

Minutes of the Children, Young People and Families Reference Group

Meeting 1 – 2 August 2023

12.30 -4.30pm via MS Teams videoconferencing

Reference Group Members

Leah Van Poppel, Principal Member & Co-Chair
Sylvana Mahmic, IAC Member
Liz Reid, IAC Member
Mija Gwyn
Melo Kalemkeridis
Skye Kakoschkey-Moore
Tahlia Blanshard
Katharine Annear
Ellen Gould
Leslie White
Abraham Darouiche
Tash Binder

NDIA Representatives

Kathy ^{s47F - personal privacy} Director, Strategic Advice
Gemma ^{s47F - personal p} Assistant Director, Independent Advisory Council Secretariat
Karyn ^{s47F - personal privacy} Project Officer, Independent Advisory Council Secretariat
^{s47F - personal privacy}, Assistant Director, Independent Advisory Council Secretariat
Matilda ^{s47F - personal priv} Communications Officer, Independent Advisory Council Secretariat
Tiffany ^{s47F - personal priva} Indigenous Apprentice, Independent Advisory Council Secretariat

Attending

Alexis Diamond, Branch Manager Early Years Strategy, Department of Social Services
Professor Bruce Bonyhady AM, NDIS Review Co-Chair

Apologies

Marissa Carlyon
Vanamali (Mali) Hermans

1. Co-Chair's welcome and open

1.1. Co-Chair welcome

Ms van Poppel opened the meeting by acknowledging the Traditional Owners and their continuing connection to land and sea.

She welcomed our new members and recognised that our meetings must be accessible to meet all needs. She advised the Reference Group to make their points clearly without using jargon or acronyms.

Ms van Poppel noted Marissa Carlyon and Mali Hermans as apologies, and that Ms Reid and Mx Annear would leave early.

Ms van Poppel acknowledged the work of Ms Mahmic as Co-chair in the last term of the Reference Group. The Minister has not announced appointments to vacant positions on the Independent Advisory Council (IAC), so this Reference Group meeting will not have a Co-Chair.

1.2. Confirmation of Minutes, Matters Arising and Declarations of Interest

Members who attended the previous meeting confirmed the minutes from Meeting 3 held 11 May 2023.

Ms van Poppel reminded Members of the importance of declaring all interests and that the Secretariat keeps a record of all declarations.

Members made the following declarations:

- [s47F - personal privacy](#)

Members confirmed the matters arising register.

2. Introductions and What You've Heard

2.1 Member introductions, incorporating issues Members have heard in their communities

In this session members gave a brief introduction of themselves and their experience. Members then discussed the main issues they have heard in their networks, including:

NDIS planning

- NDIS should let parents know before the meeting that they have the option to roll the plan over if there are no changes in the child's support needs. This could avoid spending on professional assessments.
- Planning meetings are often traumatic for families.
- Transitioning into the Local Area Coordinator (LAC) model from Early Childhood (EC) is difficult for parents, who feel their child is being moved into an adult model of planning and support.
- Young children are getting plans for 2 years, which is not appropriate for such young children. It does not reflect ages and stages.
- There needs to be better information and communication to parents about how to get the most out of their child's plan. Information also needs to be provided in languages other than English.

Transition from childhood to adulthood

- The NDIS does not understand the unique needs of young people, particularly in terms of the developmental stages of transitioning to adulthood, eg. autonomy and identity. There isn't recognition of the space between being a child and being an adult.
- Between the ages of 17 and 25 young people have rights and capacity but are not well supported by NDIS.
- There were reports that young people with disability are being discouraged from working until they leave school.
- Young people find it difficult to take part in their community due to the limited funding of supports and lack of opportunities. This is especially true for culturally and linguistically diverse (CALD) peoples and those in rural areas.
- Members highlighted that young people don't always want support from their parents. For example, for personal needs like showering.
- Young people need appropriate supports to develop independence from their parents, so they can develop skills in finances, etc. They need education in these areas before they leave school.
- There can be few housing options for young people, especially for those with complex needs.
- There are reports of funding being cut soon after the young person with disability leaves school. This creates added challenges as they navigate education, community involvement and work options.
- When young people have limited agency, they can become frustrated and rebel against plan supports. If they don't use their plan this may mean future plans are reduced.

Early intervention

- There are reports from plan managers and support co-ordinators that in the first year a child has a plan, up to two thirds of the plan is being spent on functional assessments from private providers. This highlights the deficit focus of the scheme and may contribute to increased wait times for allied health therapy.

- Early intervention is often led by medical professionals. Parents are not always aware of their important role or might not be empowered to speak up for their child.
- Wait times for occupational therapy in the Northern Territory can be up to a year. Therapy is being delivered less effectively via videoconference, often by an interstate provider.

The connection between NDIS and other services

- The NDIS and Department of Education do not work together well.
- NDIS supports should be delivered in schools. Delivering NDIS services in the child's natural environment is considered best practice for development and inclusion.
- There is a high number of children in Out of Home Care and the justice system who have diagnosed and undiagnosed disability. These at-risk children need to get support early. This would likely mean the NDIA working closely with other government agencies and services.
- Early Childhood education services have an important role in enabling children to access NDIS and be school ready. These services provide a supportive and nurturing environment for children to receive NDIS services.
- There is a need for national, state and territory governments, and non-government agencies, to collaborate better.
- Children and adults with complex care needs are better supported by wrap-around care, with multiple services working together to provide support.

