practices out of convenience, because it is what they have always done, or under the guise of participant or staff safety.<sup>287</sup> Submissions from providers left the impression that more emphasis is placed on authorisation of and reporting on restrictive practices, instead of prioritising reduction and elimination.

We acknowledge the significant efforts required by behaviour support practitioners, providers and workers to move away from historical practices of restriction in disability services. However, we strongly believe providers must take responsibility for the reduction and elimination of restrictive practices. It is critical that all providers build a positive rights-based culture and ensure they have the capability and strategies needed to reduce and eliminate the use of restrictive practices. <sup>288</sup> The NDIA through reasonable and necessary supports and funding approaches for 24/7 living supports, Navigators and Shared Support Facilitators also have important roles to play in ensuring appropriate living arrangements (see Recommendations 4 and 8).

#### The Panel's vision

# Efforts to reduce and eliminate restrictive practices must be reinvigorated across all parts of the system

All Australian governments should take action consistent with our commitments under the UNCRPD to promote the rights, freedoms and dignity of people with disability.

Governments should work urgently to reduce and eliminate the use of restrictive practices, and take swift action to deter and address violations of the rights of people with disability. This should include pursuing compliance and enforcement action more assertively against providers for the unauthorised or inappropriate use of restrictive practices, or for the use of prohibited practices. This should also include further action by the new National Disability Supports Quality and Safeguards Commission (National Disability Supports Commission) to more proactively respond to particularly harmful interventions — including working with state and territory authorities to take stronger compliance action against the use of prohibited practices, and with the NDIS Evidence Committee (see Action 23.2) to review additional interventions and practices that may be harmful.

High-quality behaviour support planning should be delivered by a market of highly competent behaviour support practitioners. Practical advice and support on BSPs should be delivered by government, to give providers clear guidance for quality improvement and action.

Consideration should be given to an alternative model (potentially outside individual budgets) for funding providers to develop and implement behaviour support plans to ensure timely access and adequate funding for quality behaviour support. The need for behaviour support should be identified early (for example, through the risk assessment and safeguard building process, see Action 16.2), providers should be able to access funding to have a BSP developed quickly in order to meet their regulatory obligations, and funding and pricing arrangements for support delivery should account for the costs of ongoing implementation of behaviour support (including accounting for any staff training requirements, and recognising that the least restrictive approach may be more costly).

Providers should take responsibility for their role in reducing and eliminating restrictive practices, empowered by education and support from all levels of government. Providers should be focused first and foremost on ensuring a good quality of life for the people they support. Workers should have the training and support they need to enable this. Through this focus, restrictive practices will genuinely only be used as a last resort, and will always be the least restrictive option possible.

## Reinvigorate efforts to urgently drive reduction and elimination in the use of restrictive practices

\*Legislative change required

#### Action 18.1\*

<u>All Australian governments</u> should agree a joint action plan for meaningful collaboration and a stronger focus on corrective actions against providers to reduce and eliminate restrictive practices, and review interventions and practices that may be harmful.

This should align with the objectives and commitments of the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector. This should include immediate action to operationalise information sharing on restrictive practices, adopt best-practice and nationally consistent authorisation arrangements, and ban prohibited practices in order to achieve safer outcomes for people with disability. It should also include taking stronger compliance action against providers inappropriately and/or illegally applying restrictive practices. In addition, the new National Disability Supports Quality and Safeguards Commission and the new NDIS Evidence Committee (see Action 23.2) should review interventions and practices that may be harmful to people with disability.

#### Action 18.2

The new National Disability Supports Quality and Safeguards Commission, working with other agencies as relevant, should work with behaviour support practitioners and providers to urgently improve the quality of behaviour support plans, enhance quality of life for participants and eliminate poor provider practices.

Immediate priorities should include practice leadership, capability uplift for behaviour support practitioners and ensuring that regulatory and market settings support best practice. There should be a clear action plan, which brings together specific initiatives and considerations for quality improvements, with appropriate timeframes for action. Further consideration should also be given to alternative models for funding providers to develop and implement behaviour support plans to ensure timely access and adequate funding for quality behaviour support, including use of the risk assessment and safeguard building process (see Action 16.2) to identify the need for a Behaviour Support Plan.

#### Action 18.3

The new <u>National Disability Supports Quality and Safeguards Commission</u>, working with state and territory agencies, should better support providers to deliver on their role in reducing and eliminating restrictive practices.

All agencies should work with providers to build a positive rights-based culture that is focused on improving quality of life for participants. This should be achieved through coordinated education and support from the regulatory system to build the necessary culture, governance and leadership in providers, strategic leadership by providers, training for staff, and high-quality behaviour support for participants that will reduce and eliminate restrictive practices.

# Effective quality and safeguarding institutions and architecture across the full disability ecosystem

Quality and safeguarding in disability supports is not pursued in a strategic, coordinated or consistent way

The NDIS is a large and complex system, with over 610,000 participants served by over 16,000 registered providers, over 154,000 unregistered providers, and over 325,000 workers.<sup>289</sup> A range of individuals and organisations have roles and responsibilities to support a quality, safe experience of supports for participants.

Many of the challenges experienced in quality and safeguarding suggest the system is not coordinated, or consistent. We have found that regulation is not being approached in the strategic, coordinated and consistent way that people with disability deserve, and that a scheme as large as the NDIS — as well as the wider disability support ecosystem — warrants. There is also confusion about who is responsible for what, and a lack of information sharing to support the system to deliver good outcomes.

"...the NDIS has many moving parts, with many roles. This complexity
may lead to an end point where there is nobody that has... responsibility
to make sure that things are going well overall for the individual."

- Robertson Review 290

Roles and responsibilities for quality and safeguarding are fragmented and unclear. The 2016 NDIS Quality and Safeguarding Framework (the Framework) set a vision for the activities of different groups with quality and safeguarding roles and responsibilities and how they would be coordinated. This included the roles of formal regulators such as the NDIS Quality and Safeguards Commission (NDIS Commission), and the availability of supports for participants to self-advocate and develop their natural safeguards. This has not eventuated in the way the Framework envisaged it would, with a lack of clarity about who is responsible for ensuring participants are supported and safe and how these different players should work together. Participants and supporters have told us they find navigating the quality and safeguarding system to be unintuitive and confusing.<sup>291</sup>

"The current complex landscape is fragmented and often inaccessible and ineffective for people with disability seeking remedies, recognition or resolution of their complaints or negative experiences with disability supports. The burden of this complexity falls on people with disability, their families and supporters..."

- Disability Advocacy Network Australia (DANA)<sup>292</sup>

The Framework also takes too narrow a view, focusing on quality and safeguarding for NDIS supports but not the broader ecosystem of supports for people with disability — which has resulted in quality and safeguarding in the NDIS being considered in isolation. Given the Review is recommending a major investment in foundational supports, relying on a narrow Framework and NDIS Commission — focused just on the NDIS — will be even less appropriate in the future.

Current information sharing arrangements do not facilitate a joined-up view of risk and safeguarding for participants — with different parts of the system holding different information about participants and therefore each only having a partial view.

As a result, the regulatory system is not as effective as it should be, and those who should intervene to prevent harm are not able to identify issues and trigger responses. A lack of information sharing also leads to inefficiencies in the regulatory system — for example, resulting in duplicative requirements for providers to report on the use of restrictive practices to both the NDIS Commission and the relevant state or territory authority. We have also found the right balance is not being struck between protecting the personal information of people with disability and sharing sufficient information to underpin effective safeguarding.

There is a lack of consistency and coordination in quality and safeguarding efforts both within the NDIS, and between the scheme and other supports outside the scheme. Not all NDIS supports and services are regulated in the same way or by the same regulator. For example, both the National Disability Insurance Agency and the NDIS Commission set rules for providers and workers. Not all NDIS providers are regulated by the NDIS Commission either. For example, NDIS Commission regulation does not apply to directly commissioned supports like Local Area Coordinators, despite having direct relationships with people with disability.<sup>293</sup>

Beyond the NDIS, there are separate and overlapping regulatory frameworks for other disability, care and support services. Differing regulation makes it difficult to consistently understand what standards of quality and safety to expect, how services and supports compare, what rights consumers have, and how to make a complaint or access support when issues arise.<sup>294</sup> This leads to significant confusion, frustration, and ultimately poor outcomes for participants, families and carers.

Differing regulation also presents challenges for the many providers and workers who operate in multiple care and support programs. Providers and workers have told us it can be difficult and time-consuming to understand and reconcile the regulatory requirements associated with different service systems.

"...the current system imposes onerous, repetitive and often inconsistent demands on providers due to the duplication of reporting requirements between state and federal authorities"

- The CEO Collaboration<sup>295</sup>

#### The NDIS Commission was not resourced sufficiently for its scope

While it has delivered a range of achievements to date, we believe there are opportunities to improve the NDIS Commission's capability and effectiveness. The NDIS Commission is still a new regulator, developing in its maturity and capability. The transition period to national regulatory arrangements only recently concluded in July 2023. Since it was established, the NDIS Commission has made progress in a range of areas. This includes the development of the NDIS Code of Conduct, the implementation of a registration scheme for providers, and nationally consistent worker screening. <sup>296</sup> It has also exercised its Own Motion Inquiry powers to investigate issues including supported accommodation, platform providers, and support coordination and plan management. <sup>297</sup>

However, the scale of the NDIS Commission's task is far larger than was envisaged when it was established. There are more participants and providers (including unregistered providers) than were originally anticipated. The NDIS Commission has consistently been under-resourced relative to its roles and responsibilities.

"Frontline operation teams do not have adequate employee numbers to manage the volume of reportable incidents, complaints, or compliance activities currently within the Commission's oversight. Participants are at risk due to the inability of the Commission Branch functions to perform thorough assessments to ensure the ongoing safeguarding of participants has occurred and NDIS providers are meeting legislative obligations."

- Community and Public Sector Union<sup>298</sup>

The NDIS Commission has also been constrained by inadequate information and communications technologies investment. This has undermined efforts to build better data capability to inform its work. It has also resulted in missed opportunities to reduce burden on providers through improved user experience of NDIS Commission portals and processes and timelier decision-making.

"Renewal of NDIS Registration through the online portal was reported

to take at least 8 hours due to an arduous online portal."

- Occupational Therapy Australia<sup>299</sup>

The NDIS Commission has also not sufficiently embedded a best practice approach to regulation.

The NDIS Commission is seen as not sufficiently accessible or responsive. This has negatively affected public trust and confidence. Many participants and the broader community, including some providers, are not aware of the NDIS Commission or its role in the system. Those that are aware have told us many times that the complaints processes are not accessible, and they do not receive adequate or a timely responses when they raise issues. <sup>300</sup> Both government and non-government organisations, including representative and advocacy organisations, have described experiences suggesting lack of collaborative engagement by the NDIS Commission.

We have also heard from many people who believe the NDIS Commission "lacks teeth" to respond to concerns about provider conduct, and does not do enough when faced with inappropriate or illegal conduct.<sup>301</sup> The Disability Royal Commission made similar observations about the need for the NDIS Commission to transition towards more active monitoring and enforcement.<sup>302</sup>

#### The Panel's vision

#### The unified disability support ecosystem must be overseen by effective, well-coordinated and responsive regulatory institutions

The NDIS Commission has already started on a path to improve its approach. This includes developing a new Strategic Plan, Regulatory Approach, Data and Digital Roadmap, Workforce Plan and Operating Model and commissioning reviews of its regulatory capability.<sup>303</sup> There is an opportunity to build on these efforts through implementation of our recommendations.

Collaboration, and especially timely two-way information and data exchanges between all parts of government, should be strengthened to advance common quality and safeguarding objectives, improve outcomes for people with disability and deliver efficiencies in the regulatory system. This should include urgently finalising the Prescribed Bodies Rule to enable better information sharing across governments (for example, to improve visibility of risk factors and flags for people with disability, and reduce duplication in provider reporting requirements). There should also be greater consistency in the regulation of disability supports nationally and with adjacent systems in the care and support sector. This would ensure consistent protections for all people with care and support needs.

We are recommending a major investment in foundational supports and considering quality and safeguarding across the disability support ecosystem will be critical. Coordination and consistency across all parts and levels of government must be underpinned by both legislative and policy architecture — as well as culture — across the system that sets clear objectives, roles and responsibilities, drives collaboration and information sharing, and harmonises laws and regulations to reduce complexity. These efforts should be underpinned by a new Disability Supports Quality and Safeguarding Framework, covering all disability supports. This should set a clear strategy and accountability for quality and safeguarding across the whole disability support ecosystem.

The quality and safeguarding system should have strong, capable and credible national leadership through expanding the coverage of the current NDIS Commission to be the new National Disability Supports Quality and Safeguards Commission (National Disability Supports Commission), with responsibility for the regulation of all Australian Government funded disability supports. Expanding the current NDIS Commission's coverage will provide consistent protections for people with disability accessing a range of supports, reduce regulatory burden for providers, and drive efficiencies for government.

The National Disability Supports Commission should be well-equipped to take on the challenge, with adequate resourcing and capability, and a proactive approach to best practice regulation. This should include sophisticated and timely use of data to identify and respond to issues, assertive responses to inappropriate and illegal conduct, and a more proactive, open, transparent and much more responsive approach to engaging with people with disability, providers and workers.

## Embed effective quality and safeguarding institutions and architecture across the disability support ecosystem

\*Legislative change required

#### Action 19.1

The <u>Disability Reform Ministerial Council</u> should agree a Disability Supports Quality and Safeguarding Framework.

The new Framework should replace the 2016 NDIS Quality and Safeguarding Framework. It should set responsibilities, drive coordination and underpin accountability across quality and safeguarding arrangements for disability supports within and outside the NDIS. The Department of Social Services should lead the development of the new Framework in partnership with the new National Disability Supports Quality and Safeguards Commission, the National Disability Insurance Agency and state and territory agencies, with strong engagement with people with disability.

#### Action 19.2\*

<u>All Australian governments</u> should prioritise greater collaboration, consistency and timely exchange of data and information to ensure effective quality and safeguarding, including expanding the coverage of the NDIS Quality and Safeguards Commission to become the National Disability Supports Quality and Safeguards Commission.

The new National Disability Supports Quality and Safeguards Commission should have responsibility for the regulation of all Australian Government funded disability supports. State and territory governments should work towards greater national consistency in their regulation of other disability supports. Barriers to effective sharing of relevant information should also be resolved as a priority to ensure the right parties have the right information at the right time to prevent or respond to issues. Consideration of the timing for the expansion of the coverage of the NDIS Quality and Safeguards Commission should have regard to the sequencing of our reforms and those that respond to the Disability Royal Commission.

#### Action 19.3\*

The <u>Australian Government</u> should ensure the new National Disability Supports Quality and Safeguards Commission has the resources, powers and approach to proactively and effectively regulate the disability supports market.

This should include ensuring the new National Disability Supports Quality and Safeguards Commission (National Disability Supports Commission) has the right resources, capability, powers, levers and strategy to drive improved quality and safeguards in disability supports and services, and an open and transparent approach in its engagement with the disability sector. Particular focus should be given to strengthening data and digital capabilities to support an enhanced regulatory intelligence function, and to adopting a more assertive approach to using the full range of regulatory levers available to the new National Disability Supports Commission. The new National Disability Supports Commission also needs certainty of funding across the next five years so it can plan appropriately for the full reform and transition period.

#### Part three

# Stewardship of the unified ecosystem

"To create a joined-up ecosystem of support... a whole of government approach is needed... History suggests that an agreement of some sort that will hold governments publicly and fiscally accountable will be required to ensure that these services

- National Disability Services 304

are available to support people with disability."

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#### A new compact between Australian governments

# Governance arrangements across the disability supports ecosystem have been evolving

Over time, governments of Australia have committed to a series of overarching agreements and strategies that aim to create an Australia where people with disability have the same rights, recognition and opportunities as everyone else. The NDIS is only one part of this.

To put into effect Australia's commitment to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), governments agreed the National Disability Agreement (NDA) in 2008. This aimed to improve the lives of people with disability and set out funding arrangements, roles and responsibilities and priority actions for disability services in Australia. 305

In 2010, the first National Disability Strategy (NDS) was developed following the findings of *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*.<sup>306</sup> The report documented the experience of people with disability, including social exclusion, discrimination, lack of services and support, poor employment opportunities and outcomes and a lack of accessibility.<sup>307</sup> The NDS "was the first time all levels of government committed to a unified, national approach to improving the lives of people with disability" and addressing societal change.<sup>308</sup>

The introduction of the NDIS represented a significant investment in Australia meeting its obligations under the UNCRPD. The NDIS is governed under a series of bilateral agreements between the Australian Government and each state and territory which set out roles and responsibilities as well as funding arrangements.<sup>309</sup>

The successor to the NDS is Australia's Disability Strategy 2021 – 2031 (ADS). The ADS was agreed by all governments in 2021 with the aim of improving inclusion and progressing attitudinal change. It is underpinned by five Targeted Action Plans, covering employment, community attitudes, early childhood, safety, and emergency management and has explicitly added changing community attitudes as an outcome area.<sup>310</sup>

These agreements and strategies sit alongside other government agreements. Australia is a signatory to the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). UNDRIP affirmed the right of First Nations people to self-determination and participation in decision-making matters that affect their rights, including First Nations people with disability.<sup>311</sup>

In 2020, all governments and First Nations people, as represented by the Coalition of Peaks, committed to the National Agreement on Closing the Gap. This commits all governments to work in new ways to drive better outcomes across particular socioeconomic outcomes. The agreement is underpinned by priority reforms including

strengthening the community-controlled disability sector. Disability is also identified as a cross-cutting outcome area that needs progress to mitigate the compounding effects of intersectional inequality.<sup>312</sup>

# Current national governance and funding arrangements for disability have not delivered the hoped-for outcomes

The promise of these commitments to people with disability remains a work in progress. People with disability continue to experience discrimination and poorer outcomes on a range of key measures including health, education, employment, and social connection.<sup>313</sup>

- Health: Those with profound or severe disability are almost nine times as likely as adults without disability and almost twice as likely with adults with other disability to assess their health as fair or poor.<sup>314</sup>
- Education: Of people aged 15 to 64 with disability acquired before the age of 15, more than one in five left school before aged 16 compared with one in 11 of their peers without disability.<sup>315</sup>
- Employment: People with disability experience lower labour market participation rates than their peers — 53.4 per cent compared to 84.1 per cent.<sup>316</sup>
- Social connection: People with disability aged 15 to 64 are twice as likely
   (17 per cent) to experience social isolation as those without disability (8.7 per cent).
   This is consistent across all age groups, the largest gap being between people aged
   15 to 24 with disability (18 per cent) and those of the same age without disability
   (6.6 per cent).<sup>317</sup>

In addition, rates of disability for First Nations people are higher than the general population.