Parents and carers

- The design of programs is not appropriate for autistic people, and there is a reliance on parents to give the supports needed for them to participate.
- Peer supports and training for parent leaders have positive outcomes. There needs to be greater connection to peer supports and inclusion pathways, in addition to therapeutic supports.
- Relationship stress and family stress impact parents' mental health. During COVID the number of mental health visits in a mental health plan were doubled, this was a positive thing. Reducing these by half now is not appropriate.

3. Reference Group Workplan

3.1 Discussion of priorities for the workplan for this period

Ms van Poppel explained that there was an initial discussion of the workplan in the last Reference Group meeting. Now the new members are confirmed, the reference group needs to develop a workplan for its full-term 1 July 2023 to 31 December 2024.

Ms van Poppel asked the following questions about the summary document of issues raised in member reports in the last year:

- Are there things that stand out to you from the priorities in the main document?
- Are there things missing in that?

- What are the things to consider in the environment when creating the workplan?

The following priority areas were identified:

Transitions

- Members were concerned the NDIS is not well designed to support children as they grow through life stages.
- They highlighted 'the gap' in the establishment of the children's taskforce. Members are concerned about how the needs of participants aged 15-18 years will be addressed.
- There was also discussion of the role of community and family in supporting children with disability through life stages. This was largely in relation to building their independence and advocating for them while they learn to advocate for themselves.
- There needs to be more work done on the transition from LAC to EC Partner planning.

Individual agency – for child, young person, parents and carers

- Young people should have greater agency as NDIS participants and should be allowed choice and control.
- Having a voice earlier and building young peoples' capacity is important in facilitating the transition from adolescence to adulthood.
- Young people should have more say in how the NDIS is run and there is support for the notion of a Youth Advisory Council. Policies and solutions affecting children and young people should be co-designed with them.
- The need to consider practically in how to hear the voice of young people. For example, through appropriate channels of technology.
- Members highlighted the importance of parent agency. The parent view has a vital role in regard to how they engage. There is a need to move away from the reliant/medical model to an empowered model.

Where the NDIS meets other government and community services

- New members were introduced to the concept of 'mainstream interfaces'. For example, how the NDIS interacts with other systems like justice, education, or community services. Members acknowledged that the large cohort of children joining the NDIS may be partially caused by other services and systems not meeting their needs. They also discussed how important it is to consider these other services and systems.
- Members noted the need for regular contribution to the work NDIA is undertaking on Reform for Outcomes initiatives, and ensuring there is consideration of the voice of young people.

It was noted that the IAC is limited in how it can affect organisations outside the NDIA. For instance, they cannot track how their advice is or is not being implemented. Members questioned:

- What is our appetite for providing advice to government organisations outside the NDIA?
- How welcome is our advice in other aspects of government?

- How do we know if our advice is being properly implemented when the legislation does not require other government departments to implement our advice or even engage with it?

Inclusion

- Members highlighted that supports should be delivered in the natural environment of the child. This assists with their development and also promotes the inclusion of children with disability and their family. They are concerned about reports that children are receiving NDIS supports in schools away from their peers and/or the classroom which further isolates them.

Ms van Poppel confirmed that the work plan would be finalised in an out of session meeting.

4. Update on the Early Years Strategy

4.1 Update on the Early Years Strategy and next steps

Ms Alexis Diamond gave the Reference Group an update on the work the Department of Social Services has been doing on the Early Years Strategy. They have finished consultation and are now working to translate this into a strategy.

Members noted:

- They were impressed with the engagement work they have done so far.
- They would like to continue to be consulted and updated as this project progresses.
- That the content of the Strategy should be sense checked by the disability community to ensure the experiences and views of children have been translated accurately.

5. NDIS Review Panel

5.1 Discussion with NDIS Review Panel

Professor Bruce Bonyhady AM, Co-Chair of the NDIS Review Panel provided an update. Prof Bonyhady noted the five key challenges outlined in the 'What We Heard' report:

- The 'one and all view' of the NDIS is not sustainable long term or fair. This issue needs to be resolved differently for adults and for children. Other community and government services are no longer there to meet the varied needs of people experiencing disability.
- The concept of 'reasonable and necessary' is not being applied consistently. This lack of clarity is causing high costs and is not fair.
- There is a higher-than-expected number of children entering the NDIS. Supports offered are not always best practice or family centred. Disability needs to be better integrated into the education system, so that young people are having an inclusive, rather than isolated, education experience.
- It is recognised that NDIS markets are not always working. There are thin markets, a depleted workforce, and a lack of effective regulation.
- The NDIS must be sustainable.

The following was discussed by Members and Prof Bonyhady:

- 'Reasonable and necessary' is often used by a stranger to explain why supports are being removed.
- The inconsistency across participants plans is not necessarily bad. People with disability can have different needs even when compared to someone with the same or similar disability.
- Some people may be denied supports if they are expected to have already received them.
- The unexpected number of children entering the scheme may not indicate that more children have disability. It may just mean more children are getting the help they need.
- Eligibility should be based on needs, but many people are seeking a diagnosis to prove their needs.
- Participants and families need to understand that the purpose of the NDIS is creating better outcomes, not just delivering services. Young people should have a say in what outcomes they want from NDIS supports.
- Other government and community services need to connect better with the NDIS so that no young person or child goes without the supports they need.
- The NDIS Review must be clear on what it needs from state and territory governments. This includes what must be delivered and who will fund it.
- The implementation of the NDIS Review's recommendations should be monitored externally.
- There needs to be a transition period for any changes made to the NDIS.
- Cost increases are largely due to provider blowout, however there is negative commentary in the broader community that participants and their families are to blame.

6. Meeting close

6.1 Other Business

There will be an out of session meeting to create and confirm the Childrens, Young People and Families Reference Group's Work Plan.

Ms van Poppel thanked new members for their honesty and new perspectives. Ms van Poppel also thanked existing members for giving new members space to contribute and building on their voices.

6.2 Next Meeting

- The next meeting is scheduled for 12 October 2023, and will be held online.

The meeting finished at 4:36 pm



Minutes of the Children, Young People and Families Reference Group

Meeting 2 – 12 October 2023

12.30 -4.30pm via MS Teams videoconferencing

Reference Group Members

Leah van Poppel
Marissa Carlyon
Abraham Darouiche
Professor Les White
Skye Kakoschke-Moore
Jake Briggs
Vanamali (Mali) Hermans
Mija Gwyn
Sylvana Mahmic
Melo Kalemkeridis
Tahlia Blanshard
Tash Binder
Liz Reid
Ellen Gould

NDIA Representatives

Samantha Taylor, Acting General Manager, Children's Taskforce and Acting General Manager, Policy, Advice and Research
Loretta Kingston-Brown, Branch Manager, Early Childhood Services, Children's Taskforce

Secretariat

Kathy s47F - personal privacy Director Strategic Advice
Gemma s47F - personal Assistant Director, Independent Advisory Council Secretariat
Matilda s47F - personal priv Communications Officer, Independent Advisory Council Secretariat

Attending

Auslan Interpreters

Apologies

Katharine Annear



1. Co-Chair’s welcome and open

1.1. Co-Chair welcome

Ms van Poppel opened the meeting with an Acknowledgement to Country. She also acknowledged the impact of the upcoming Referendum on First Nations people.

Ms van Poppel noted that we are waiting for the appointments of six IAC member vacancies to be resolved through the government decision-making process. She acknowledged that this is a difficult situation and thanked the existing members for their continued hard work.

Ms van Poppel thanked members for their patience and Sam Taylor for coming to the meeting.

1.2. Confirmation of Minutes, Matters Arising and Declarations of Interest

Members approved the minutes from the last meeting.

Members had nothing to add to the current Matters Arising.

Members declared the following conflicts of interest:

- [s47F - personal privacy](#) [Redacted]

Ms van Poppel explained the Work Plan will soon go to the IAC for them to review. This is to ensure alignment across IAC and Reference Group work.

The IAC Secretariat will send Reference Group members a document combining the results of the Workplan session held in the last Reference Group meeting and the recent out of session Workplan session.

2. What You have Heard in your community

2.1. Issues Members have heard in their communities

NDIS access and planning

- Concerns high assessment costs and long wait times for a diagnosis will result in some children missing out on disability support, especially in families with multiple children with disability.
- Calls for NDIS planners to use a trauma informed approach, especially for parents and families with experience in the out of home care system.
- Concern some Early Childhood Partners (Partners) and NDIS planners are directing children with developmental delay to therapy without connecting the family to the peer supports they need.
- Reports of the NDIS reviewing supports the family thought were confirmed and that this can cause a lot of stress.
- Members highlighted the need for more cultural safety training for NDIA and [Partner in the Community](#) staff.

NDIS service and supports

- Concern families do not know how to find safe service providers for their children. Members suggested that Partners could give parents resources on this.
- Continued concern that some NDIS funded therapies are discouraging parents from playing an active role in their child's development. Members were also troubled by the number of parents asking for these therapies instead of safer and better family-focused approaches.
- Members explained some participants are afraid of how the NDIS and other services may respond if they make a complaint. Therefore, the NDIS needs safe and anonymous ways to complain.
- Members highlighted the difficulties of being a carer with disability, including a lack of understanding by the NDIS of how their carer role can impact their disability.
- Members reported that support workers do not always understand how to engage with young children or give older children the mentorship they need. They recommended better regulation for the support work industry and work to increase the status of disability support work.
- Members highlighted that behaviour support plans are often difficult for parents to understand and are therefore not always used correctly at home and school.

Community and other government services

- Reports the NDIS and child protection services have difficulty working together. This can put children with disability in out of home care at risk of homelessness when they turn 18 years old.