- One in five (72,700) First Nations children aged under 18 have disability,
   compared with one in 12 children in the general population.
- Approximately 35 per cent (274,400) of First Nations people under 65 years of age have disability, three times higher than the general population.<sup>318</sup>
- Around 202,200 First Nations adults between 18 and 64 have disability representing 45 per cent of all First Nations adults. This increases to 79 per cent or nearly four out of five First Nations adults aged over 65.<sup>319</sup>

Despite this reality, and the commitments under the UNDRIP and the National Agreement on Closing the Gap, First Nation issues are not appropriately prioritised through current disability governance arrangements.

For First Nations people with disability, this represents a critical gap in a commitment by all Australian governments under the National Agreement on Closing the Gap.

Not enough has been done to identify, develop or strengthen independent accountability mechanisms that work with government to identify and eliminate racism, embed and

practice meaningful cultural safety, monitor progress, listen and respond to concerns about mainstream institutions and agencies, and report publicly on transformation.<sup>320</sup>

"[First Nations] peoples are more likely to experience disability but are less likely to access support services than other Australians.

This demonstrates a fundamental problem with the accessibility of disability support services for [First Nations] peoples."

- Australian Human Rights Commission<sup>321</sup>

The separation of governance, strategy and investments in NDIS bilateral agreements and broader disability commitments under the ADS contributes to an unbalanced ecosystem. In 2021-22, 93 per cent of all government funding for disability was directed to the NDIS.<sup>322</sup> There are few disability supports outside the NDIS and many mainstream and community services remain unavailable, inaccessible and not inclusive (see *Recommendations 1 and 2*).

The Productivity Commission reviewed the NDA in 2019 and found it had not had a strong influence on policy, and no longer had a connection with disability support funding that was governed under bilateral agreements between the Australian Government and states and territories.<sup>323</sup> In particular, it found the complexity and lack of connection between differing national policy and strategy arrangements had contributed to a failure to deliver a connected system that drives access and inclusion for people with disability.<sup>324</sup>

While the ADS has only been in operation for a short time, we have identified a number of issues that are likely to limit its effectiveness. We acknowledge all levels of government have committed to deliver more comprehensive reporting through the ADS and significant work has been undertaken in developing an outcomes framework and formal reporting mechanisms. However, many of the activities in current Targeted Action Plans represent narrow jurisdiction-specific programs that were in place prior to the ADS being agreed.

The ADS is also not a multilateral funding agreement between governments with investment directly linked to outcomes. As bilateral NDIS agreements are the sole agreement linking funding and deliverables, parties have focused on meeting their responsibilities within the NDIS at the expense of a thriving foundational support system and accessible and inclusive mainstream services for all people with disability. Other sector specific Federation Funding Agreements do not currently have practical clauses to ensure outcomes are measured and achieved.

"Re-organising funding and access to disability supports must support universal access and continuity of services without resulting in further cuts to services. Any inter-governmental agreement underlying it must bind state and territory governments to their commitments."

- Health Services Union 325

# Financial cost sharing, incentives and accountabilities are currently unbalanced

The NDIS is jointly funded and governed by all Australian governments. State and territory governments make annual fixed scheme financial contributions reflecting their respective population sizes, and adjust their contribution each year by a set escalation rate of 4 per cent to reflect inflation and population changes.<sup>326</sup>

The Australian Government also provides annual scheme financial contributions. This includes all administration costs and 100 per cent of the costs of those aged 65 and over, in line with broader aged care funding arrangements. The Australian Government also pays all costs associated with higher participant numbers and higher per person care and supports above the agreed capped escalation rate of 4 per cent per annum in state and territory bilateral agreements.

The 2017 Productivity Commission review of NDIS costs identified that funding for the scheme should be sufficient, predictable, and incentivise effectiveness and efficiency.<sup>327</sup> It also noted the need for Commonwealth-state collaboration and accountability and the importance of a connected system.

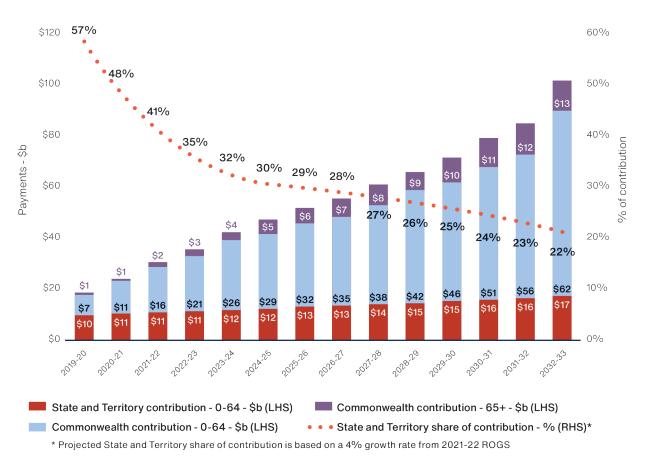
"Ideally, the NDIS would operate as part of a seamless system of mainstream and disability services that takes a lifetime, insurance-based approach. That is, early interventions and well-targeted preventative care would occur in a coordinated way to minimise the overall costs of mainstream and disability services, and maximise the wellbeing of participants in those systems...Gaps in the NDIS can impose costs on mainstream services, and vice versa."

- Productivity Commission 328

As at 30 June 2023, the NDIS supports over 610,000 participants, at a cost of \$35 billion in 2022-23, with further forecast growth to \$92 billion in 2032-33.<sup>329</sup> This has seen the Australian Government's share rise to 59 per cent in 2021-22, while state and territory government contributions have fallen to a combined 41 per cent.<sup>330</sup>

Under current settings, in 2032-33 the Australian Government's share will rise further to 78 per cent, while the state and territory contribution will fall to just 22 per cent (*Figure 16*).

Figure 16
State and territory contributions to the NDIS (0-64 years), 2019-20 - 2032-33



The financial arrangements for the NDIS were designed to recognise states and territories do not have the same access to growth revenues as the Australian Government. However, a fixed rate of increase for states and territories means there is no direct financial incentive to support policy and governance responsibilities to improve scheme sustainability. Governments have taken a first step to help moderate cost-growth with the NDIS Financial Sustainability Framework agreed by National Cabinet in April 2023. This provides an annual growth target in total costs of the NDIS of no more than 8 per cent by 1 July 2026 with further moderation of growth as it matures. Current arrangements reduce the urgency for all governments to work collaboratively around shared responsibilities for NDIS participant outcomes and to improve the effectiveness of the entire disability supports ecosystem. There can also be perverse incentives for all governments to underinvest in foundational disability supports and mainstream services outside of the NDIS.

"States, schools or other services should not be blamed for following the incentives created by the NDIS. From the perspective of the State or Territory this behaviour is highly responsible: it maximises the resources coming into the State; benefits people with disabilities within the State or Territory; while reducing the pressure on the State's own tax payers."

- Dr Simon Duffy and Dr Mark Brown 332

Given the developments of the last ten years, we believe there is a need to align financial incentives, accountabilities and cost sharing arrangements between governments to ensure better outcomes for all Australians with disability.

"To create a joined-up ecosystem of support NDS agrees that a whole of government approach is needed... History suggests that an agreement of some sort that will hold governments publicly and fiscally accountable will be required to ensure that these services are available to support people with disability."

- National Disability Services 333

A powerful mechanism for ensuring governments deliver on commitments is independent monitoring and public reporting. Reporting on outcomes for both the ADS and the NDIS are provided to Disability Reform Ministers. Neither approach involves independent review nor are there consequences for non-performance

While work is underway to develop the National Disability Data Asset, there is also limited access to data at present. This means there continue to be gaps in the evidence available about outcomes related to inclusion and access for people with disability.

# The voices of people with disability are fragmented in disability policy, planning and implementation processes

People with disability are involved in planning and implementation of disability supports as members of the National Disability Insurance Agency (NDIA) Board, the NDIA's Independent Advisory Council (IAC), and Australia's Disability Strategy Council. However, none of these bodies has a remit across the entire disability supports ecosystem.

These structures mirror the existing segregation of responsibilities for the NDIS, foundational and mainstream supports.

This approach contributes to an arbitrary divide between people with disability who have access to the NDIS and those that do not. It creates fragmented coverage of issues that affect people with disability, and means no single voice can speak across all the elements of policy that affect the lives of people with disability. This means the voices of people with disability are often diluted and less effective in influencing decision-making.

Particular groups of people with disability experience additional barriers in influencing policy. These include children and young people, those with experiences of intersectional barriers and discrimination, people with intellectual and/or psychosocial disability and/or autism, and those who are non-verbal.<sup>334</sup>

"A substantial percentage of NDIS participants are aged under 18, yet their voices are not represented. At a recent major conference about the NDIS, there was no representation of children and young people, their voices or their unique needs"

- Youth Disability Advocacy Service 335

"...section 127 of the NDIS Act should be amended to provide that

he NDIA Board must include at least one First Nations person at all times"

- Royal Commission into Violence, Abuse, and Neglect of

People with Disability 336

"All levels of government should provide mechanisms to support the involvement of people with intellectual disability on Disability Advisory Committees"

- Victorian Advocacy League for Individuals with Disability 337

While governments have been good at setting up a range of consultative groups to help with design and implementation of policies, we have heard that these groups are too often absent from decision-making and have little influence on major decisions about supports and services.

#### The Panel's vision

# A compact between governments for a comprehensive and unified disability ecosystem

A new Disability Intergovernmental Agreement (IGA) between all governments and encompassing the whole disability support system would provide a framework to govern a comprehensive and unified disability support system. Through the proposed Disability Outcomes Council (see Action 20.5), this would independently hold all governments accountable for investment, delivery and outcomes, and give people with disability certainty that they will have access to the right supports at the right time.

#### The Disability IGA should include:

- Shared responsibilities for an inclusive and accessible Australia to meet commitments made through the UNCRPD to uphold the rights of people with disability
- Clearer funding arrangements in a new multilateral Federation Funding Agreement schedule that reinforces shared accountabilities for mainstream services, foundational supports and the NDIS and incentivises effective and efficient support delivery across them
- Rebalanced incentives, roles and responsibilities across governments to ensure risk, as well as investment, is shared
- Creation of an independent body and processes modelled on Closing The Gap, including people with disability to report on progress meeting government commitments and on creating an inclusive Australia
- A dedicated schedule that shows how governments will prioritises and uphold commitments to First Nations people under the National Agreement on Closing the Gap and UNDRIP
- A performance reporting framework to measure agreed performance targets in the Disability Support Outcomes Framework to support greater assurance and accountability.

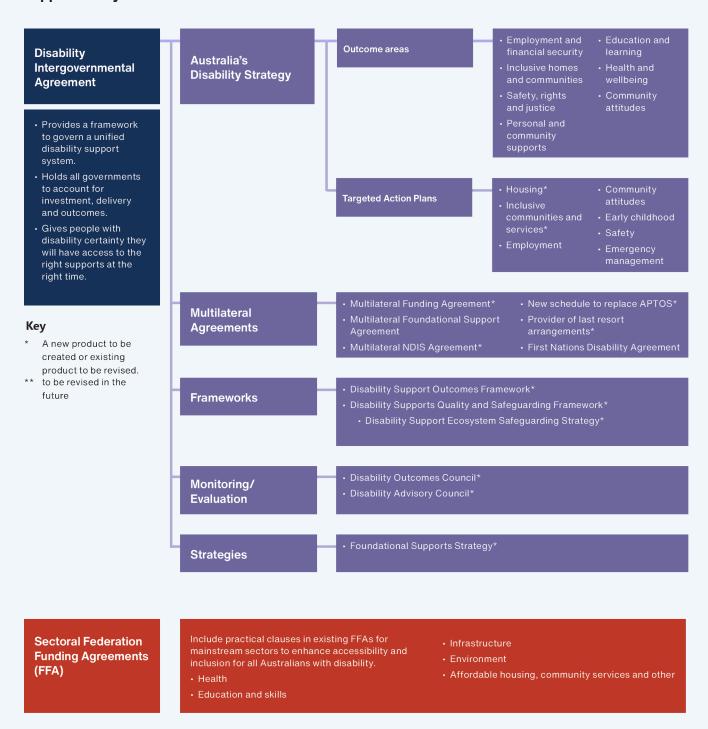
To reinforce and make these federated arrangements practicable, all governments should have clear and complementary roles for funding, regulation, market stewardship and shared responsibilities and working arrangements at the interfaces between the NDIS and other service systems.

This reform will require governments to work together in new ways, including deeper engagement from Disability Reform Ministers, strengthened capabilities at all levels of government, and the ongoing oversight and engagement of National Cabinet.

Figure 17 provides a snapshot of our vision for the future of these arrangements. Our future state brings everything together under one Disability IGA, and incorporates shared frameworks, strategies, and councils proposed in our recommendations.

Figure 17

A new Disability Intergovernmental Agreement to underpin delivery of a unified disability support ecosystem



#### Create a new compact between Australian governments

\*Legislative change required

#### Action 20.1

National Cabinet should agree a new Disability Intergovernmental Agreement to underpin delivery of a comprehensive and unified disability support ecosystem.

This Intergovernmental Agreement (IGA) should build on the foundation of Australia's Disability Strategy and confirm the commitment of all governments to the United Nations' Convention on the Rights of People with Disability. It should include measurable commitments and targets for improving the accessibility and inclusivity of mainstream services and the range and level of foundational services (see Recommendations 1 and 2), as well as ensuring Australian governments are accountable for the future success and sustainability of the NDIS (see Action 21.1). It should have the practical effect of guaranteeing support to all people with disability — not just those in receipt of NDIS-funded supports. Progress in meeting commitments should be independently assessed by a new Disability Outcomes Council (see Action 20.5). This should complement the role for the Productivity Commission in overseeing priority IGAs, such as progress under Closing the Gap.

#### Action 20.2

<u>National Cabinet</u> should agree new funding arrangements to align incentives and share costs in the disability support ecosystem.

A new multilateral Federation Funding Agreement schedule to the new Disability Intergovernmental Agreement should reinforce shared accountabilities for the whole ecosystem. For foundational supports, costs should be shared equally (50:50) between the Australian government and state and territory governments. From commencement of the agreed NDIS Financial Sustainability Framework growth target in 2026-27, future increases in NDIS costs should be shared in a way that better shares risk and aligns incentives. Options include fixing the ongoing shares of those aged under 65 at the 2026-27 level or equally sharing the future growth in costs (potentially with an 8 per cent cap on the contributions from states and territories).

The Council on Federal Financial Relations should continue work to strengthen Federation Funding Agreements, through the inclusion of new practical clauses, to promote inclusion of people with disability and increased accessibility in mainstream services. The new practical clauses should detail mainstream service responsibilities and service delivery obligations for people with disability. Performance and outcome measures in relation to these mainstream services should be included in the Disability Supports Outcomes framework (see Action 23.1) and Disability Outcomes Council should establish a mechanism to monitor and publicly report

on the investment and performance of all governments in delivering inclusive and accessible mainstream services. This will be complemented by the recommended legislative reforms in Actions 2.1 and 2.3.

#### Action 20.3\*

<u>National Cabinet</u> should establish a new permanent Disability Advisory Council reflective of the diversity of people with lived experience of disability to advise Disability Reform Ministers.

The new Disability Advisory Council (DAC) could replace or augment Australia's Disability Strategy Advisory Council and should have a broad remit to advise governments across the disability support ecosystem. The new Council should be reflective of the diversity of people who have lived experience of disability. It should ensure people with disability are included in all aspects of planning, design, monitoring and evaluation of disability support. The DAC should produce and publish a separate report providing disability community perspectives on the performance of governments drawing on, and accompanying, the Disability Outcomes Council's reports to National Cabinet through Disability Reform Ministerial Council (see Action 20.5). The National Disability Insurance Agency (NDIA) Independent Advisory Council (IAC) should continue to advise the NDIA Board, and the Chair of the IAC should be an ex-officio member of the new DAC. These measures should be complemented by other innovative and best practice strategies to hear the voices of people with disability, and ensure the full diversity of experiences and views are included.

#### Action 20.4

<u>National Cabinet</u> should develop a dedicated First Nations Schedule under the new Disability Intergovernmental Agreement to embed a First Nations Disability Forum and an independent sector-specific accountability mechanism.

This will fill accountability gaps and deliver on disability sector strengthening efforts and Priority Reforms under the National Agreement on Closing the Gap. The Schedule should be created in partnership with the relevant First Nations stakeholders and led by the First Nations Disability Representative Organisation. The Schedule should establish and appropriately resource a First Nations Disability decision-making forum that adheres to the Strong Partnership Elements (Clause 32) of the National Agreement on Closing the Gap. The forum should drive community-led design, implementation and evaluation. The Schedule should also establish and appropriately resource an independent, sector-specific accountability mechanism, that aligns with approaches taken across the care and support sector, such as a First Nations

Disability Commissioner to support, monitor and report on mainstream agencies and institutions' ability to identify and eliminate racial ableism and embed and practice meaningful cultural safety across a unified disability ecosystem.