- Members are optimistic the current increase in public awareness of disability rights will lead to a greater effort to understand and include them in other government and community services.
- Reports families of children with disability can find it hard to take part in community activities because of social and physical barriers.
- Members shared how disability experts in state and territory education systems can help schools include children with disability by working with the NDIS.
- Concern that schools and the NDIS understand inclusive education differently and that school principals will be left to decide how children with disability will take part in their school.
- Reports children with disability are sometimes excluded in schools even when they have lots of NDIS support.
- Members explained that a student's disability can mean they have less time for learning and socialising. The way some schools are set up and run can mean they get even less time.
- Members highlighted how some rules for accessible services make them less accessible for some people with disability.

Disability community

- Members are concerned the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability recommended changes may not be made as quickly as they need to be made.
- Members highlighted that social connections help young people with disability find their first job.
- Members highlighted that the way the media discusses disability can make it harder for children with disability to be included amongst their peers.

Action 1: The Reference Group to have further discussion regarding Out of Home Care at a future meeting. (This relates to transitions in the draft workplan priorities)

Action 2: Circulate Media Diversity Australia Disability Reporting Handbook 2021.

3. Update on the Children's Taskforce

3.1. Discussion of the work of the Children's Taskforce

Ms Taylor and Ms Kingston-Brown shared the recent work of the NDIA's children's Taskforce, including:

- Work to prepare for the NDIS Review recommendations.
- Supporting the work of Partners and National Delivery staff in remote communities working with children and families. This includes creating resources and running knowledge-sharing sessions.
- Supporting Partners to move away from a planning focus to a navigation-based role where they support families and connect them to services.

- Connecting with experts and stakeholders in the field and building their engagement strategy.
- Finalising some work items for the Early Childhood Early Intervention (ECEI) Reset
- Work to prepare for the Australia-wide rollout of PACE, the NDIA's new digital business system.
- Connecting with other government agencies on the national approach to early childhood and [Australia's disability strategy](#).

Members noted:

- Long wait times to see Partners can lead families to seek advice elsewhere. Members are concerned by the number of families wanting NDIS funding rather than the other supports Partners might recommend to them.
- Medical advice currently guides many early decisions on a child's disability or developmental delay. Programs like the [NDIS' Early Supports](#), which build the parent's capacity, are important for taking families out of the medical model towards a social model of disability.
- Families can be unsure of what information they need to look for. It is important to offer information in places and ways parents can find it. This includes using simple language like 'helping my child communicate' instead of 'assistive technology'.
- NDIS participants need help to self-manage. Some families don't realise self-management can be a big responsibility.
- Co-design should be used to understand how information should be shared with families.
- The good work the Children's Taskforce has done on co-designing [resources for early childhood educators](#).
- Early childhood education has an important role in supporting children with developmental delay to reach their full potential.

4. Royal Commission

4.1. Members discussed the Royal Commission report

Members shared their early reflections on the outcome of the Royal Commission, including:

- Questions around how long someone with disability should volunteer before they can get a job.
- Concerns around the language of 'managing' people with disability in the justice system, used especially in volume 8, Criminal Justice and People with Disability of the Royal Commission report.
- Identified transport, early childhood and post-school pathways as possible gaps in the report.
- Discussion about how long it will take to implement some of the recommendations which members identified as less complex, like those on the Support Worker Registration Accreditation Code of Conduct.

- Discussion of the Disability Services and Inclusion Bill currently before parliament and how this will relate to the Disability Rights Act proposed by the Royal Commission.
- Questions around the relationship between a new Disability Rights Act proposed by the Royal Commission and the Human Rights Act (1986).

5. Reform for Outcomes

5.1. Discussion of NDIA's Reform for Outcomes work

Ms Sylvana Mahmic and Ms Skye Kakoschke-Moore gave updates on their work with the NDIA's [Reform for Outcomes](#).

Regarding the workforce capability work, members recommended:

- Specialist planners who understand children and families.
- Training to help planners understand trauma and how to protect participants from its effects.
- Collecting data on all the skills planners currently have, to find knowledge gaps to target with training.
- The co-design work should also focus on how to keep good staff.
- Focusing the recruitment strategy on hiring people with disability.
- Hiring disability-led training organisations and giving NDIA staff a safe space to ask questions and learn from people with disability.

Members gave the following feedback on the plan flexibility Reform for Outcomes co-design work:

- Flexible plans could include the ability to move funding from [different categories beyond your core supports](#) or choose a section of your plan to review.
- Members highlighted the importance of flexible plans in times of crisis like natural disasters and family or sexual violence.
- Members suggested allowing participants over 16 years old to gradually increase their responsibility for their plan. A flexible plan would support them to build their capacity and the skills needed to manage their plan at 18 years old.
- Members recommended plans are flexible for common changes, like starting or leaving school. For other life events like starting a family or moving house a participant would apply for a [change in circumstance plan reassessment](#).

Action 3: Secretariat to share the notes from the chat with Ms Mahmic and Ms Kakoschke-Moore.

Action 4: Secretariat circulate Reform for Outcome questions for further feedback.



6. Meeting close

6.1. Other Business

None.

6.2. Next Meeting

This is the last meeting for the year, the meetings dates for next year will be sent to members as soon as they are decided on.

The meeting finished at 4:30 pm

Minutes of the Children, Young People and Families Reference Group

Meeting 3 – 20 March 2024

12.30 -4.30pm via MS Teams videoconferencing

Reference Group Members

Leah van Poppel (Principal Member and Co-Chair)
Marissa Carlyon
Abraham Darouiche
Professor Les White
Skye Kakoschke-Moore
Jake Briggs
Vanamali (Mali) Hermans
Mija Gwyn
Sylvana Mahmic
Melo Kalemkeridis
Tahlia Blanshard
Tash Binder
Ellen Gould

NDIA Representatives

Samantha Taylor, Acting General Manager, Children's Taskforce and Acting General Manager, Policy, Advice and Research
Michelle Kellert, Branch Manager, Complex Support Needs (session 4)
Simon O'Brien, Acting Branch Manager, Government Initiatives (session 4)
Fran ^{s22(1)(a)(i) - irrelevant m} Director Planning, Complex Support Needs (session 4)
Caitlin ^{s22(1)(a)(i) - irrelevant mater} Mainstream Interface & Initiatives, Government Initiatives (session 4)

Secretariat

Gemma ^{s47F - personal} Assistant Director, Independent Advisory Council Secretariat
Matilda ^{s47F - personal priv} Communications Officer, Independent Advisory Council Secretariat

Attending

Auslan Interpreters

Apologies

Katharine Annear
Sharon Boyce (Co-Chair)

1. Co-Chair's welcome and open

1.1. Co-Chair welcome

Ms van Poppel opened the meeting with an Acknowledgement to Country.

Ms van Poppel noted that Sharon Boyce is an apology today. Today would have been Sharon's first meeting as Co-Chair of this group.

Ms van Poppel noted that since the last meeting Liz Reid has resigned from her position on IAC and this reference group [s47F - personal privacy](#)

Ms Samantha Taylor, General Manager of the Children's Taskforce was welcomed to the meeting. Ms Taylor is observing the full meeting and providing an update on the Children's Taskforce.

Ms van Poppel noted the recent appointed of Adjunct Professor Janine Mohamed as the DCEO First Nations.

1.2. Confirmation of Minutes, Matters Arising and Declarations of Interest

Members approved the minutes from the last meeting on 12 October 2023.

[s47F - personal privacy](#)

Members noted the Matters arising.

2. What You have Heard in your community

2.1. Issues Members have heard in their communities

Members noted key issues they are hearing in the community:

NDIS Services and Support

- Concerns that there are increased waiting times with the PACE system for people needing plan review, for both scheduled reviews and change of circumstances.
- Reports that LACs are writing the 'about me' section in PACE and the information is wrong. Other participants have the section edited and shortened due to character number limitations in PACE. People need to be given voice and write this themselves.
- When going through the planning process with Local Area Coordinators (LACs) it can be unclear if the plan is based on an initial conversation or if there will be a designated planning meeting.

- Concerns LACs do not look at reports to prepare for planning meetings.
- For people in crisis there is a lot of confusion how to escalate a change of circumstances, and there are risks to the participant.
- When a participant with a primary disability then seeks support for an additional disability it is retraumatising.
- People with a complex trauma history a retraumatised when trying to get support from the NDIS or making a complaint.
- There are financial barriers to the NDIS when a person needs to pay out of pocket for a functional capacity assessment to get access.
- Confusion in community about if a functional capacity assessment is needed for Category B disabilities.
- Participants are asked to resubmit information to evidence access to a support they have always needed. At times the report may cost more than the requested support.
- Participants are being asked for more evidence that they still require access and only have 28 days to respond, which causes stress.
- There is a workforce shortage, and this is made worse when therapists are writing reports instead of working with children on therapy.
- Concerns the interpretation of reasonable and necessary has been tightened, particularly for consumables.
- Supports are inconsistent and multiple children in one family of similar age with similar disabilities and receiving very different funding in plans.
- Many young people with Autism Spectrum Disorder in rural and remote areas not getting access to the NDIS.
- Concern that NDIA is using the term 'co-design' to label work that is not genuine co-design.
- Plan extensions from one year to two years have not been well communicated and have caused confusion.
- Concern about the limitations in funding for behaviour support plans. Funding may only allow for the plan to be developed but there is no funding for a practitioner to work with the family.
- Parents find the lines of questioning about restrictive practices difficult in planning meetings, they feel their parenting is being questioned.

The disability community

- Young people with intellectual disability don't have a voice or choice and control. Family members do all the decision-making.
- The capacity of young people can be built with peer support. It can help them get more involved if they are able to be in social groups with their friends rather than just with family.
- People in remote areas do not have access to enough support and the States and Territories need to take a greater role. First Nations participants also have additional cultural needs.

- Concerns in the autistic and broader community about the Inklings program and that it is linked to ABA therapy.
- Concerns that different schools have different requirements when children need to access therapies on site. Children are missing therapy when schools make it too hard, or they are getting taken out of school in order to get therapy.
- Education is a vital component in a child's growth and development, and the variance in the experience of families causes a lot of stress.
- There needs to be greater effort in the community and services for supported decision-making.
- A new 'Social Services Regulator' will be established in Victoria, which will incorporate the functions of the Disability Services Commission, Victorian Disability Worker Commission and the Disability Worker Registration Board. It is hoped this will take in consideration the complaints pathways and registration processes etc for disability workers within NDIS.