#### Action 20.5\*

<u>National Cabinet</u> should establish a Disability Outcomes Council to monitor and publicly report on the performance of all governments in meeting the outcomes, commitments and benchmarks outlined in the Disability Intergovernmental Agreement.

The Disability Outcomes Council (DOC) should be responsible for monitoring, reviewing, and reporting on the investment, outcomes, and benefits of all governments across the new disability support system against the new Disability Support Outcomes Framework (see Action 23.1). The DOC should draw on inputs from the Productivity Commission, given its role in reporting on government services and monitoring priority intergovernmental agreements, and from the proposed forecaster function (see Action 21.1). Reports should be made to National Cabinet through the Disability Reform Ministerial Council and published. This approach is modelled on the approach to Closing the Gap. The DOC should help embed a robust culture of monitoring and program evaluation across the disability support sector and agencies administering the scheme. Establishment of the DOC should be overseen by the NDIS Review Implementation Advisory Committee, which should then transition into the DOC (see Action 24.1). In establishing the DOC, consideration must be given to how the Committee will interact with the National Disability Commission recommended by the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, particularly in relation to reporting on improvements in inclusion.

# Accountability for administration and sustainability

### Responsibility for financial sustainability of the NDIS is shared

The NDIS is a significant investment by all governments on behalf of all Australians. Its sustainability is essential to maintain community support and ensure it can deliver for those who need it now and in the future.

Under current legislative arrangements ultimate responsibility for NDIS sustainability is shared. The *National Disability Insurance Scheme Act 2013* (NDIS Act) specifies that Disability Reform Ministerial Council (DRMC), the Minister, and the National Disability Insurance Agency (NDIA) Board should have regard to the need to ensure scheme sustainability in performing functions or exercising powers under the NDIS Act (Part 2, section 4(17)), but the NDIA is responsible for managing, advising and reporting on scheme sustainability (section 118(b)).<sup>338</sup>

# The current approach to forecasting for the NDIS weakens confidence in the scheme and misses an opportunity to assess the benefits it delivers

The Annual Financial Sustainability Report (AFSR) provides an annual assessment of the financial sustainability of the NDIS.<sup>339</sup> Reviews of the AFSR projections have found them to be "not unreasonable".<sup>340</sup> However, the immaturity of the NDIS and its dynamic operating environment have led to great uncertainty in forecasting.<sup>341</sup> The actuarial forecasts on which the AFSR is based use past trends to predict the future.<sup>342</sup> This may work well in a mature scheme, but has not in a relatively new and evolving scheme like the NDIS.<sup>343</sup>

Significant revisions to scheme forecasts undermine credibility, lead to ongoing questions around scheme sustainability, and cause uncertainty and anxiety for people with disability, families and carers.<sup>344</sup> Improving the accuracy of NDIS projections can instil greater confidence in scheme stability and reassure governments and the community that costs are predictable and can be trusted.<sup>345</sup>

Commentary on scheme sustainability has almost exclusively focused on costs, and the AFSR predominately assesses scheme sustainability through a lens of financial costs. This fails to acknowledge sustainability is about more than just costs and misses an important opportunity for a balanced discussion on the benefits of the NDIS. 346 Measuring scheme benefits and its impact to society and the economy is integral to safeguarding the sustainability of NDIS. 347

### Agencies involved in administering the NDIS have not been set up for success

Under current arrangements, the relationships between the NDIA, NDIS Quality and Safeguards Commission (NDIS Commission) and the Department of Social Services (DSS) are blurred. There is a lack of clarity around policy and administrative responsibilities across agencies, resulting in gaps, duplication, and inefficiencies. This contributes to inefficient operation of the NDIS and poorer outcomes for people with disability.

In particular, there is misalignment and a lack of clarity about responsibilities for important functions, including market stewardship, pricing, policy, regulation, and commissioning. For example, the NDIA, the NDIS Commission, and the DSS all have roles in NDIS markets, but what each agency does to set policies and facilitate effective market operation is unclear.

"Many roles under the NDIS can be confusing for participants, supporters and providers alike. For instance, the difference between the roles and functions of the National Disability Insurance Agency (NDIA) and the NDIS Commission is not well understood"

- People with Disability Australia 348

This lack of clarity in roles and responsibilities is exacerbated by resourcing constraints. Resourcing for the NDIA to date has been set well below the rate originally suggested by the Productivity Commission.<sup>349</sup> This has affected the NDIA's ability to effectively administer the scheme. One of the major challenges the NDIA has faced has been staff caps. At times this has restricted its ability to perform its role effectively.<sup>350</sup> This has extended to the NDIA's Partners in the Community program, which has resulted in Local Area Coordinators becoming planners instead of performing their vital role in building social and community capital.

The NDIS Commission has also experienced structural and resourcing issues since their establishment that have impacted their ability to fully deliver their remit (see Action 19.3).

#### The operations of the NDIS are not sufficiently codified

NDIA decision-making is guided by government agreements, legislation and subordinate regulation (for example NDIS Rules), operational guidelines and informal policy guidance. We have heard that operational guidelines have lacked transparency and are opaque, with decision-making affecting participants often based on policy guidance at the discretion of the Chief Executive Officer.

"...there is a 'hidden nature' of NDIA decision-making and lack of clear evidence linking the NDIS Act and decisions, accompanied by poor communication of decisions by the NDIA. The impact of the perceived hidden nature of decision-making is twofold: producing a negative impact on public trust and confidence about decisions and the transparency of decision-making processes; and hindering NDIS participants to exercise their rights to review and appeal processes."

- Law Futures Centre, Policy Innovation Hub and The Hopkins Centre, Griffith University 351

We have heard about a lack of consistency and transparency in NDIA decision-making around access and reasonable and necessary supports, and makes for an adversarial process for applicants and participants.

"The NDIS is also very inconsistent. Too often I hear of two different people needing the same thing for the same disability for the exact same reasons and one might get exactly what they need whereas the other is left having to either fight for it"

- Participant 352

"The NDIS are constantly changing the 'ballpark' on the decisions they are making. I want honesty and transparency."

Carer 353

This issue is not new. The 2019 Tune Review highlighted the importance of the legislative framework and administrative practices enshrining transparency as a principle in engaging with all people with disability.<sup>354</sup>

#### The Panel's vision

# Accountabilities for governance and sustainability should drive shared responsibility for a comprehensive and unified ecosystem

All governments have a duty to ensure every dollar of disability funding is well spent and delivers benefits for people with disability. To achieve this, greater clarity is required in roles, responsibilities and decision-making across the ecosystem.

The new Disability Intergovernmental Agreement should also outline a new governance structure for the broader disability support ecosystem, with DRMC (reporting to National Cabinet) being accountable for the sustainability of the disability support ecosystem. DRMC should continue to be accountable for the policy and legislation for eligibility and entitlements framing the sustainability of the NDIS (see also Action 21.2). The NDIA Board should remain responsible for sustainability of the NDIS within that legislative framework. The NDIA Board should continue to identify and report on NDIS financing and sustainability issues to Disability Reform Ministers. This will be a major input into the assessment of the overall sustainability of the disability ecosystem.

DRMC should be supported to make appropriate assessments of the overall sustainability of the disability support ecosystem via an expert forecaster. Sustainability should be considered at a whole-of-ecosystem level. This would include input from the AFSR as a major source, along with a consideration of the benefits provided to participants, the impact of the NDIS on other systems, and the benefits to the broader Australian community. This will require the NDIA and DSS to develop different forecasting models to improve the accuracy of NDIS projections.

Updating Australian Government administrative arrangements will help ensure the unified disability support ecosystem is well governed (*Figure 18*). This should include clarifying roles and responsibilities and utilising shared processes, workforces, providers, and systems and identifying opportunities to better coordinate the disability supports ecosystem with the broader care economy.

Clarified administrative arrangements should be underpinned by ongoing funding certainty for the NDIA and the National Disability Supports Commission. This would ensure the costs of administering the NDIS effectively can be met and the reform agenda implemented in full.

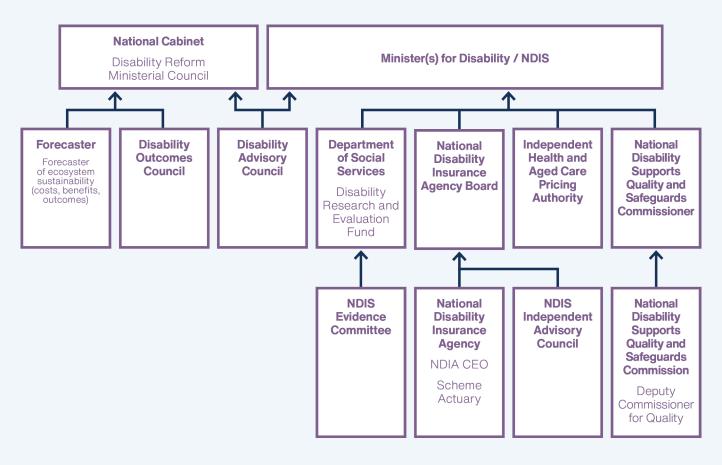
The significant investment in the NDIS and the establishment of a unified ecosystem requires representation at the highest level in government. This should improve connections with intersecting portfolios, including Employment and Workplace Relations, Social Services and Health. An enduring role for the Minister for the NDIS in Cabinet will support this.

To support consistent decision-making, all key policy parameters should be elevated to legislation and NDIS Rules, instead of relying on operational guidelines and informal policy guidance for decision-making. This would improve transparency, lead to less disputation, and give applicants, participants and nominees avenues for appealing decisions.

If an individual is not satisfied with the NDIA's interpretation of legislation or rules, they would continue to be able to appeal to the Administrative Appeals Tribunal and Federal Court. If the Federal Court finds in favour of the participant, it would be a matter for governments to decide whether to accept any widening in the scheme or seek to change the rules.

Figure 18

A new governance structure for a unified disability support ecosystem



### Clarify accountability for sustainability and governance of the disability ecosystem

\*Legislative change required

#### Action 21.1\*

### <u>National Cabinet</u> should be accountable for the sustainability of the unified disability ecosystem, including the NDIS.

Consistent with National Cabinet's focus on the sustainability of the NDIS in 2023, this accountability should extend to the whole disability ecosystem. The Disability Reform Ministerial Council (DRMC) should support National Cabinet with an ongoing role for prioritising and agreeing disability policy reform directions. DRMC should appoint a forecaster to review and provide advice to National Cabinet on total disability spending and projections, including NDIS scheme expenditure and projections, and the financial sustainability of the disability ecosystem, including the NDIS. The approach to assessing the sustainability of the disability ecosystem should acknowledge the benefits, as well as costs, of disability supports.

In relation to accountability for the sustainability of the NDIS, responsibilities within the existing legislation should be operationalised more clearly. Specifically, DRMC (reporting to National Cabinet) should continue to be accountable for the policy and legislation for eligibility and entitlements framing the sustainability of the NDIS (see Action 21.2) and the broader ecosystem outside the NDIS. The NDIA Board should remain responsible for sustainability of the NDIS within that framework and broader ecosystem. The NDIA Board should then continue to identify and report on NDIS financing and sustainability issues to Disability Reform Ministers. This will be a major input into the assessment of the overall sustainability of the disability ecosystem.

The Annual Financial Sustainability Report (AFSR) produced by the Scheme Actuary should report on the overall sustainability of the NDIS, by measuring costs, benefits and net fiscal impact on other schemes and programs (including the disability ecosystem). The Scheme Actuary should also develop different forecasting models, including for specific cohorts, to improve the accuracy of NDIS projections. The AFSR should be a major source of information supporting the forecasts of overall scheme sustainability.

#### Action 21.2\*

The <u>Department of Social Services</u>, in consultation with state and territory governments, should review existing National Disability Insurance Agency operational guidelines to identify and prioritise opportunities to strengthen the *National Disability Insurance Scheme Act 2013* and Rules.

This should elevate key policy parameters to legislation and rules where relevant, instead of relying on operational guidelines and informal guidance within the National Disability Insurance Agency (NDIA) to ensure transparent governance of the NDIS. Key elements of the scheme's operations, including sustainability and reasonable and necessary supports, should be codified in legislation and rules as much as is practical. Where the NDIA continues to rely on Operational Guidelines, they must be aligned with the principles in the legislation.

#### Action 21.3

The <u>Australian Government</u> should ensure that the Minister responsible for the NDIS remains a Cabinet Minister.

Given the scale of the NDIS, this should facilitate the fiscal, policy and delivery impacts of the NDIS being factored into relevant government decision-making, including across the care economy.

#### Action 21.4\*

The <u>Australian Government</u> should clarify roles of relevant agencies for administration market stewardship, pricing, policy, regulation, commissioning and legislation.

This should include the Department of Social Services, the future National Disability Supports Quality and Safeguards Commission, the National Disability Insurance Agency and the Independent Health and Aged Care Pricing Authority. Over time, government should consider opportunities to more closely coordinate the administration and planning of disability supports, workforce and safeguard mechanisms with other programs and regulation across the care and support systems. This should focus on driving improvements in efficiency, effectiveness and outcomes in areas such as quality and safeguarding, research and innovation, market stewardship and assessment of function and support needs.

### A highly-skilled, person-centred, disability-aware culture across all disability agencies and governments

The National Disability Insurance Agency (NDIA) and the NDIS Quality and Safeguards Commission (NDIS Commission) play critical roles as delivery and regulatory agencies of the NDIS. Staff working in these agencies require extensive skills to work with each individual and their supporters in a way that is person centred, strength based, trauma informed, disability aware, and acknowledges the inherent dignity and unique individuality of each person. We have heard both of how excellent work by the staff of the NDIA has been critical in assisting many people with disability to achieve their goals, 355 and where there is room for improvement.

"There are many thousands of staff working for the NDIA. Staff at the NDIA are dedicated, responsive, professional and care about outcomes for people with disability. However, there is room for improvement when it comes to the communication, flexibility, and responsiveness of the NDIA's current operational processes and procedures."

- Advocacy for Inclusion 356

"The planner should read my file before commencing a meeting and ask me questions. I am the plan nominee for my child who has very limited communication (non-verbal). At each meeting I am given the third degree and made to feel like I am rorting the system... After each planning meeting I am left in tears and feel extremely stressed. The planners are generally rude, lack empathy and have limited (if any) understanding of disability.

Please employ people with lived experience of disability. Please adequately train staff."

The NDIA supports over 610,000 people with disability across Australia with access, planning, and funding. We recognise the scale of this task, and the challenges associated with establishing a complex scheme in the tight timeframes set out in bilateral schedules. It is a significant achievement. We acknowledge the commitment, expertise, and purpose displayed by staff in the NDIA and the NDIS Commission.

- Carer 357

Further work on the culture and capability of the NDIA and the current NDIS Commission is needed to regain the trust of the community

We have heard concerning reports from people with disability about their interactions with the NDIA. These issues include, a lack of understanding about disability in general and particular conditions and/or diagnoses, adversarial approaches particularly in appeal processes, inconsistent advice, bureaucratic language and processes, and an absence of trauma-informed practice.<sup>358</sup>

"The planners don't understand the needs of people with a disability.

All they are doing is ticking a box. LAC's and planners not reading documents/reports prior to planning or review meetings. The main call centre is completely useless. They can't answer any questions and when raising a complaint — the complaints team are incredibly rude and even hang up on you."

The range of experiences with the NDIA ranged from confusing and frustrating to damaging and traumatic. Poor experience with NDIA staff or Partners in the Community was one of the most common themes in participant submissions and consultations.

"...putting up with the ignorant, sometimes disrespectful comments the delegates make, because of their ignorance about the implications of my disability is hard. It adds to my burden"

- Participant 360

- Participant and advocate 359

"NDIS planners do not want to help the people who need help and support and if they helped and supported them with the right information and really listened they would see that people are crying out for help.

I feel you need people in these jobs with a lived experience. I have been in a plan review with a person to where the planner was yelling at the person due to wasting her time."

- Provider 361

The Joint Standing Committee on the NDIS (JSC)'s Inquiry into the Capability and Culture of the NDIA found similar issues, including significant administrative burdens, a requirement to repeatedly prove disability, cost cutting at the expense of participants, and a lack of adequate training, experience and understanding of disability.<sup>362</sup>

The JSC made observations about culture and capability in its final report on the NDIS Commission in 2021. In particular, the Committee recommended the Australian Government ensure adequate resourcing for the NDIS Commission and review staffing levels (noting actions most recently taken in the 2023-4 Budget to increase the NDIS Commission's staffing and ICT capability). The JSC also observed multiple submissions had raised concerns about the adequacy of staff training in relation to awareness of disability types and disability service provision, roles and responsibilities of the NDIS Commission, understanding of the NDIS Code of Conduct, and adequacy of understanding in relation to cultural awareness of issues experienced by First Nations people with disability.<sup>363</sup>

While we are encouraged by recent staff uplift and additional funds for ICT improvements, there continues to be a need for ongoing improvements to culture and capability.

There are opportunities for the current NDIS Commission to improve practice, particularly in relation to methods for complaints handling approaches for people with disability, data usage, responsiveness, and relationships and referrals to other regulators (see Action 19.3).

"The Commission reviews incident reports but, due to their internal capacity constraints, often does not respond or seek further information until up to twelve months later when key personnel and/or participants have left the organisation... The tone of requests for information can be both negative and disrespectful. Sometimes, the response proposed by Commission staff is out of step with current expectations, such as consideration of person-centred practice or privacy considerations.