The NDIA Review

- Children and Young People with Disability Australia (CYDA) ran 3 community surveys about the NDIS review which revealed 6 key themes: people want to understand the practical impact of the review particularly in regard to workforce; unmet need, especially for foundational supports; flexibility in managing funding, improved care coordination; the need for a whole of life approach.
- Families need assurance that long term commitments won't be disrupted by reviews like the NDIS review.
- Regarding all the reforms there seems to be a sense of some good things happening in the system. For example, there is a lot of investment in aspects of chronic health care specifically targeting better coordination for children who are participants and their families.
- There is not information about the NDIS review that is young person friendly, and this is creating fear as people are fearing the worst.
- Concerns that people with cerebral palsy or who are autistic with lower supports needs will be removed from the Scheme.

Action 1: Information to be provided out of session to respond to members concerns about increased plan delays with PACE.

3. Update on the Children's Taskforce

3.1. Update on the NDIA's Children's Taskforce

Ms Taylor presented an update on the NDIA's children's Taskforce, including:

- The Taskforce was set up almost a year ago, with the aim to improve how the NDIS works for children and young people.

- It is now doing more work to make sure the Agency is listening to young people. The IAC's Advice for improving the NDIS for children and young people will help guide this.
- It is recognised some of the information from the NDIS Review can be scary. The Agency wants to work with community to respond to this, and work on things it can act on now.
- In regard to the Inklings pilot program, Ms Taylor noted that Inklings is all about child agency and supporting families where there is an observed concern. It trains parents to better engage with their child. The pilot in WA is in early stages. The announcement of a pilot in SA is separate to what is happening in WA, and there is consultation with autistic communities about what this will look like.

Members noted:

- There are no guidelines that exist for how to do great co-design with young people and families, this reference group should be a key resource for the Agency to develop its guidelines.
- They would like to know what mechanisms would be considered for how to make the voice of the child is heard directly wherever possible.
- When talking about improving practice, it is important to listen to the participant and their family and what works for them, and balance this with considering the experience of the practitioner as well as evidence from research.

4. Child protection interface

4.1. Child protection interface

Ms van Poppel welcomed Michelle Kellert, Branch Manager Complex Support Needs Branch, Simon O'Brien, Acting Branch Manager Government Initiatives, and Fran 647F - personal privacy Director Planning, Complex Support Needs.

The Agency staff gave an overview of activities underway to support the child protection interface, including that:

- Complex Support Needs Branch (CSN) supports some of the more vulnerable children and children at risk in the Scheme, including those connected to other agencies.
- There are currently 1700 children being supported by CSN.
- There are 8 Memorandums of Understanding with different jurisdictions to work with families.
- There is no consolidated data on numbers of kids with NDIS packages in Out of Home Care. The Agency is in process of setting up agreements with state agencies, this will hopefully allow real life reporting on data for kids in various settings.
- The transition to adulthood is recognised as a vital period for support. A comprehensive practice guide has been developed for planning staff. This is considered the ages of around 15 to 25.

- The NDIA is working closely with the Department of Social Services on the implementation of Safe and Supported (2021-2031), the national framework for protecting Australia's children.

Members noted:

- The need for more shared data to understand numbers of children in Out of Home Care with NDIS packages and their diversity.
- When a young person is involved with child protection and is nearing the age of 18, there needs to be thinking and planning done for them 12 months ahead of their 18th birthday to make sure they have the right supports and accommodation.
- Reports of parents being suggested that they give up guardianship of their children when asking for more support. Kids are missing out because families don't see the LACs as safe and don't want to risk exposure to child protection.
- Members would like more information about situational factors that move children into CSN.
- Are there other things the NDIS can be doing to coordinate a child's support and engagement.

Action 2: Mr O'Brien to provide more information on Safe and Supported.

5. NDIS Review Recommendations

5.1. NDIS Review Recommendations

Samantha Jenkinson, IAC's Independent Advisor summarised key messaging in the NDIS Review recommendations 1,2 and 6, which relate to supports for children under 9 and foundational supports.

Members noted:

- There must be capacity to identify development delay with consistency and timeliness.
- There must be timely access to supports that are individualised to the need of the child.
- A participant needs to be able to get started with their plan supports once it is approved.
- Children's engagement in education must be supported.
- There must be ongoing and regular communication to the community about the NDIS review to help manage community anxiety.
- 'Foundational supports' needs a clear definition. Can the NDIS say if it currently funds any that is considered a foundational support, that may not be funded in the future?
- Family capacity building is vital. Families must be supported to see possibility and have the thinking 'what is possible for my child'. The medical model is entrenched in a deficit model.
- There must be equity in support, so families with more resources and education don't get better supports.
- Regarding screening and assessment, it needs to be considered who already has the knowledge and sensitivity to do this well, so families aren't retelling their stories.

- Would like to see a big picture view of birth to 18, including transitions, pathways, child and family agency, and individual voice.
- Better coordination with schools is necessary.
- Would like to see a trained parent peer worker in every organisation providing foundational supports.

Ms van Poppel noted that the IAC is trying to work on what it can do to influence any changes from the NDIS Review. IAC will keep communicating with reference groups about what it is looking at.

6. Meeting close

6.1. Other Business

None.

6.2. Next Meeting

The next meeting of the reference group will be a combined IAC and reference group meeting on July 3 and 4. This meeting will be hybrid, so members can attend face to face in Melbourne or online.

Action 3: Secretariat to share video and transcript from Children's Taskforce session Ms Taylor.

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Minutes of Equity and Inclusion Reference Group

Meeting 3 – 22 June 2023

12.30pm - 4.30pm via MS Teams

Members

Leah van Poppel, Principal Member & Co-Chair
Adjunct Associate Professor Jennifer Cullen, Co-Chair
Margherita Coppolino
Judith Drake
Nigel Pernu
Suzy Trindall
Felix Walsh
Barbel Winter
Tricia Malowney OAM

NDIA Representatives

Jodie Stangel, Branch Manager, Complex Support Needs
Brooke ^{s47F - personal privacy} Director, Agency Policy
Kathy ^{s47F - personal privacy} Director Strategic Advice
^{s47F - personal privacy}, Assistant Director Communications, Independent Advisory Council Secretariat
Gemma ^{s47F - personal privacy} Assistant Director, Independent Advisory Council Secretariat
Karyn ^{s47F - personal privacy} Project Officer, Independent Advisory Council Secretariat

Attending

Alan ^{s47F - personal privacy} Independent consultant
Captioner

Apologies

Jadnah Davies
Faye Dickson
Benjamin Garcia-Lee
Catherine McAlpine

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1. Co-Chair's welcome and open

1.1. Principal Member's welcome and update

Ms van Poppel opened the meeting and welcomed Ms Cullen to provide Acknowledgement of Country. Ms Cullen also acknowledged Aboriginal and Torres Strait Islander peoples past, present, and those attending the meeting.

Ms van Poppel noted apologies from Members Catherine McAlpine and Benjamin Garcia-Lee, and Sam Bennett from the NDIA

Ms van Poppel noted that the group last met in March and this is the last meeting of this reference group before current Member term ends. She noted new membership will be confirmed soon and thanked members for their patience.

1.2. Co-Chair welcome

Ms Cullen noted that the meeting would have a focus on supported decision making and complex support needs, with the Agency Policy Branch and Complex Support Needs Branch joining the meeting to discuss these topics.

Ms Cullen noted that updates on the Agency First Nations Strategy and Cultural and Linguistic Diversity Strategy (CALD) Strategy are not on the agenda today. Written updates were included in the meeting pack.

Ms Trindall provided an update of the First Nations Strategy work she has been involved in, noting:

- Safe engagement has been a big part of the conversation and it is positive that people in the regions are enabling connections on the ground.
- It has been a positive experience and communication has been good. Ms Trindall has been able to provide feedback 1:1 with the First Nations Engagement Officer.
- The group has had opportunity to meet with the NDIS review panel.

Ms Cullen noted the fantastic contributions that Ms Trindall has been making to the First nations work.

In regard to the CALD Strategy, Ms Cullen reflected that she had attended the first gathering in Melbourne. It was well organised and it was great to have an intergenerational spread in the room, with elders as well as new leaders engaged.

Ms Cullen read the update on the LGBTIQ+ Strategy provided by the Co-Design and Engagement Branch:

“Following Liz Callaghan’s attendance at the last Equity and Inclusion Reference Group meeting, we provided a briefing to incoming Senior Executives on proposed next steps for the LGBTIQ+ strategy. Following this discussion and the success of the CALD summit held earlier this year, the decision was taken to start conversations with the LGBTIQ+ and disability community on next steps by holding a summit in the later part of 2023. Our intention is to co-design the summit with LGBTIQ+ and disability stakeholders.

Once this approach is finalised, we will provide a briefing to the IAC Equity and Inclusion Reference Group on the proposed approach. Recent staff departures from the LGBTIQ+ strategy team has resulted in some delays in progressing this work. We anticipate being able to provide a full briefing to the IAC Equity and Inclusion Reference Group at the next meeting scheduled for Thursday 24 August 2023.”

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Ms Coppelino noted that Inclusive Rainbow Voices (IRV) was launched last month at the Victorian Pride Centre. The live stream of the launch can be viewed on the website which is now live ([IRV website](#)). IRV will consult with the LGBTIQ+ disability community around developing a strategic plan. It is Victorian focussed at the moment, but another State has approached IRV about extending its work.

Ms Coppelino noted the anti-transgender rights and drag story is having a major effect on the LGBTIQ+ community and requested the Agency find a way to check in with LGBTIQ+ participants. There needs to be messaging that NDIA is safe and inclusive.

Mr Pernu noted his own personal challenges and Ms Drake offered to provide some support with appropriate linkages to support workers. Ms van Poppel also noted the Secretariat may be able to support if required.