This gives rise to questions about the current knowledge level of Commission staff involved with incident reviews. The result is that incident reporting can be seen as a compliance requirement focussed on process rather than outcomes."

- Provider 364

A disability legal and advocacy service advised that following a complaint, they continued to follow up on behalf of the complainant over an 18-month period.

"The Commission finally conceded that they had not communicated with us or our the (sic) client about the final outcome of the investigation until now, had closed the matter without speaking to him, and had communicated only with the Provider."

-Villamanta Disability Rights Legal Service 365

These issues should be addressed to fulfil the NDIS Commission's current and recommended expanded role in the future to promote quality supports and ensure the safety of people with disability.

We acknowledge steps taken by governments to increase the numbers of people with disability employed (for example, the NDIA's 2021-22 Annual Report states 18 per cent of staff have disability). However, the NDIA is a public sector outlier when it comes to employing people with disability. Over the last three decades rates of employment of people with disability in Australian public service entities have fallen from 6.8 per cent in 1986 to 4 per cent in 2020. This trend should be reversed.

### The Participant Service Guarantee should prioritise quality decisions and better experiences for people with disability

The 2019 Tune Review made a series of recommendations about the NDIA's Participant Service Guarantee (the Guarantee), particularly in relation to legislating the Guarantee and the inclusion of relevant timeframes.<sup>368</sup>

In 2022, the NDIS Amendment (Participant Service Guarantee and Other Measures) Act 2022 came into force. The Guarantee is included in the Participant Service Charter and provides metrics for timeframes in which access, planning, implementation, plan reassessment and variations, reviewable decisions, and nominee matters will be determined. There are also timeframe metrics for the NDIA to respond to complaints and for the call centre to respond to incoming phone calls.

Establishing timeframes and performance metrics was a welcome development. But it is clear there are further opportunities to strengthen the Guarantee to improve participant experience and the quality of decisions made. For example, participants should have opportunities to provide satisfaction scores on NDIA interactions, including access requests and internal reviews. Additionally, consideration should also be given to turnover and satisfaction rates for NDIA employees, including contractors.

#### The Panel's vision

### A highly skilled workforce across all areas of disability policy, regulation, service delivery and leadership

The Australian Government should take action to improve the culture and capability of the NDIA and the National Disability Supports Commission in order to drive better outcomes for people with disability.

Professional development for all staff should cover disability awareness, intersectionality and trauma informed practice. It should also include reflective practice (examining what worked well and ensuring it is built into future practice) to ensure all staff have the skills and experience to meet the needs of the people they serve. All public servants engaged in disability policy, regulation, programs or delivery should understand the social model of disability, the commitments made through the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and have understanding of disability awareness and intersectionality.

The NDIA and the National Disability Supports Commission should prepare and publish culture and capability plans to improve and maintain person centred, disability aware practice. There should be an annual independent audit to review the development of these skills. Results of these audits should be published on the websites of both agencies. Net promoter score-style surveys should be undertaken with participants and stakeholders to regularly gauge sector confidence.

A revised Participant Service Guarantee should develop qualitative measures to determine the quality and transparency of decision-making. This data will help improve the experience of people with disability in their interactions with the NDIA.

The new Disability Intergovernmental Agreement should include measurable culture and capability outcomes for public servants employed in areas of disability policy development and implementation in all governments. These should be reported to the New Disability Outcomes Council for public reporting and tabling in Parliament.

### Embed a highly skilled, person-centred, disability aware culture across all disability agencies and governments

\*Legislative change required

#### Action 22.1

When undertaking capability reviews, the <u>Australian Public Service Commission</u> should have regard to the capacity, capability and culture of the National Disability Insurance Agency, National Disability Supports Quality and Safeguards Commission, and Department of Social Services to deliver relevant reforms.

Capability reviews should include people with disability and assess how agencies can ensure the right skills and capabilities are in place to deliver complex reforms for people with disability and families (including designing and testing reforms with people with disability), manage significant shifts to a broader disability support system and adapt to changes in roles and responsibilities.

#### Action 22 2

The National Disability Insurance Agency and the new National Disability Supports

Quality and Safeguards Commission should publish culture and capability plans
every two years, supported by independent audits and staff, participant and
stakeholder surveys.

Plans should set out specific actions for enhancing, maintaining and continually improving a person-centred and disability-focused culture and high levels of internal capability. These plans should be agreed by the Minister(s) for Disability/ NDIS and published to ensure transparency and accountability. This should be supported by annual independent performance and culture audits.

#### Action 22.3\*

The <u>Australian Government</u> should re-design the Participant Service Guarantee to prioritise high quality, transparent and efficient decisions and improved participant experience.

The Participant Service Guarantee should include new metrics in addition to timeframes to measure quality of decisions and incentivise better participant experience. This could include quality and transparent decisions for participants and employee satisfaction scores, including for partners. This should be designed with participants.

#### Action 22.4

The <u>Disability Reform Ministerial Council</u> should agree measurable culture and capability outcomes as part of new funding arrangements.

All Australian, state and territory government agencies responsible for disability policy and/or service delivery should model best practice in the promotion of disability aware, socially inclusive, person-centred culture. These outcomes should be embedded in funding arrangements (see Action 20.2), documented in the Disability Support Outcomes Framework (see Action 23.1) and reported to the Disability Outcomes Council (see Action 20.5).

## A learning system that measures what matters and builds an evidence base of what works

The NDIS currently supports over 610,000 participants though a \$35 billion investment in 2022-23.<sup>369</sup> Such a significant investment that has such a large impact on the lives of Australians should be backed up by a rigorous commitment to evidence-based practice, evaluation and continuous improvement.

At present there are also significant data gaps that limit the ability to measure what matters for people with a disability across the entire disability support ecosystem, both within the NDIS and beyond in the foundational support systems.

Future research, evaluation and data infrastructure should cover both foundational and NDIS disability support systems. This is critical to provide an evidence-base that underpins an effective disability support ecosystem for all people with a disability.

# Measurement of participant, social and economic outcomes is poor and the NDIS Outcomes Framework is not fit-for-purpose

Under current data and evaluation frameworks, it is very difficult to link supports, investment and outputs to the achievement of participant goals and outcomes and broader societal benefits. In short it is difficult to demonstrate what works, for whom, and why.

The scheme currently measures aspects of participant and family member satisfaction and outcomes but does not capture the entirety of the impact of the NDIS on the lives of participants. This makes it hard to know what matters to participants and their family members.

The Review encountered and identified substantial gaps in data availability and linkage which meant a complete assessment of participant, social and economic benefits was not possible. For instance, it was difficult to measure the costs incurred previously by families and charities. Accurately evaluating the benefits of previously unpaid care for people that are now supported through paid care was also not possible.

The data gaps and evidence limitations have most likely led to a significant underestimation of net social and economic benefits. Addressing these limitations in data collections and quality is crucial to accurately measure the true impact of the scheme.

The current NDIS Outcomes Framework (the Framework) is limited in its coverage and does not include whole of system interactions between the NDIS, mainstream and other service systems. The outcomes it does measure are not directly linked to scheme costs.

As a result, it is difficult to determine value and the impact of the scheme on quality of life and wellbeing for participants and their families. The Framework relies on participant satisfaction surveys, draws on insufficient data to measure participant outcomes and scheme effectiveness adequately.

Analysis of the appropriateness of the current Framework found it has few objective measures, limited measurement of outcomes outside the Scheme and difficulty measuring progress when evaluating whether participant goals were met.

### Significant NDIS policy and operational decisions are not made on a transparent and independent basis

We have heard concerns that NDIS participants are able to access therapies that may not be able to demonstrate evidence based high quality outcomes for people with disability and in some cases cause harm (such as some interventions and practices under Applied Behavioural Analysis).<sup>370</sup> Within the Australian Government there are examples of evidence based benchmarking for public funding for other systems — for example, under the Medicare Benefits Schedule. These approval processes require robust evaluation of therapies and supports based on their validity, effectiveness, safety and the cost-benefit assessment of their efficacy in maintaining or developing the wellbeing of the person.

High-quality, open and independent research and evaluation activity, alongside knowledge translation of best-practice evidence into policy and provider actions, are critical to optimising outcomes, safeguarding participants, inspiring public trust, and supporting scheme sustainability.

### The NDIS has not been set up in a way that enables continuous learning

All governments should invest more in better research and evaluation of the disability support ecosystem. This should include increased sharing of data in a safe and secure manner so researchers, service providers and other governments can support improved evaluation. These investments would help build the foundations for a culture of continual learning and innovation in the NDIS and the broader disability ecosystem.

Governments recently agreed to establish a National Disability Data Asset (NDDA), which will link NDIS, social security, tax, health, hospital, housing, employment and justice data. It is a major opportunity and follows many years of work by Australian, state and territory governments, especially New South Wales, with the disability community. It will enable governments and researchers to examine the impact of a very broad range of policies and develop new data insights. However, despite the importance of the NDDA for long-term policy development and research, funding for this initiative has only been provided for two years.

NDIS data is currently structured to support actuarial analysis, because this has been its central purpose to date. However, a much broader use of NDIS data is needed. To enable this, the data should be structured according to the International Classification of Function. It is also important that data is made more easily available to researchers (with all important safeguards) to ensure independent scrutiny of the scheme.

Providers and workers are a critical part of the disability support ecosystem. Their approach to delivering supports depends on up to date knowledge of what works and what is best practice. Despite some initiatives like the NDIS Commission's Workforce Capability Framework and Provider Alerts, as well as some National Disability Insurance Agency (NDIA) policy documents, overall there is an inadequate systemic focus on knowledge translation to update providers and workers.

#### Research funding

Funding of research to underpin development of the NDIS and the disability ecosystem is hampered by insufficient funding. Funding is required to support research projects and building research capacity in universities, research institutes and disability community organisations.

The lack of a dedicated research funding source is striking given the significance of expenditures on the NDIS and disability and contrasts with medical research which is supported by the Medical Research Future Fund and the National Health and Medical Research Fund. Commitment to improved funding has enabled Australia to become a world leader in medical research and there is a similar opportunity in disability research.

The Australian Government has committed to establishing a National Disability Research Partnership (NDRP) under Australia's Disability Strategy. It brings together the Australian Government, people with disability, families, carers, representative organisations and researchers. It is developing an NDRP research agenda. This is a small but important initiative with significant potential to grow.

#### The Panel's vision

### An evidence-based NDIS can promote an investment approach and optimise outcomes

All governments should invest more to enable better research, evaluation and knowledge translation. Increased and improved research and evaluation will help demonstrate the value of the NDIS to governments and taxpayers and help participants meet their goals through innovative and evidence-based supports.

Australian governments should replace the current NDIS Outcomes Framework with a new Disability Support Outcomes Framework. The new framework should be focused on clear objectives and key outcomes covering both foundational and NDIS supports. The new outcomes should also identify data gaps and linkages to other related research and analysis.

The Department of Social Services should establish a new NDIS Evidence Committee modelled on the Pharmaceutical Benefits Advisory Committee and the Medical Services Advisory Committee. The Evidence Committee should evaluate and recommend evidence-based therapies that warrant NDIS support, including having regard to their cost effectiveness. A stronger evidence base providing clear regulation and guidance on effective therapies and supports should provide better quality, improve outcomes, and make navigating the scheme for participants and their families easier.

Australian Governments should establish a new Disability Research and Evaluation Fund (DREF) to coordinate and fund research and independent evaluation activities. The DREF would help address critical knowledge gaps in Australian and international disability research that is most relevant to the Australian disability and service delivery context. The DREF would fund work to strengthen disability data availability and use, and build the evidence base to better support people with disability outside of the NDIS. The DREF should also promote participatory disability research and knowledge translation of evidence-based practices to policy makers and service providers.

All governments should promote higher levels of disability data quality, linkage and sharing through additional investments in critical data infrastructure. The NDIA should ensure that its data is structured to align with the International Classification of Function, to significantly enhance its usefulness for research. An evidence base reflecting the actual lifetime experiences of people with disability will improve the quality, effectiveness and responsiveness of the disability support ecosystem and foster a culture of continuous learning and improvement.

Australian Governments should build on and secure the long-term funding of the NDDA. A more comprehensive evidence-based picture of the disability support landscape would help the scheme demonstrate value for money to governments and taxpayers, and most importantly help participants improve outcomes and meet their goals in the most effective manner through innovative and evidence-based supports.

### Measure what matters, build an evidence base of what works, and create a learning system

\*Legislative change required

#### Action 23.1

<u>National Cabinet</u> should agree to replace the current NDIS Outcomes Framework with a new Disability Support Outcomes Framework.

The new Framework should be focused on objectives and key results covering both foundational and NDIS supports. Accountability for disability support outcomes should include measurement against agreed objectives and key results to drive an agenda of continuous improvement. Development of the Framework should be designed with people with disability and led by DSS (see Action 20.5). The Framework should be included as a schedule in the new Disability Intergovernmental Agreement (see Action 20.1).

#### Action 23 2\*

The <u>Department of Social Services</u>, in consultation with the National Disability Insurance Agency, the new National Disability Supports Quality and Safeguards Commission and the Independent Health and Aged Care Pricing Authority, should establish and manage an NDIS Evidence Committee to provide guidance on reasonable and necessary disability supports.

The Evidence Committee should evaluate and recommend evidence based therapies that warrant NDIS support in the budget setting process or funding as foundational supports with regard to benefits, quality, safety, and cost effectiveness. The Evidence Committee should also advise agencies and governments on other evidence related dimensions of NDIS operations.

The Evidence Committee should address gaps in scientific and economic insight by assessing and determining the efficacy and cost-benefit of supports for NDIS funding. Practice Standards for providers would ensure they deliver supports that are safe and evidence-informed, supported by regulatory oversight by the new National Disability Supports Quality and Safeguards Commission.

The Evidence Committee's annual work plan will be approved by Disability Reform Ministerial Council. While Evidence Committee deliberations on the merits of supports will be independent and transparent, any recommendations concerning the eligibility of supports for NDIS funding will require final approval by relevant decision-makers.

#### Action 23.3\*

The <u>Department of Social Services</u> should establish a new Disability Research and Evaluation Fund to coordinate and fund research and independent evaluation activities.

The Disability Research and Evaluation Fund (DREF) should be in the order of \$40-50 million per year and consideration could be given to drawing on income from accumulated unspent funding from jurisdictions' contributions to NDIS transition (the proposed 'Reserve Fund'). The DREF should fund the development of a robust evidence base to inform the operations of the disability support ecosystem. This should include identifying and addressing knowledge gaps in Australian and international disability research relevant to the Australian context, and supporting the work of the NDIS Evidence Committee (see Action 23.2). The DREF should also fund greater data investment and research on the experiences of people with disability not eligible for NDIS to facilitate collaboration in the disability sector and improve the evidence underpinning effective support for people outside the scheme. The DREF should support and promote knowledge translation of best practice evidence by policy makers and service providers. It should support leading research initiatives and seek to build disability research capacity, so that Australia can become a world leader.

#### Action 23.4

### <u>All Australian governments</u> should agree to jointly invest in actions to improve disability data quality and sharing.

This should build on the Disability Reform Ministerial Council agreement for the NDIA to improve the quality, availability and use of disability data through additional investments and fostering a culture of continual learning. The NDIS data structure should be aligned with the International Classification of Function. All governments should invest in developing a robust evidence base on the lifetime experiences of people with disability. This should include investing in the National Disability Data Asset, a triennial Australian Bureau of Statistics Survey of Disability, Ageing and Carers, improved longitudinal insights into labour market barriers, and other disability related data. Governments should also commit to greater collection and sharing of data regarding foundational and mainstream services with linkage to other administrative datasets

#### Action 23.5

The <u>Australian Government</u> should ensure that all disability reporting mechanisms facilitate the collection, analysis and publication of intersectional indicators.

All people with disability should be able to easily access and understand information that is relevant to them. This means that all data and reporting mechanisms across the disability ecosystem must begin collecting, reporting and publishing against intersectional characteristics including First Nations, culturally and linguistically diverse, LGBTIQA+SB, gender and age as a minimum standard. This approach should be taken across the National Disability Insurance Agency, National Disability Data Asset (NDDA), ADS and the future Australian Bureau of Statistics' Survey of Disability, Ageing and Carers (including population data, NDIS participants and complaint, government investments, outcome measurements and implementation tracking) (see Action 23.4). Where data is not collected or is not able to be published, a gap should be publicly identified along with a commitment to develop mechanisms to address the gap, through the appropriate data improvement plans. Funded efforts should also be made to adopt this minimum standard across the disability ecosystem including the NDDA.

### **Part four**

# A five year transition

"Listen to the most important people, the people with

the disabilities."

- Participant371

#### The foundations for successful implementation

Taken together, our recommendations represent a blueprint, not only for the NDIS, but for the future of the broader ecosystem of support for all people with disability. Investment of time, resources and expertise in best practice implementation will ensure these changes deliver for all people with disability.

#### Implementation should be guided by lessons from the past

Implementation of these recommendations has much to learn from the experience of the initial NDIS roll-out, as well as subsequent reforms. While changes to a national scheme of the scale and complexity of the NDIS will inevitably experience road bumps, we have identified several common issues to be taken into account in implementing our recommendations.

Notwithstanding deep engagement with the disability community by governments between when the Productivity Commission reported in 2011 and the commencement of the NDIS on 1 July 2013, the initial NDIS roll-out has been criticised for its emphasis on meeting short-term targets and unrealistic deadlines. This meant implementation was not always aligned with the original intentions for the scheme.<sup>372</sup> The speed and complexity of the rollout also meant that despite best intentions, elements of the previous systems found their way into the NDIS.<sup>373</sup>

The subsequent attempted introduction of Independent Assessments in 2021 further demonstrated a failure to implement reforms as intended or in partnership with people with disability. This process suffered from insufficient design with people with disability and the sector, a lack of consultation with independent experts, and inadequate testing.<sup>374</sup> This undermined community trust and created lasting fear, stress and uncertainty for NDIS participants, families and carers.

We also recognise that people with disability, their families, carers, Disability Representative Organisations, workers and disability service providers are exhausted by never-ending change. There is significant reform fatigue, and everyone craves consensus and certainty around the transition to a better future for the NDIS.

Our recommended approach for transition takes these lessons into account. This includes a five-year transition period, robust design and testing with people with disability, and a focus on retaining the features of the NDIS that are working well and replacing those that are not.

#### Transition will take time and careful sequencing

Our recommendations must be considered and implemented as a package over a five-year transition period. During this period, implementation should be sequenced strategically to address critical dependencies, manage risks and mitigate or minimise disruptions for participants, providers and workers.

Implementation of some recommendations should be prioritised in the short-term to make immediate improvements to the participant experience, such as foundational supports (see Recommendation 1), updating guidance for making access requests (see Action 3.2) and strengthening the workforce (see Recommendation 15).

For more complex recommendations, a staged transition approach will be necessary to allow for more substantial consultation, design and testing prior to a phased roll-out. For example, a staged transition is recommended for changes to the participant pathway (see Action 3.8) and implementation of a new regulatory model for providers (see Action 17.2).

Sequencing should also consider essential implementation enablers that cut across many recommendations.

"Ask the people living the NDIS – the participants and staff -

to contribute meaningfully to an ACTUAL REDESIGN. Give redesign

the TIME it needs to GET IT RIGHT."

- Provider<sup>375</sup>

### A suite of legislative changes will be needed to underpin reforms

Some of our proposed reforms will require changes in relevant legislation. We expect a package of amendments to primary legislation and associated legislative instruments will be required. This will include changes to the *National Disability Insurance Scheme Act 2013* and NDIS Rules to deliver improvements to the participant pathway. A full list of recommendations possibly requiring legislation changes is at Appendix D.

As with all our reforms, these legislative changes should be effectively coordinated across government and done in close consultation with the disability community.

#### A well-coordinated national effort is required to deliver these changes

All governments need to work together in new ways to deliver these recommendations, learning from the experience of incomplete or inadequate implementation of previous reviews' recommendations.

This must be embodied in both the new compact between governments (see Recommendation 20), and a joined-up approach to implementation. A successful and smooth transition will rely on agencies with implementation responsibilities across all governments better coordinating their distinct activities. Dedicated coordination and monitoring functions will help drive the reforms and ensure dependencies between implementing agencies are addressed.

#### A concerted effort will be needed to bring everyone with a stake in the NDIS along on the journey

Implementation of these recommendations affects people with disability, their families, carers, Disability Representative Organisations, workers, disability service providers and governments. We have consistently heard from all stakeholders that implementation of NDIS reforms to date has not been sufficiently consultative. Where consultation has occurred, it has often been tokenistic, siloed and rushed.

"Listen to the most important people, the people with

the disabilities."

- Participant<sup>376</sup>

"What I would really love to see is for the NDIA to talk to us,

the providers, as well as the participants. We are all the people who

directly or indirectly use the NDIS. But I think that, there is a lost

opportunity. The people are the most amazing resource, and I don't

think it is being tapped into"

- NDIS Communities of Practice<sup>377</sup>

Implementation should ensure all groups with a stake in the NDIS have a genuine voice in the process. This should be reflected in design with people with disability, their families, carers, Disability Representative Organisations, workers and disability service providers. It also extends to the make-up of implementation bodies and governance structures, which should prioritise inclusion of people with disability.

"[The NDIA should] lead its consultation processes in a spirit of collaboration of all interested stakeholders by creating forums where everyone can engage with each other, at the same time: participants, allied health representatives, NDIA, Government, and other relevant stakeholders"

- Australian Physiotherapy Association<sup>378</sup>

"[There needs to be a] commitment to the voice of lived experience for input to ongoing design, and consultation with experts where appropriate"

- National Mental Health Consumer and Carers Forum<sup>379</sup>

### A best practice approach to implementation will improve outcomes

Recommendations must be delivered sensitively in consultation with people with disability and in line with implementation best practice. This is essential to build and maintain confidence in the integrity of the NDIS with people with disability and the Australian community.

A best practice approach to implementation should align with these following principles:

- Genuine design with people with disability, their families, carers, Disability Representative Organisations, workers and disability service providers that centres and leverages the lived experience and expertise of the disability community and sector. This would involve people with disability at all stages of the design process, including identifying when new processes are ready to be implemented.
- Design of new services, processes, platforms and communications materials in line with the Australian Government Digital Service Standard, including taking an agile and user-centred approach to all stages of the design process.<sup>380</sup>
- An inclusive and proportional approach to testing all new processes. This would ensure testing of new processes is both sufficiently robust and proportional to complexity and scale. It will also allow priority reforms to be phased in and start delivering benefits as soon as possible.<sup>381</sup>
- Rigorous and transparent reliability and validity testing of functional and needs
  assessments for the purpose for which they are intended. This must include involving
  people with disability and independent experts and conducting transparent trials
  with participants.<sup>382</sup>

- Design of culturally safe and tailored approaches in partnership with First Nations and culturally and linguistically diverse communities. This should deliver on Priority Reforms under the National Agreement on Closing the Gap, including ensuring government agencies are culturally safe and responsive to the needs of First Nations people.<sup>383</sup>
- Continuous and independent evaluation of implementation to monitor for unintended consequences and identify opportunities for improvement.
- Frequent and transparent communications\_with stakeholders, including current participants. This should aim to not only help people to understand the reforms and how they may be affected, but also to build and maintain trust in the scheme by showing how people with disability are being included in the implementation process.

Implementing recommendations in line with these principles will require a significant investment in and uplift of design capability within government. To enable this, we propose establishing the NDIS Experience Design Office based in the National Disability Insurance Agency (NDIA). It should draw on specialists with relevant design and subject-matter expertise. The NDIS Experience Design Office's remit should include commissioning and overseeing projects for the design of reforms to the participant pathway, in line with the principles outlined above. The design of these reforms requires a mixture of policy, operational and services expertise. Accordingly, the Department of Social Services should have embedded staff in the NDIS Experience Design Office.

### Existing participants must experience a smooth and fair transition

We have heard from participants, families and carers who both want to see the NDIS change, but are anxious about what changes to the NDIS mean for them. Implementation should focus on how existing participants transition to new arrangements. A number of factors will need to be considered to ensure that all existing participants experience a smooth and fair transition.

Participants should have an opportunity to design, test and engage with changes to the pathway (see Recommendations 1.3 and 1.6) before they have to interact with them. This must involve much more than simply informing people about change. Participants should help drive the change journey through a transparent, inclusive and detailed design process.

Changes to access and budget setting processes can only be implemented once the recommended foundational supports are in place to offer support outside the NDIS (see Recommendation 1).

### The combined impact of our recommendations will deliver long-term scheme sustainability

We have previously emphasised sustainability is about more than just costs – it is also about outcomes.

Adopting our recommendations will focus the scheme on improving participant experiences and outcomes while ensuring value for money. A participant-centred scheme, focused on outcomes will be a successful and sustainable scheme.

The Review has examined the potential impact of our recommendations on scheme projections. If implemented together, we are confident our reforms will secure the future of the scheme and meet National Cabinet's NDIS Financial Sustainability Framework annual growth target in total costs of the NDIS of no more than 8 per cent by 1 July 2026 with further moderation of growth over time.

By the time the reforms mature in 2032-33, we expect cost growth in the scheme itself to have gradually moderated and be within the implied target of \$87 billion in 2032-33, compared with the latest unpublished NDIA estimate of \$92 billion.

However, this will be impossible without significant investment outside of the scheme.

First and foremost, investments are needed in foundational supports and in making mainstream services more accessible and inclusive. These will reduce pressure for NDIS support. It will also create a fairer and better system of support for all people with disability.

#### Establish appropriate architecture to implement reforms

\*Legislative change required

#### Action 24.1

The <u>Disability Reform Ministerial Council</u> should agree architecture to support implementation and delivery of the NDIS reform agenda.

The following bodies should include, and be inclusive of, people with disability, families and carers, and the disability sector.

- NDIS Review Implementation Advisory Committee: The Advisory Committee should be appointed by the Disability Reform Ministerial Council (DRMC). It should monitor and advise on the initial period of implementation, including monitoring levels of engagement by the implementing agencies with people with disability. It should be made up of representatives from the disability community and sector, as well as government and other external experts with relevant expertise. Appointments should prioritise people with disability, families and carers. It should have an independent chair and report to DRMC. The Advisory Committee should exist for a limited period of time until the Disability Outcomes Council (DOC) is established. At this point, it should transition into the DOC (see Action 20.5). Secretariat support should be provided by the Department of Social Services (DSS). The Advisory Committee's scope should not interfere with the lines of authority of the National Disability Insurance Agency (NDIA), NDIS Quality and Safeguards Commission (NDIS Commission) or DSS; but rather should work in partnership with agencies to ensure successful implementation of reforms.
- NDIS Review Implementation Working Group: The Working Group should coordinate implementation of reforms across all Australian governments. It should work closely with relevant Commonwealth, state and territory service delivery agencies with implementation responsibilities, including the NDIA, the NDIS Commission and the Independent Health and Aged Care Pricing Authority. It should be chaired and supported by DSS and be made up of Commonwealth, state and territory senior public servants, including from DSS, NDIA, the NDIS Commission and the Department of the Prime Minister and Cabinet. The Working Group should provide updates to the Advisory Committee. Its duration can be expected to be the five year transition period for these reforms. Recruitment should prioritise people with disability, families and carers.
- NDIS Experience Design Office: The NDIA should establish a specialist NDIS Experience Design Office function to commission and oversee a range of agile projects for the design of reforms to the participant pathway (see Action 24.3), which should be informed by subject matter experts. The Design Office should be staffed by specialists with relevant policy and service delivery design experience and subject matter expertise. Staff from DSS should be embedded

in the Design Office to provide policy expertise. Recruitment should prioritise people with disability and other lived experiences of disability. The Design Office should provide updates to the Working Group and Advisory Committee.

#### Action 24.2

### The new NDIS Review Implementation Advisory Committee should report to the Disability Reform Ministerial Council every six months or as needed.

During the limited period for which the Advisory Committee exists, it should report regularly to the Disability Reform Ministerial Council on implementation progress and risks, including the approach to inclusion of and accountability to people with disability. This should be based on updates from the NDIS Review Implementation Working Group and the NDIS Experience Design Office.

#### Action 24.3

### The new NDIS Experience Design Office should commission agile projects to design and test reforms to the participant pathway.

Projects should be appropriately resourced and delivered with different degrees of independence appropriate to requirements. All projects should include people with disability in design, testing and decision-making. Every effort should be made to ensure that the voices of people with intellectual disability, those with more complex needs and their advocates, supporters and Disability Representative Organisations are heard, as these are the people at the centre of the NDIS. Projects should follow the Australian Government Digital Service Standard to ensure robust, transparent and inclusive design and testing.

Projects to implement reforms to how information is gathered about participant needs and how people with disability are supported by Navigators should build on the principles and implementation considerations set out in the *Co-Group Feedback to the NDIS Review Panel*, developed as part of the Review's participatory engagement process (for further details on the Co-Group's work see <u>Appendix C</u>).

Once projects are complete, the Department of Social Services will take carriage of ensuring key policy parameters are reflected in the *National Disability Insurance Scheme Act 2013* and NDIS Rules following consultation and agreement through Disability Reform Ministerial Council (consistent with the elevation of policy parameters relating to entitlements, processes and obligations being elevated to the legislative framework – (see Action 21.2)).

Reforms within scope include changes to access, assessments, budget setting and navigation.

### Coordinate and consult on amendments to relevant legislation to enact proposed reforms

\*Legislative change required

#### Action 25.1

The <u>Department of Social Services</u>, with input from the National Disability Insurance Agency and NDIS Quality and Safeguards Commission, should review the recommendations from this Review and develop a proposed package of legislative reforms.

This should consider implications for the *National Disability Insurance Scheme Act 2013* and NDIS Rules, and other primary Commonwealth legislation and associated legislative instruments. A full list of recommendations and actions expected to require legislative change is provided at Appendix D.

#### Action 25.2

The <u>Department of Social Services</u> should undertake deep public consultation and engagement on proposed package of legislative reforms.

Consultation should include people with disability, families, carers, Disability Representative Organisations, providers and workers to understand and address potential concerns or unintended consequences of legislative reforms.

### Develop an implementation roadmap that factors in critical dependencies and risks and ensures a smooth transition for existing participants

\*Legislative change required

#### Action 26.1

#### National Cabinet should agree and publish an implementation roadmap.

This should be developed by the NDIS Review Implementation Working Group in partnership with the disability sector and Commonwealth and state and territory agencies with implementation responsibilities. The roadmap should ensure continuity of supports for participants throughout the transition and account for critical dependencies and risks. Critical early reforms include:

- <u>Negotiation of a new Disability Intergovernmental Agreement</u> and associated funding arrangements is essential to cement governments' commitment and align incentives for the delivery of accessible and inclusive mainstream services, sufficient foundational services and sustainable NDIS supports.
- <u>Timely passage of enabling legislation and rules</u> will be necessary to implement a range of reforms. Sequencing of reforms should consider likely timeframes for the passage of relevant legislation.
- Improved availability, quality and effectiveness of foundational supports is a necessary precondition for a range of other reforms, including for the participant pathway. Sufficient investment in and coordination of foundational supports, including building the market and workforce to deliver these supports, will be critical to better balance the NDIS and the eco-system around it and ensure that all people with disability receive the supports they need.
- Reforms to the participant pathway are essential to improve the participant experience and ensure the long-term sustainability of the NDIS. These reforms require substantial design and testing, including consultation with people with disability, which will be dependent on a significant uplift in government design capability. Successful implementation of changes is also dependent on recruiting and training the National Disability Insurance Agency (NDIA) needs assessment workforce, specialist functional capacity assessors, and delegates with decision-making responsibilities. Reforms to the pathway must be phased in to deliver benefits as soon as possible, while being carefully sequenced to avoid negative consequences to participants.
- Immediate focus on attracting, retaining and training workers to meet the future demand of the NDIS. This will require joint action across the care and support sector, making it easier for workers to move across the sector, build their skills and open up more career opportunities. This will need to be complemented by efforts to reduce pressure on demand for labour, including early intervention supports and improved uptake in technology.

- Investing in digital and data infrastructure and coordination is key to delivering a person-centred scheme, strengthening scheme integrity and improving market functioning. Well-coordinated digital and data infrastructure across the NDIS landscape underpins a range of proposed reforms and is essential for improving the experience for participants and ensuring the delivery of safe and quality supports by providers and workers. Building this capacity and capability is also necessary for the NDIS market to function well, and to strengthen measures to protect the integrity of the scheme.
- Introduction of the Navigator function is critical to help people with disability navigate the new ecosystem of disability supports to find and coordinate services and to better support participants with monitoring spending and managing funding. This function must be designed with people with disability, adequately resourced, and delivered by appropriately trained staff. Transition will need to be signalled early but implemented gradually, to minimise disruption and stress for current participants and impacts on the market.
- Effective NDIA commissioning capability is necessary to deliver key services, including Navigators, Specialist Navigators, and lead practitioners. There is a significant dependency on the NDIA having the capacity and capability to commission services to meet participants' needs and to partner with First Nations communities to enable community-led commissioning.
- Implementing reforms to quality and safeguarding will require sustained effort over a number of years, moving with urgency to address most significant areas of risk. This is likely to require a prioritised and sequenced approach, including taking account of the recommendations made by the Disability Royal Commission.
- Design and implementation of a new graduated risk-proportionate regulatory
   model for the whole provider market will be a significant change process for
   government and providers. It is dependent on development of a Provider Risk
   Framework, substantial IT upgrades and integration with NDIS payment systems
   and other whole-of-government digital infrastructure. Implementation should be
   sequenced and staged to mitigate workforce impacts in an already tight labour
   market, particularly for early childhood therapy providers.

#### Action 26.2

The <u>National Disability Insurance Agency</u> should ensure existing participants experience a smooth and fair transition to the new participant pathway.

Participants should be given sufficient time to understand changes to access and budget setting processes. It is critical that information is shared openly during the design of the processes and the disability community is involved in and helps shape the change journey.

- Changes to access and budget setting processes should be implemented together with the relevant foundational supports (see Recommendation 1).
- To provide certainty, participants should have at least a two year transition period before they could be asked by the NDIA to be considered under the new consistent and equitable approach to determining eligibility for access to the NDIS (see Actions 3.1 and 3.7).
- Children under the age of 7 would have an extended transition period until
  they turn 9 and would be transitioning from the early childhood approach.
   This means the new approach to determining eligibility for access to the NDIS
  (see Action 6.3) could be applied once a child turns 9.
- Once a participant has met access requirements through the new approach, following a functional capacity assessment, they would not be required to be reassessed unless there are exceptional circumstances (see Action 3.1).
- Transition to new budget setting arrangements for 24/7 living supports (see Action 8.1) should be graduated. Participants should be supported to explore shared support arrangements but should not need to move from their current home unless they choose to do so. They should have the opportunity to try new living arrangements before they commit to them (consistent with the approach described in Action 8.3). New participants, and those who choose to move, will access the new budget setting process and be allocated a Housing and Living Navigator to support them through the process.

#### Action 26.3

The new NDIS Review Implementation Working Group should coordinate communications across relevant agencies to regularly update and inform stakeholders on implementation progress.

The Working Group should ensure communications developed and implemented by agencies involved in reforms are coordinated and clearly help stakeholders, including existing participants and the sector, understand the reform program and what it means for them. Agencies should also provide updates covering what changes have been implemented and what are on the horizon. Communications should consider opportunities for reaching stakeholders both through existing channels and mechanisms, and where there can be innovative approaches taken.

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### Appendix A

## **Acronyms and Glossary**

## **Acronyms**

Acronym	Term
AAT	Administrative Appeals Tribunal
ADL	Assistance with Daily Life
ADS	Australia's Disability Strategy
AFSR	Annual Financial Sustainability Report
API	Application Programming Interfaces
APTOS	Applied Principles and Tables of Support
ASA	Adult Safeguarding Agencies
AT	Assistive Technology
BSP	Behaviour Support Plan
CFFR	Council on Federal Financial Relations
COAG	Council of Australian Governments Reform Council
CTG	Closing the Gap
CVS	Community Visitor Schemes
DAC	Disability Advisory Council
DDA	Disability Discrimination Act 1992
DOC	Disability Outcomes Council
DRMC	Disability Reform Ministerial Council
DRO	Disability Representative Organisation
DREF	Disability Research and Evaluation Fund
DSOA	Disability Support for Older Australians
DSP	Disability Support Pension

Acronym	Term
DSS	Department of Social Services
FFA	Federation Funding Agreement
GP	General Practitioner
HACC	Home and Community Care
IAC	NDIS Independent Advisory Council
IGA	Intergovernmental Agreement
IGR	Intergenerational Report
IHACPA	Independent Health and Aged Care Pricing Authority
ILC	Information, Linkages and Capacity Building
JSC	Joint Standing Committee on the National Disability Insurance Scheme
LAC	Local Area Coordinators
LGBTIQA+SB	Lesbian, Gay, Bisexual, Intersex, Queer or Questioning, Sistergirl and Brotherboy
MoU	Memorandum of Understanding
NDA	National Disability Agreement
NDDA	National Disability Data Asset
NDS	National Disability Strategy
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS Act	National Disability Insurance Scheme Act 2013
NDRP	National Disability Research Partnership
NIIS	National Injury Insurance Scheme
PSG	Participant Service Guarantee
SDA	Specialist Disability Accommodation
SIL	Supported Independent Living
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples

## Glossary

Word	Definition
24/7 living supports	Participants who require at least 8-hours of active support and/or supervision with activities of daily living and some level of support for the remaining hours of the day while at home, including overnight (whether active or passive assistance). For some participants, 24/7 support may entail active support for every minute of every day, however, this is only in specified circumstances.
Access list	A series of lists designed to automate and streamline access decisions for people with disability to the NDIS. <sup>384</sup> List A - a list of conditions that are likely to meet of all elements of the disability
	requirements under section 24 of the NDIS Act.  List B - a list of conditions that are likely to result in permanent impairment in line with sections 24 or 25 of the NDIS Act.
	List C - a list of programs previously funded by state and territory governments where access was deemed to be equivalent to NDIS access criteria.
	List D - a list of conditions where a child under 7 will meet early intervention requirements under section 25 of the NDIS Act without further assessment.
Adolescents	Individuals in the phase of life between childhood and adulthood — roughly between the ages of 10-19. $^{\rm 385}$
Ageing SDA	Specialist Disability Accommodation (SDA) dwellings with a design category of Basic, and all Legacy stock. The Basic design category applies to SDA dwellings that were built before 1 April 2016 (Existing SDA) without specialist design features but with a location or other features that cater for the needs of people with disability and assist with the delivery of support services. Legacy stock refers to SDA dwellings that are designed to house 6 or more long-term residents.
Annual Financial Sustainability Report (AFSR)	The AFSR provides an assessment of the financial sustainability of the NDIS and is required under the <i>NDIS Act</i> (Section 180B). It is produced using data at 30 June each year. A summary of each year's AFSR is included in the NDIA Annual Report. <sup>386</sup>
Application Programming Interfaces (APIs)	A digital tool that allows software and digital product developers to plug into parts of existing digital systems when designing and building new tools and products. APIs can be used to enable data sharing between organisations and government agencies. <sup>387</sup>
The Applied Principles and Tables of Support (APTOS)	The Applied Principles and Tables of Support (APTOS) are agreed between Australian, state and territory disability ministers. They set out roles and responsibilities of the NDIS and other service systems having regard to the funding and provision of supports to people with disability.
Assistance with daily life (ADL)	An NDIS support category that covers a range of supports, including assistance with self-care activities and assistance with household tasks, such as gardening or cleaning. It also includes community nursing supports, and short-term accommodation and assistance. Supported Independent Living (SIL) is also funded under this support category. The NDIA sometimes refers to the ADL support category as 'Core – Daily Activities' in published reports.

Word	Definition
Australian Government Digital Service Standard Criteria	A set of best-practice principles for designing and delivering government services. It helps digital teams to build services that are user-friendly, inclusive, adaptable, and measurable. <sup>388</sup>
Australia's Disability Strategy (ADS)	Australia's Disability Strategy 2021–2031 was signed by First Ministers of all Australian governments. It sets out a vision for an inclusive Australian society to ensure people with disability can fulfil their potential as equal members of the community. <sup>389</sup>
Australia's Disability Strategy Advisory Council	The Advisory Council's role is to advise Australian governments and disability ministers on the implementation of the ADS. Advisory Council members are all people with disability. 390
Behaviour support or positive behaviour support	A range of proactive strategies implemented to identify and address the underlying causes of behaviours of concern through an individual functional behavioural assessment and development of a positive behaviour support plan. <sup>391</sup>
Behaviour support plans (BSP)	A document providing evidence-based strategies to help improve the wellbeing of the person with disability who has "complex behaviours of concern". It should be prepared in consultation with the person, their supporters and others who may assist to address their needs. 392
Bilateral agreement	Bilateral agreements are between two parties and cover areas of shared interest to achieve a particular outcome. In the NDIS context, bilateral agreements are usually between the Australian Government and one other state or territory. <sup>393</sup>
Block funded	Refers to a 'traditional' model of government funded service delivery where a department, agency or other service delivery organisation receives funding in a 'block', often based on fixed criteria with respect to expected numbers of clients, or services to be delivered over a given period of time. This is often contrasted with an activity based funding model where a department, agency or service delivery organisation receives funding based on the amount of services provided, and an assumed efficient price for each service. It is also distinct from an individual funding model such as the NDIS, where a participant receives an individualised budget that they can use to purchase market-provided services and supports.
Budget setting	In the NDIS context, budget setting is the process of determining the amount of reasonable and necessary support funding included in a plan.
Cabinet Minister	Along with the First Minister of a government, Cabinet ministers form the main decision-making group within executive government – the Cabinet. A Cabinet minister's role includes directing government policy and making decisions about issues, spending time considering and discussing current problems within their portfolio of responsibilities and how these can be solved, and presenting bills – proposed laws – from their departments. <sup>394</sup>
Capability review	Capability reviews are assessments of an Australian Government agency's ability to meet future objectives and challenges. They are undertaken by the Australian Public Service Commission. <sup>395</sup>
Capacity building	Increasing people's knowledge, skills and abilities. This can apply to an individual – for example, developing their skills in a certain area to allow them to live more independently. It can also apply to a community as a whole – for example, building the capacity of organisations to be more inclusive.

Word	Definition
Care and support sector	The care and support sector describes a range of sectors involved in the provision of paid care and support. This includes aged care, disability support, veterans' care, and in some cases, early childhood education and care. For the purpose of this report, when we refer to the care and support sector, we do not include early childhood education and care. <sup>396</sup>
Choice and control	The right to make decisions about what is important, to decide what supports are required and who will deliver them. $^{\rm 397}$
Citizens' jury	A citizens' jury provides the opportunity for citizens to learn about a complex issue, deliberate together and develop well-informed, common ground recommendations or solutions to difficult public issues. The citizens' jury process also allows decision-makers and the public to discover what people really think once they have heard from a balanced range of witnesses and taken a close look at a topic. <sup>398</sup>
Commissioning	A process of purchasing supports or services from a provider or group of providers. The commissioning process could involve agreeing on what supports and services are delivered, as well as how much would be paid for delivering the support or service. Governments typically commission supports or services, but communities can also commission supports or services.
Commonwealth Mobility Allowance	A payment to people with disability or with other health conditions who need to travel for work or study but are unable to use public transport without considerable assistance. It is not available for people already receiving funded supports from the NDIS.
Community supports and activities	Supports and activities run by, in and for the local community. They include everything from local businesses to local sporting or recreational groups.
Compensation schemes	Schemes outside of the NDIS that provide payments for supports for losses or injury. These can include motor vehicle accident and compulsory third party schemes, workers compensation schemes, general insurance claims covering permanent illness or injury, and legally determined compensation arrangements.
Complex communication support needs	People who need support to communicate to meet their needs. Some people may not use spoken language and will rely on other methods of communication such as pointing or gestures. Some people use technology or a communication partner to assist them in communication. <sup>399</sup>
Complex Support Needs Pathway	A National Disability Insurance Agency term for NDIS planning for people with complex support needs. $^{\rm 400}$
Corrective measures	Measures that resolve problems, enable improvements to be identified and avoid the same problems recurring (for example, complaints processes and compliance actions). <sup>401</sup>
Council of Australian Governments	The Council of Australian Governments (COAG) was established in 1992 as the peak intergovernmental forum in Australia comprising of the Prime Minister, state and territory First Ministers and the President of the Australian Local Government Association (ALGA). Its role was to manage matters of national significance or matters that need coordinated action by all Australian governments. On 29 May 2020, National Cabinet agreed to the cessation of COAG. National Cabinet is the successor to COAG.

Word	Definition
Council of Australian Governments Reform Council	Prior to its cessation in 2014, the COAG Reform Council assisted COAG to drive its national reform agenda by strengthening accountability for the achievement of results through independent and evidence-based monitoring, assessment and reporting on the performance of governments. The Council was funded by all governments but was independent of individual governments and reported directly to COAG.
Council on Federal Financial Relations	The Council on Federal Financial Relations (CFFR) comprises the Australian Government Treasurer and all state and territory treasurers. It is the gatekeeper of the Federation Funding Agreements framework and makes sure that agreements are negotiated and administered efficiently. <sup>404</sup>
Cross-billing	In the NDIS context, cross-billing payments are made by the Australian Government to state and territory governments for supports provided to participants by state and territory service systems on behalf of the NDIS (for example, taxi subsidy schemes provided to NDIS participants).
Decision-supporters	Someone chosen by an individual to help them to make a decision. They do not make the decision on behalf of the individual and can be friends, family, carers, peer networks, advocates or support providers. <sup>405</sup>
Developmental concerns	Delay/s in the development of a child younger than 6 compared to other children of a similar age, but where the delay does not meet the definition of developmental delay in section 9 of the <i>NDIS Act</i> . <sup>406</sup>
Developmental delay	Delay/s in the development of a child younger than 6 that meets all criteria outlined in section 9 of the NDIS $Act$ .
Developmental measures	Measures that strengthen the capability of people with disability, their families and supporters, workers and providers to reduce the risk of harm and promote quality (for example, education, training and information). <sup>408</sup>
Developmentally vulnerable	Children who demonstrate a significantly lower than average ability in developmental competencies in particular domains (i.e. below the 10th percentile). 409
Dignity of risk	Supporting people to take informed risks to improve the quality of their lives.  This means rather than seeking to eliminate all risk – which can be highly restrictive and out of proportion to the level of risk involved – the NDIS should work with participants to define acceptable risk levels to achieve their goals.
Disability	Used in the context of the internationally recognised social model of disability. This is a commitment by all Australian governments under Australia's Disability Strategy 2021-31. It describes disability as a social construct. Under this model, intersecting societal barriers are the obstacles to equal participation, not people's impairment.
Disability Action Plans and Disability Inclusion Action Plans	A plan that details how an organisation will ensure its goods, services, workplace, premise and facilities are inclusive and accessible for people with disability.
Disability Reform Ministerial Council (DRMC)	Commonwealth, state and territory ministers with responsibility for disability policy meet regularly through the Disability Reform Ministerial Council (DRMC). It is established as a Ministerial Council with reporting lines to National Cabinet. For the purpose of the <i>National Disability Insurance Scheme Act 2013</i> , DRMC is the Ministerial Council with functions outlined in Part 5, s12. <sup>411</sup>
Disability Support Pension (DSP)	In Australia, the DSP is a welfare benefit payable to people with disability who are assessed as having a low capacity to work.

Word	Definition
Early childhood	The period of time between birth and 8 years old.
Early childhood approach	The way the NDIA helps children with disability and developmental concerns younger than 9 and their families access supports appropriate to their needs. <sup>412</sup>
Early childhood partner	Organisations funded by the NDIA to deliver the early childhood approach for children with developmental delay and disability younger than 9.413
Early intervention	Providing support as early as possible to reduce the impact of disability or developmental delay and build skills and independence. <sup>414</sup>
Early supports	A short-term program delivered by early childhood partners aimed at addressing specific concerns about a child's development and building family capacity. <sup>415</sup>
Enrolled provider	Enrolment reflects the Review's recommendation and means a person or organisation that undergoes a process of enrolment to deliver lowest-risk supports under the National Disability Supports Commission (see Recommendation 17).
Evidence based support	Supports provided where there is evidence that the support is effective and beneficial for someone with similar needs and circumstance. 416
Federation Funding Agreement	When an agreement involves funding from the Australian Government to the states and territories, it is covered under the Intergovernmental Agreement (IGA) on Federal Financial Relations. Under the IGA on Federal Financial Relations, payments to the states are outlined through schedules to one of five overarching sectoral Federation Funding Agreements or through one of the National Agreements. <sup>417</sup>
Formal safeguards	Rules and the actions that are taken by organisations with formal responsibility for the safety of people with disability. 418
Foundational supports	Disability-specific supports that are available for and benefit people with disability, families and carers outside of NDIS individual budgets.
General foundational supports	Disability-specific supports that are available to benefit all people with disability, and where appropriate, their families and carers and people aged over 65. This includes information and advice and peer support.
Group homes	Homes where multiple people with disability, often five or more, live together under a single roof and receive support. They usually have a separate room for a support worker to provide onsite overnight assistance. Apart from staff, only people with disability reside in the dwelling. Each person has their own bedroom, while common areas, like a kitchen, bathroom or dining room, are shared with all the people living in the home. Group homes are generally provider-led, where the rhythm of everyday life is dictated by staff and service providers and residents have little or no say over who they choose to live with.
Home and community care programs	State and territory programs that deliver lower intensity disability care supports, such as personal and domestic assistance (including cooking and cleaning) to support people with disability live as independently as possible. Programs are targeted at people with disability aged under 65 and Aboriginal and Torres Strait Islander peoples aged under 50, who do not have an NDIS individualised budget.

Word	Definition
Housing and living	In this report we use the term 'housing and living', rather than 'home and living', to directly recognise that there are two distinct but interrelated components to the supports of interest to this Review — housing supports (i.e. accommodation and the built environment) and living supports (i.e. support to assist participants with activities of daily living). When working together well, these housing and living supports should create a sense of home for people with disability.
Inclusive and accessible	Inclusion is where everyone is treated equally and has an active role in society. Inclusive and accessible services and communities ensure people with disability can access appropriate support and participate as equal members of society.
Individual budgets	NDIS funding that is individually determined and made available to a single person.
Information, Linkages and Capacity Building – (ILC)	ILC is a set of supports designed to increase the capacity of people with disability, their families and carers to achieve their goals and increase the capacity of the community to be more inclusive. Originally, ILC was known as Tier 2.
In-kind programs	Some pre-existing programs funded and provided by governments which provide reasonable and necessary supports to people with disability on behalf of the NDIS. When these supports are provided to an NDIS participant, the government that delivers the service receives a discount to their contributions to the NDIS to the value of the supports provided to the participant (i.e. the cost of the service provided to the participant is considered an "in-kind" contribution to the NDIS).
Intergenerational Report (IGR)	The Intergenerational Report is produced by the Australian Government. It projects outlooks for the Australian economy and the Australian Government's budget over the next 40 years. It examines the long-term sustainability of current policies and how demographic, technological and other structural trends may affect the economy and the budget. <sup>419</sup>
Intergovernmental Agreement	An intergovernmental agreement (IGA) is an agreement made between the Australian Government and state and territory governments. While IGAs are not legally binding, they express the commitment of governments to work together on certain objectives or goals. <sup>420</sup>
Intermediary	An individual or organisation who acts as a 'middle person' in assisting participants to interact or engage with others, including providers.  Intermediaries in the NDIS include roles such as: local area coordinators, early childhood partners, support coordinators, remote community connectors and plan managers.
Lead practitioner	An allied health, developmental or early childhood educator who is the main professional working with the family. They help coordinate the team around the child, provide information and advice, emotional support, identify and address needs and support the family to develop self-advocacy skills.
LGBTIQA+SB	Lesbian, Gay, Bisexual, Intersex, Queer or Questioning, Sistergirl and Brotherboy. Sistergirl and Brotherboy are culturally distinct queer identities in First Nations communities. These terms are also used as terms of endearment throughout First Nations communities.

Word	Definition
Local area coordinators	A contractor funded by the NDIA to deliver a range of coordination services in a particular location to people with disability aged 9 or older and their families. 421
Longitudinal data	Longitudinal data refers to a dataset where observations regarding a given individual, business or other unit of observation is collected repeatedly over time. This is often also referred to as panel data. A balanced panel implies that for each time period in the sample, there are a complete set of observations for each individual or observational unit in the panel. An unbalanced panel refers to the situation where not every individual or observational unit may record the
	full set of observations in every time period.
Mainstream services	Mainstream services (also known as universal or essential services) are government services outside the NDIS that all Australians can access and benefit from, regardless of whether or not they have a disability. They include things like health care, education, transport, and employment services.
Market stewardship	The market stewardship role of governments is to support: informed participant choice; continuous improvement in service quality and effectiveness; access to quality supports; and appropriate regulation and safeguards for people with disability. A number of government agencies have a market stewardship role of NDIS markets.
Medicare	Australia's universal health insurance scheme that provides guaranteed access to a wide range of health and hospital services at low or no cost.
Multilateral agreement	A multilateral agreement is an agreement between the Australian Government and more than one other party. Within disability, multilateral agreements are agreements between the Australian Government and more than one state and/or territory
National Agreement on Closing the Gap	The National Agreement on Closing the Gap (2020) is a commitment by all Australian governments and First Nations people as represented by the Coalition of Peaks to work in new ways to drive better outcomes.  These outcomes are represented through the four Priority Reforms and 17 socio-economic targets.
National Cabinet	National Cabinet is a forum for the Prime Minister, Premiers and Chief Ministers to meet and work collaboratively. It is the successor to the former Council of Australian Governments. <sup>422</sup>
National Injury Insurance Scheme	A program designed alongside the NDIS to provide lifetime care and support on a no-fault basis to individuals who suffer a catastrophic injury resulting in substantial and permanent disability. Intended to be established for four types of injuries: motor vehicle accidents, workplace accidents, medical accidents and general accidents (occurring in the home or community).
Natural safeguards	Actions and features that are part of people's day-to-day lives and support them to manage their safety (also called informal safeguards).423
Natural settings	Places where children live, play and learn like the family home, school or early childhood education and care or community.
NDIS Independent Advisory Council	The Independent Advisory Council (IAC) is established under Part 3 of the <i>National Disability Insurance Scheme Act 2013</i> and represents the participants' voice in the NDIS. The IAC has a statutory function to advise the NDIA Board on the most important issues affecting participants, carers and families. <sup>424</sup>

Word	Definition
NDIS outcomes framework	Surveys that measure the outcomes of NDIS participants and their family members and supporters over time. The surveys ask NDIS participants about how their lives are changing in areas like daily living, choice and control, health and wellbeing, relationships, community participation, work and learning. Family members and supporters are also asked about their experiences while caring for a person in the scheme.
Nominees	A person appointed to act for or make decisions on behalf of a participant. Nominees can be appointed by participants or courts, and can be child representatives, correspondence nominees or plan nominees. <sup>425</sup>
Participant	A person who meets the NDIS access requirements. <sup>426</sup>
Participant journey	The path of interactions a person who meets the NDIS access requirements takes to access NDIS-funded supports.
Participant pathway	The interactions that a participant experiences in relation to the NDIS. This includes learning about the NDIS, applying for the Scheme and planning. <sup>427</sup>
Participant Service Guarantee (PSG)	The Participant Service Charter includes timeframes for the NDIA's processes – set out under the Participant Service Guarantee and legislated through the <i>NDIS Act</i> . The NDIA must make decisions about access, plan approvals, plan reviews and nominee changes within these timeframes. This gives participants, families and carers greater certainty about how long processes will take. Each quarter, the Agency reports against Participant Service Guarantee timeframes in the Quarterly Report. <sup>428</sup>
Person with disability	A person who has any or all of the following: impairments, activity limitations (difficulties in carrying out usual age-appropriate activities), and participation restrictions (problems a person may have taking part in community, social and family life). <sup>429</sup>
Personal Care In Schools	Disability-related supports provided by state and territory governments to students to assist them with routine activities in school. This assistance generally covers meals, toileting and personal hygiene, dressing, mobility, along with complex supports (i.e. medicine, health supports).
Plan inflation	In the NDIS context refers to the increase in plan values between participant plans, usually every 12 months.
Planning process	The process of developing a plan, including evidence gathering, planning meetings, the discussion of a participant's goals and aspirations and the statement of participant supports. <sup>430</sup>
Positive rights-based	The culture and approach providers should have in place when delivering behaviour support and restrictive practices that is focused on improving the quality of life and protecting the rights of people with disability.
Preventative measures	Measures that proactively regulate providers and workers to reduce the risk of harm and promote quality (for example, provider registration and worker screening). <sup>431</sup>
Provider of last resort	A provider who is responsible for delivering an essential support or service when the market fails and there is no other timely way to deliver these supports or services. The provider can be a government or non-government organisation.

Word	Definition
Psychosocial disability	Arises from the interaction between a person with a long-term mental health condition (that may be episodic) and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. 432
Psychosocial supports	Supports for people with psychosocial disability to rebuild and maintain connections, manage daily activities, build social skills and participate in education and employment. <sup>433</sup>
Quality	The extent to which supports meet or exceed a person's needs and expectations. <sup>434</sup>
Reasonable and necessary	The test for determining whether a support should be funded by the NDIS in a participant's plan. $^{\rm 435}$
Registered provider	A person or organisation that undergoes a process of registration to deliver supports under the current NDIS Quality and Safeguards Commission (or future National Disability Supports Commission). <sup>436</sup>
Residential aged care	Aged care homes (sometimes known as nursing homes or residential aged care facilities) for older people who can no longer live at home and need ongoing help with everyday tasks or health care. <sup>437</sup>
Restrictive practices	Practices or interventions that restrict the freedom of movement or rights of a person with disability. <sup>438</sup>
Risk-proportionate regulation	A risk-based approach allows a regulator to properly assess the risks of non-compliance and respond in a proportionate way to the harm being managed. 439
Safeguards	Actions designed to protect the rights of people to be safe from the risk of harm, abuse and neglect, while maximising the choice and control they have over their lives. 440
Safety	Typically means being free from injury or danger. It does not matter if the injury or danger is intentional (on purpose) or unintentional (by accident). <sup>441</sup>
Shared supports	Refers to shared living supports. The term is agnostic to the setting in which supports are delivered. Supports can be shared across a household living together under one roof, but they can also be shared amongst a resident group that have their own apartments in a single development or separate but co-located homes embedded within the community.
Social security	Social security refers to a system of social welfare benefits, payments or services available to people on the basis of particular socio-economic needs.
Specialist Disability Accommodation (SDA)	Housing with specialised design features available to participants with extreme functional impairment and/or with very high support needs. SDA funding can be included in a participant's plan and is paid directly to SDA providers to cover building and maintenance costs.
Specialist School Transport	Disability-related transport supports provided by state and territory governments to students to safely transport students with disability to and from school.
Substitute decision- making	Processes and arrangements that involve someone making decisions on another person's behalf. Can include appointment of guardians, administrators and financial managers. <sup>442</sup>

Word	Definition
Substitution effects	In the context of the NDIS, this refers to the replacement of particular government funded disability services, supports or assistive technologies outside the NDIS with broadly equivalent NDIS funded disability services, supports or assistive technologies.
Supported decision-making	Processes and arrangements that involve supporting individuals to make decisions about their lives, rather than making decisions for them. <sup>443</sup>
Supported Independent Living (SIL)	A type of living support for participants with a higher level of support need – that is, those who require 8 or more hours of active support and/or supervision per day to complete daily activities as well as some level of support for the remaining hours of the day, i.e. 24/7 support. Generally, only participants over the age of 18 are eligible for SIL and support is shared, although not always.
Supports	Within the disability community and the NDIS, it means 'an activity or service that the NDIS provides funding for'.
Sustainability of the NDIS	Where the NDIS provides supports that are reasonable and necessary, demonstrably net-beneficial, and cost-effective. Governance arrangements provide clear accountabilities for managing lifecycle costs and financial risks. Scheme expenditure is predictable and provides benefits to participants, carers and the broader community, ensuring that Australians remain willing to contribute to it in an enduring manner.
Targeted foundational supports	Early intervention and low intensity care supports that are primarily for specific groups of people with disability outside the NDIS who are in most need of additional support. Some NDIS participants may prefer targeted foundational supports from supports available as part of their individualised budget. This includes things like home and community care supports (such as shopping and property maintenance) for people with chronic-health related conditions and other disabilities, aids and equipment, early supports for children with development concerns and psychosocial support services.
Taxi subsidy schemes	Financial assistance provided by state and territory governments to people with disability that subsidises their taxi travel needs.
National Disability Supports Quality and Safeguards Commission	The new National Disability Supports Quality and Safeguards Commission reflects the Review's recommendation to expand the coverage of the current NDIS Quality and Safeguards Commission to regulate all Australian Government funded disability supports (see Recommendation 19).
Thin markets	A market where the supply or availability of supports is too low, or the demand for supports is too low or spread out for competition between multiple providers to occur. In the NDIS, thin markets most commonly occur in rural and remote areas, but can also occur in metropolitan areas, where there is a specific support need – such as for specialist or culturally informed services.
Tier 2	The term Tier 2 originated from the 2011 Productivity Commission report into Disability Care and Support – which set out the design of the NDIS. Tier 2 referred to the types of supports people with, or affected, by disability may need to access. This included things like information, linkages and referrals. In 2015, all governments agreed to rename Tier 2 as Information, Linkages and Capacity Building (ILC). <sup>444</sup>
Transitioned participants	Participants who were accessing defined Australian Government, state or territory specialist disability support programs in operation prior to the NDIS and entered the scheme through Bilateral Agreements between the Australian Government and individual states and territories.

Word	Definition
Unauthorised restrictive practice	In the NDIS, this is where a restrictive practice is used by a provider or worker without receiving authorisation from the relevant state or territory authority, or not used in accordance with a behaviour support plan. <sup>445</sup>
Unregistered provider	Under current arrangements, a provider that supports an NDIS participant, but is not registered as an NDIS provider.446
Utilisation rate	Refers to the amount that a participant spends of their allocated NDIS plan budget, usually expressed as a percentage.
Western concept	Consistent with the social model of disability, the recognition of disability as a 'western concept' acknowledges that 'disability' as it has been traditionally understood and represented in Australian policy and systems is based on a western cultural ideals and values.

#### Appendix B

## **Terms of Reference**

### Building a strong, effective NDIS

#### Context

The NDIS aims to improve the wellbeing of Australians by investing and empowering people with disability and supporting them to achieve their goals and participate in the community and economy.

The NDIS takes a lifetime approach to achieving these outcomes, investing in people with a disability early to improve outcomes later in life and improve system sustainability.

An effective NDIS will improve outcomes for:

- people with disability and their families and carers, helping them achieve their life goals and participate in social and economic life; and
- society, by strengthening communities and reducing avoidable system costs, including social security, employment, health, housing and justice.

There will be two parts to the Review:

Part 1 will examine the design, operations and sustainability of the NDIS covering issues outlined in the full-Scheme bilateral agreements between the Commonwealth and jurisdictions.

Part 2 will examine ways to build a more responsive, supportive and sustainable market and workforce.

An overarching objective for both parts of the Review will be to put people with disability back at the centre of the NDIS, restoring, trust, confidence and pride in the NDIS amongst them and their families and carers as well as the broader Australian community, while ensuring the sustainability of the scheme so that future generations receive the benefit of the NDIS.

### Part 1: Design, operations and sustainability of the NDIS

#### **Objectives**

The Independent Review Panel will make findings and recommendations to Disability Reform Ministers on:

- a. the participant experience and costs of engaging with the Scheme and opportunities to rebuild trust and improve key scheme design and administration, including by examining:
  - the user journey, including awareness and access to the scheme, assessment,
     planning, review processes, and navigation of supports and key transition points;
  - ways to improve the evidence-based understanding and usage of services covered in a plan now and over time;
  - ways to improve and make more timely decision making in relation to home modification, assistive technology and accommodation; and
  - ways to ensure participants are well informed and supported as relevant remaining in-kind services are transitioned into the NDIS.

With a view to putting people with disability back at the centre of the NDIS.

- b. the effectiveness and sustainability of the NDIS, including the achievement of participant meaningful employment and lifetime outcomes and broader social and economic benefits, through the provision of reasonable and necessary supports and consider:
  - the effectiveness of: Information, Linkages and Capacity Building; Local Area
     Coordination and Community Connectors; and early childhood early intervention;
  - the suitability of the NDIS outcomes framework and data to measure effectiveness, and options to improve the ongoing monitoring and evaluation of the Scheme's effectiveness, including economic and social participation for participants and their families; and
  - the fiscal sustainability of the scheme, including the longer term fiscal trajectory.
- c. ways to better ensure the delivery of value and outcomes for participants and government, including capacity building and assistive technology supports;
- d. scheme governance arrangements and the extent they support effective operation of the scheme, including the roles and interaction between the NDIA and NDIS Quality and Safeguards Commission and DSS, and the NDIA's and the NDIS Quality and Safeguards Commission operational models and costs;
- e. efficiencies within the Scheme and improving the interaction between the NDIS and other significant related policies and systems, including mainstream services delivered by the Australian Government, the states and territories, local government, and the community sector;

- f. whether there has been any service and financial impact, positive or negative, on other service systems and programs and the adequacy of supports for people with disability outside the NDIS; and
- g. financial risks and the drivers of cost pressures, and the most appropriate levers to manage these risks and cost pressures.

## Part 2: Building a more responsive and supportive market and workforce

#### **Objectives**

The Independent Review Panel will make findings and recommendations to Disability Reform Ministers on reforms to:

- h. foster and steward an innovative, effective and sustainable market where providers (commercial or otherwise) invest, grow and improve outcomes for participants and the Scheme;
- improve the pricing and payment system to incentivise providers to improve outcomes for participants, improve productivity, support workforce development and ensure market and system sustainability;
- j. improve access to supports in thin markets including cultural and regional, remote and very remote communities and service categories – and ensure participants with complex needs have continuity of support where a provider withdraws from the market;
- attract, build and retain a capable workforce, including employment and training models that enhance participant experience and worker attraction, retention and career pathways;
- ensure adequate supply of appropriate and cost-effective accommodation and supports, including specialist disability accommodation, medium-term accommodation and supported independent living and individualised living options;
- m. improve consumer information and dissemination on supports / services (type of service, price, quality and availability) and the role of intermediaries to make it easier for participants and carers to find value for money supports that meet their needs and deliver outcomes;
- n. ensure the adequacy and effectiveness of the operation of the Quality and Safeguards Framework in ensuring quality, addressing conflicts of interest, and providing appropriate protection for participants;
- o. improve the efficiency and effectiveness of current price setting and regulatory functions (market oversight, monitoring and enforcement), including interaction with other relevant Commonwealth, state and territory regulatory systems; and
- p. improve performance monitoring, compliance, reporting and responses to breaches, unscrupulous behaviour, including the detection of fraud and sharp practices.

The Independent Review Panel will consider interactions across the broader care and support sector, including aged care, veterans' care and primary health care, as well as broader community based activities, and identify how programs could achieve better outcomes through an integrated approach.

### **Approach**

#### The Review will:

- analyse challenges to the effectiveness of the NDIS and the NDIS market and
  workforce, and opportunities to improve their effectiveness to support people with
  disability and their families and carers, helping them achieve their life goals and
  participate in social and economic life. This includes analysis of barriers to accessing
  and navigating the NDIS;
- consult widely to ensure participant, provider and community feedback and, where necessary, draw on specialist expertise while managing demands on those consulted;
- examine barriers that have affected the operation of the NDIS and the NDIS market and the development of a capable workforce, including an assessment of the impact of major policy changes, regulation and interaction with other systems;
- co-design directly with participants, carers and their families, and providers and workers, and prioritise potential reforms to improve the responsiveness and capability of the NDIS and the NDIS market to ensure they deliver for Australians with a disability and their families and carers, and society more broadly; and
- review the reasons for ongoing significant upward revisions of cost pressures on the scheme and identify options to ensure scheme sustainability and manage future financial risks, including growth in scheme costs.

The Independent Review Panel will be guided by Australia's commitments under the United Nations Convention on the Rights of Persons with Disabilities, Australia's Disability Strategy 202131 and the National Agreement on Closing the Gap.

It will apply best practice for designing policy that supports people with disability. This will include consideration of the needs of First Nations participants and participants with a range of lived experiences including in relation to gender, culture, socio-economic status, age, and sexuality to ensure the NDIS is catering to the diversity of participant needs and intersections between them. The Independent Review Panel will also have careful regard to the findings and proceedings of previous and ongoing reviews and inquiries, including the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and the National Autism Strategy, so that input already provided by the disability community is fully taken into account.

The Panel will also identify and provide advice on ways to monitor and manage implementation risks.

### Governance

An Independent Review Panel – comprising Professor Bruce Bonyhady AM (co-chair), Ms Lisa Paul AO PSM (co-chair), Mr Kevin Cocks AM, Ms Judy Brewer AO, Dr Stephen P King, Mr Dougie Herd and Ms Kirsten Deane OAM – will report directly to Disability Reform Ministers. Professor Bonyhady will lead Part 1 of the Review, Design, operation and sustainability, and Ms Paul will lead Part 2 of the Review, Building a more responsive and supportive market and workforce.

The Independent Review Panel will be supported by a Secretariat in the Department of the Prime Minister and Cabinet comprising Commonwealth, State and Territory officials as well as people with sector and workplace relations experience. The Secretariat will seek expert opinions where needed, including independent actuarial advice.

### **Timeframe**

A final report is to be provided by the Independent Review Panel to Disability Reform Ministers by October 2023. Where specific opportunities for reform are identified prior to the final report, the Independent Review Panel may bring forward recommendations and a supporting paper on these to Disability Reform Ministers ahead of the final report.

# Genuine engagement to inform our Review

We committed to doing this Review differently than other government reviews. We committed to consulting widely and engaging directly with as many people as possible — people with disability and their families, carers, representative organisations, providers and workers.

We provided lots of different ways for people to have their say and share their feedback and ideas for change. We particularly wanted to make sure we created space for people who don't usually participant in government reviews and inquiries.

In addition to making sure people had lots of chances to have their say we also committed to keeping everyone up to date with our work. Again we tried lots of different ways to keep people updated and to reach different audiences. Unusually for a government review, we also committed to sharing our thinking about what needed to change and how even before the final report was released.

We did all of these things because we know just how important the NDIS is to the disability community.

### Our approach to engagement

We took a staged approach to engagement.

**Stage One** focused on listening to people with disability, their families and the organisations that support them about their biggest concerns with the scheme. We knew that many of the problems in the scheme were well known and had been covered by many other reviews and inquiries. So to make sure people did not have to tell their story all over again we also looked at the reports of all of those inquiries as part of this first stage.

**Stage Two** began in May 2023. We called this the "designing solutions" stage. In June we released our *What We Have Heard* Report, which summarised everything we had heard in the first stage. Based on what we had heard we identified the biggest challenges facing the scheme. We then asked people for their ideas about how to fix them

**Stage Three** began at the end of August. We started sharing our ideas for change and asking people for feedback.

### Different ways to engage

Throughout all the stages we wanted to provide lots of different ways for people to share their experience with the NDIS and all their ideas about how to improve how it works.

Some of our activities included:

- An online submission process
- A survey
- Organising large roundtables
- Organising small meetings both in person and online
- Holding individual sessions both in person and online
- Holding webinars and "town hall" style meetings
- Partnering with organisations to hold workshops, meetings and focus groups
- Partnering with Disability Representative Organisations
- Meeting regularly with a small group of people with disability and their families to focus on changes to the access and planning process.

To make sure we heard from as many people as possible, we welcomed submissions in different formats, including written, verbal by phone, video, Auslan, artwork and poetry.

In the end we received 3,976 submissions. We are very incredibly grateful to everyone who made the effort to help us understand their experiences, their concerns and ideas for change. All helped inform and guide our work.

We also participated at workshops, conferences, meetings and events led by the disability community. We listened to ideas on how to improve and enrich the lives and outcomes of people with cognitive impairment, people with psychosocial conditions, autistic people, children and young people with disability or developmental concerns and their families, people with complex communication and support needs, people with neuro-muscular and physical disabilities, people with vision impairment, hearing loss or who are deaf.

We visited every state and territory and ran forums and workshops involving a wide range of stakeholders. This included a visit to the Northern Territory, where we were welcomed into the First Nations communities in the Tennant Creek and Ali Curung Barkly regions. We have also learnt how people from culturally and linguistically diverse communities have had to deal with the additional barriers caused by language.

We listened to early childhood advisors with deep experience and commitment to working with children and families. We participated in mental health workshops, hearing from consumers and carers about their experiences and ways they could be better supported to manage episodic or fluctuating conditions.

We are incredibly grateful to the thousands of people we have met over the past 12 months. You have been so generous in sharing your experiences, feedback and ideas for change. It has had a profound impact on our thinking and our work.

### Snapshot of listening to the community

We partnered with a number of community organisations who organised events and activities for their communities. We hoped people would feel comfortable and safe to share their experiences if sessions were run by organisations that people trusted.

We partnered with Every Australian Counts to hold 10 virtual workshops, inviting people living in rural, regional and metropolitan areas in every state and territory to come along and talk about the issues that mattered most to them.

We heard that lack of services and support stopped people from taking part in their local communities. We heard the fear of that many older parents feel wondering what will happen to their adult children when they are no longer able to care for them. Insecure housing, uncertain funding and a lack of connection to community leave parents worried about what will happen in the future.

We listened to simple, powerful ideas about how to create community peer networks to work alongside disability supports and ordinary government services, so that people were genuinely part of their local communities, not segregated from them.

To hear directly from autistic people, we asked Autism Queensland (AQ) as part of the national Autism Alliance to consult with autistic people and their families across Australia.

AQ and the Autism Alliance coordinated and facilitated engagement with autistic people, their families and communities through surveys, individual and group engagements, and creative submission. This gave us a deeper understanding of their experiences and interactions with the NDIS, to help inform our ideas for change.

### Participatory engagement on two core ideas

For most of this year we have worked in close collaboration with a small group of people with lived experience of disability to test and improve some of our ideas. We called this stream of our work "participatory engagement".

We brought together people with disability, people with operational and service delivery expertise, and sector representatives to help us test two ideas for reforming how participants interact with the NDIS. We tested views on the desirability, fairness, feasibility and sustainability of the ideas, and gathered extensive feedback on important principles and considerations for their implementation.

The ideas we tested were:

- Idea 1: A simpler way to gather information about people and their needs.
   Assessment of need, separating budget setting and planning.
- Idea 2: A better way for participants and families to get the support they need
   Navigation and community capacity building.

These parts of the design of the NDIS have a significant impact on all people with disability, their families and the boarder disability community. The process for testing these ideas aimed to understand 'what' people with disability and the sector wanted and 'how' it might be possible to deliver it.

The participatory engagement process was conducted by the NDIS Review Secretariat over five months and included:

**12 sessions with people with lived experience** (26 people)

**3 sessions with service providers** (9 people)

3 sessions with NDIA staff and intermediaries (10 people)

8 sessions with a Co-Group

(12 people with lived experience and disability sector expertise)

The aim of this process was to test our assumptions about key reforms to the participant experience, and adapt those ideas based on feedback. Although this process only involved a small sample of the diverse disability community, repeat sessions with the same groups enabled insights from the Review's broader engagement to be discussed and tested. The ideas then evolved throughout the process.

The Co-Group played an important role in allowing us to go deeper and tackle difficult questions on how to balance competing interests and trade-offs. The Co-Group brought deep sector and lived experience to support and inform the evolution of our ideas.

We acknowledge that this process was not true co-design. The Review's timelines and the significant work that had already occurred through previous reviews meant that we thought deep testing of key ideas was the best use of the limited time we had available. We firmly believe that this must be the first stage of design with, and accountability to, people with disability and the sector more broadly.

We extend our sincere thanks and gratitude to all who participated in this process, for the time they dedicated and their generosity in sharing their experience and ideas. The Co-Group's feedback to the Review will be published on the NDIS Review website later this year.

## Partnering with Disability Representative Organisations

It was important to us to engage with people in a trauma informed and supportive way. To do this, we partnered with a number of national Disability Representative Organisations (DROs) who coordinated targeted engagement and open consultations with the community on behalf of the Review.

We know that these organisations who represent millions of Australians with disability are trusted by their communities. Partnering with DROs enabled us to reach many more people, who generously shared their lived experience, insights and ideas for improvement in safe, trusted spaces. Partnering in this way also gave us the opportunity to hear the experiences of people with disability who are not often heard.

## Interviews and focus group sessions with sector and technical experts

We conducted interviews and small focus group sessions with sector experts and NDIS frontline staff who work with participants and their families as Planners and Partners in the Community. We wanted to better understand, from people with lived experience and direct sector expertise, what is driving the current participant experience and what could be improved.

#### We conducted

15 interviews and small group sessions with existing Partners in the Community (Partners) from February to April 2023. Partners play a critical role supporting people with disability and their families to access support in the community.

**22** interviews and small group sessions with NDIA Planners from February to March 2023 to better understand their role, the experience of plan development and what could be improved.

### **Engagement with state and territory governments**

In addition to our extensive engagement with the disability community, we also met regularly with officials from state and territory governments.

State and Territory Disability Reform Ministers were kept informed of the Review's progress through regular updates to the Disability Reform Ministerial Council.

This included reporting back what we had heard and what we thought it meant for the NDIS and broader system.

The Review Secretariat also set up an NDIS Review Senior Advisory Group made up of senior disability officials from each state and territory and the Australian Government. This group was engaged regularly throughout the Review on key ideas and impacts on state and territories, through a combination of meetings and full-day workshops.

We are grateful to the states and territories for generously offering their expertise and time to help the Review.

## Legislative changes

The Review has identified that the following actions may require legislative change to implement. The nature of these changes should be confirmed by the Department of Social Services' in developing a proposed package of legislative reforms (see Action 25.1).

## A unified system of support for people with disability

- Action 1.2: The <u>Department of Social Services</u>, with state and territory governments, should develop and implement a Foundational Supports Strategy.
- Action 2.1: The <u>Attorney General's Department</u>, with the Department of Social Services and the states and territories, should develop a unified and contemporary approach to disability rights, discrimination and inclusion legislation.
- Action 2.3: The <u>Department of Social Services</u> with relevant agencies should develop and trial a mechanism to publicly communicate the performance of current Disability Standards under the *Disability Discrimination Act 1992*.
- Action 2.4: <u>All Australian governments</u> should incorporate Disability Impact Assessments into new policy proposal assessment processes.
- Action 2.5: <u>All Australian governments</u> should take steps to protect the right to inclusive education for children with disability and developmental concerns in early childhood education and care and schools.
- Action 2.6: <u>National Cabinet</u> should agree to a multilateral schedule to a new
  Disability Intergovernmental Agreement that replaces the principles for determining
  the responsibilities of the NDIS and other service systems, including the Applied
  Principles and Tables of Supports to better clarify respective responsibilities.
- Action 2.11: The <u>Australian Government</u> should implement legislative change to allow participants once they turn 65 to receive supports in both the NDIS and the aged care system concurrently and clarify when aged care supports are reasonable and necessary.
- Action 2.12: The <u>Australian Government</u> should implement legislative or process change to allow access to the NDIS for Disability Support for Older Australians program participants.

- Action 2.16: The <u>Disability Reform Ministerial Council</u> should agree to cease the use of 'in-kind' arrangements in the NDIS.
- Action 3.1: The <u>National Disability Insurance Agency</u> should introduce a more consistent and robust approach to determining eligibility for access to the NDIS based on transparent methods for assessing functional capacity.
- Action 3.3: The <u>National Disability Insurance Agency</u> should change the basis for setting a budget to a whole-of-person level, rather than for individual support items.
- Action 3.4: The <u>National Disability Insurance Agency</u> should introduce new needs assessment processes to more consistently determine the level of need for each participant and set budgets on this basis.
- Action 3.5: The <u>National Disability Insurance Agency</u> should allow greater flexibility in how participants can spend their budget, with minimal exceptions.
- Action 3.6: The <u>National Disability Insurance Agency</u> should adopt a trust-based approach to oversight of how participants spend their budget, with a focus on providing guidance and support.
- Action 3.7: The <u>National Disability Insurance Agency</u> should reform the NDIS early intervention pathway to provide supports to individuals where there is good evidence the intervention is safe, cost effective and significantly improves outcomes.
- Action 3.8: The <u>National Disability Insurance Agency</u> should implement reforms to the participant pathway using an iterative, inclusive approach to design and testing, and ensure participants experience a smooth transition to the new arrangements.
- Action 3.9: The <u>Australian Government</u> should update and clarify legislation to support a more effective approach to determining access.
- Action 5.5: The <u>National Disability Insurance Agency</u> should reform the approach to appointing nominees, provide improved training and information to nominees, and increase oversight of nominee decisions.
- Action 6.2: The <u>National Disability Insurance Agency</u> should reform the pathway for all children under the age of 9 to enter the NDIS under early intervention requirements.
- Action 6.3: The <u>National Disability Insurance Agency</u> should introduce a more consistent and robust approach to assessing developmental delay.
- Action 6.4: The <u>National Disability Insurance Agency</u> should change the basis for setting a budget to a whole-of-person level, and introduce a new needs assessment process to more consistently determine the level of need for each child and set budgets on this basis.
- Action 6.5: The <u>National Disability Insurance Agency</u>, in partnership with the Department of Social Sservices and the National Disability Supports Quality and Safeguards Commission, should require early intervention capacity building supports for children be based on best practice principles and evidence.

- Action 6.6: The <u>National Disability Insurance Agency</u> should develop and implement an approach for ongoing monitoring and evaluation of the effectiveness of early intervention for children.
- Action 7.1: The <u>National Disability Insurance Agency</u> should introduce a new approach to psychosocial disability in the NDIS based on personal recovery and optimising independence.
- Action 7.2: The <u>National Disability Insurance Agency</u> should establish an early intervention pathway for the majority of new participants with psychosocial disability under section 25 of the <u>National Disability Insurance Scheme Act 2013</u>.
- Action 8.1: The <u>National Disability Insurance Agency</u> should change the budget setting process to ensure that housing and living budgets are consistent and sustainable.
- Action 9.4: The <u>National Disability Insurance Agency</u> should remove the Improved Liveability category for new Specialist Disability Accommodation (SDA) developments, and review the remaining SDA categories and associated Design Standards to evaluate their effectiveness.
- Action 9.5: The <u>Australian Government</u> should transition responsibility for advising on Specialist Disability Accommodation pricing to the Independent Health and Aged Care Pricing Authority and introduce more flexibility to the way prices are set.
- Action 9.7: The new <u>National Disability Supports Quality and Safeguards Commission</u> should strengthen Specialist Disability Accommodation (SDA) regulation to ensure dwellings are managed in accordance with the needs of participants and mandate the separation of SDA and living support providers.
- Action 9.9: The <u>National Disability Insurance Agency</u> should amend its change of circumstance and Specialist Disability Accommodation (SDA) policies to reduce the bedroom count of ageing SDA dwellings.
- Action 9.10: The <u>National Disability Insurance Agency</u> should introduce a new Specialist Disability Accommodation (SDA) category for participants funded for shared living supports but not eligible for existing categories of SDA.

# Markets and support systems that empower people with disability

- Action 10.5: The <u>Australian Government</u> should develop and implement a clear transition path for existing Plan Managers.
- Action 11.1: The <u>Department of Social Services</u> should develop a new NDIS pricing and payments framework to be administered by the National Disability Insurance Agency and the Independent Health and Aged Care Pricing Authority, including better ways to pay providers to promote the delivery of efficient and quality supports and continuity of supply.

- Action 11.3: The <u>Australian Government</u> should transition responsibility for advising on NDIS pricing to the Independent Health and Aged Care Pricing Authority to strengthen transparency, predictability and alignment.
- Action 12.2: The new <u>National Disability Supports Quality and Safeguards</u>
   <u>Commission</u> should make quality improvement a priority in capacity-building initiatives and audit processes.
- Action 12.3: The new <u>National Disability Supports Quality and Safeguards</u>
   <u>Commission</u>, working with the Department of Social Services, should design, test and implement an approach to measure and publish metrics of registered provider performance.
- Action 16.2: The <u>National Disability Insurance Agency</u> should design, pilot and implement a new individual risk assessment and safeguard building process.
- Action 16.4: <u>State and territory governments</u>, with support from the Department of Social Services, should ensure participants can access high-quality, nationally consistent Community Visitor Scheme offerings that interface with the NDIS.
- Action 16.5: <u>State and territory governments</u> should establish or improve adult safeguarding agencies to deliver a universal service offering for the safeguarding of all people at risk of harm, including people with disability.
- Action 17.1: The <u>Department of Social Services</u> and the new <u>National Disability</u>
   <u>Supports Quality and Safeguards Commission</u> should design and implement a graduated risk-proportionate regulatory model for the whole provider market.
- Action 17.2: The <u>Department of Social Services</u> and the new <u>National Disability</u>
   <u>Supports Quality and Safeguards Commission</u> should develop a staged
   implementation approach to transition to the new graduated risk-proportionate
   regulatory model.
- Action 17.3: The <u>Australian Government</u> should amend the *National Disability Insurance Scheme Act 2013* to remove the link between a participant's financial
   management of their plan and the regulatory status of their support providers.
- Action 17.4: The <u>Department of Social Services</u>, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should expand the coverage of worker screening requirements.
- Action 17.5: The <u>Department of Finance</u> and the <u>Department of Social Services</u>, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should improve, streamline and harmonise worker screening processes for care and support workers.
- Action 18.1: <u>All Australian governments</u> should agree a joint action plan for meaningful collaboration and a stronger focus on corrective actions against providers to reduce and eliminate restrictive practices, and review interventions and practices that may be harmful.
- Action 19.2: All Australian governments should prioritise greater collaboration, consistency and timely exchange of data and information to ensure effective quality

- and safeguarding, including expanding the coverage of the NDIS Quality and Safeguards Commission to become the National Disability Supports Quality and Safeguards Commission.
- Action 19.3: The <u>Australian Government</u> should ensure the new National Disability Supports Quality and Safeguards Commission has the resources, powers and approach to proactively and effectively regulate the disability supports market.

### Stewardship of the unified ecosystem

- Action 20.3: <u>National Cabinet</u> should establish a new permanent Disability Advisory Council reflective of the diversity of people with lived experience of disability to advise Disability Reform Ministers.
- Action 20.5: <u>National Cabinet</u> should establish a Disability Outcomes Council to monitor and publicly report on the performance of all governments in meeting the outcomes, commitments and benchmarks outlined in the Disability Intergovernmental Agreement.
- Action 21.1: <u>National Cabinet</u> should be accountable for the sustainability of the unified disability ecosystem, including the NDIS.
- Action 21.2: The <u>Department of Social Services</u>, in consultation with state and territory governments, should review existing National Disability Insurance Agency operational guidelines to identify and prioritise opportunities to strengthen the National Disability Insurance Scheme Act 2013 and Rules.
- Action 21.4: The <u>Australian Government</u> should clarify roles of relevant agencies for administration market stewardship, pricing, policy, regulation, commissioning and legislation.
- Action 22.3: The <u>Australian Government</u> should re-design the Participant Service Guarantee to prioritise high quality, transparent and efficient decisions and improved participant experience.
- Action 23.2: The <u>Department of Social Services</u>, in consultation with the National Disability Insurance Agency, the new National Disability Supports Quality and Safeguards Commission and the Independent Health and Aged Care Pricing Authority, should establish and manage an NDIS Evidence Committee to provide guidance on reasonable and necessary disability supports.
- Action 23.3: The <u>Department of Social Services</u> should establish a new Disability Research and Evaluation Fund to coordinate and fund research and independent evaluation activities.

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