Action 1: Secretariat to follow up further on support being offered to LGBTIQ+ in the context of anti-transgender rights activism in communities.

1.3. Minutes confirmation, Matters Arising, and Declarations of Interest

Members confirmed the Minutes from Meeting 2 – 23 March 2023 and noted the matters arising. No new declarations.

In relation to the actions, Ms van Poppel noted updates on Independent Advisory Council (IAC) advice:

- Currently there is no public reporting about the progress of IAC advice. The Agency Response is not a publicly released document. There have been positive discussions with the Agency about a published Agency Statement against Advice. Ms van Poppel will update the group as these progresses.
- The Equity in the NDIS Advice has been delayed by processes and staff changes in the Agency. The recommendations of the Advice are being implemented by the Agency, for example, through the work on the diversity strategies. It is planned the Agency will report to IAC in August this year on the progress of implementing the Equity Advice.
- The Behaviour Supports Advice went to the Intellectual Disability Reference Group at its last meeting. It will now go to the IAC for endorsement.
- The advice on the voice of children and young people, which came through the Children, Young People and Families Reference Group, has been to IAC and an Agency response is being prepared.
- The advice on participants who are ageing is also on the IAC workplan. This is likely to begin in the new financial year.

Members noted:

- It would be good to understand better how the IAC will ensure that there is a diversity lens over all its advice.
- There is a need to consider how to best channel the knowledge from this group into the work being undertaken by other reference groups.
- Concerns that the conversation is about behaviour supports, where it should be about what is causing the behaviour. Often it is about people being unable to communicate their needs.
- In talking about behaviour supports it also needs to be considered what can be done in this space (eg. empowerment, supported decision-making), not a focus on negative impacts.

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Action 2: Include the question of how to embed Equity and Inclusion in all IAC work on next meeting agenda.

2. What you've heard

2.1. Issues Members have heard in their communities

Members raised the main issues they heard in their networks, including:

NDIS access and planning

- Systemic issues with home and living supports and plans. This includes supported independent living (SIL) plan inflexibility, specialised disability accommodation (SDA) provider malpractice and lack of housing availability.
- Continuous NDIS accessibility administrative issues.
- Concerns that participants require a nominee if they are unable to sign something, which does not support supported decision making. NDIS asks for a nominee to sign NDIS access forms for people with significant physical disability who could for example potentially use a signature stamp or sign with a recognised symbol.
- Some people with psychosocial disability, who are at risk of homelessness, say they find it almost impossible to access the NDIS.
- Some plan managers say that they are seeing increased funding reductions for participants since [National Cabinet's announcement of an 8% annual growth target for the NDIS](#). There are also calls from some plan managers for the review of their service costs to account for consumer price index (CPI) increases.

NDIS service and supports

- Inconsistent and confusing messaging from local area coordinators and planners, who sometimes shift responsibility to plan managers. This relates to charging high intensity rate for participant supports.
- Calls for the NDIA to explicitly clarify the purpose of 'check ins' with NDIS participants. For example, NDIS phones some participants for 'check in' and then extends plans without a participant's knowledge.
- Reports that some people with disability (in particular those with psychosocial disability) find it hard to find suitable and safe supports workers, which is not only disempowering but puts them at risk.
- The lack of support workers options causes those people who want individualised living option (ILO) supports to be funnelled towards SDA options, given that is the only pathway to reliable support workers.
- Particular concerns for lack of support workers and housing options in rural and remote areas.
- Concerns the support system is becoming more transactional rather than relational.

NDIS Providers and disability community

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- Reports of an alleged system of incentivised referral and payment practices among registered providers.
- Calls for the expansion of lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, (LGBTIQ+) focused NDIS providers. This would be seen as providing options for culturally safe supports to LGBTIQ+ people with disability.
- Calls for the NDIA to ensure NDIS participants who identify as LGBTIQ+ are safe and receive trauma informed supports, especially in relation to the recent anti-transgender narrative in the community.
- There is a need to look at the quality of all interactions between participants and NDIS providers to ensure they are considering and supporting intersectionality.

NDIS Review

- Calls for the NDIS Review to conduct more in-depth engagement with the LGBTIQ+ community, to ensure their voices are heard and represented in the review.
- Networks have highlighted the importance of work being done by the NDIS Review, NDIS Quality and Safeguards Commission, and the Independent Mental Health Advocacy's (IMHA) [NDIS mental health toolkit](#) on equity issues related to those people with psychosocial disability.
- Noted that the NDIS Review team is looking into cross-cultural issues within SIL and SDA.
- The importance of newly established advocacy organisations for LGBTIQ+ people with disability, like [Inclusive Rainbow Voices](#).

3. Supported Decision Making Policy**3.1. The Supported Decision-Making Policy and Implementation Plan**

Ms Brooke ^{s47f - personal priva} Director Agency Policy Branch provided an update on the Supported Decision-Making Policy, which describes the NDIA's position on supported decision making.

Ms ^{s47f - personal priva} noted that:

- The work started in 2019 with the IAC Supported Decision Making advice. In 2022 it became one of the six key priorities for co-design.
- The focus of co-design was to establish a shared understanding of the issues, identify immediate improvement and look at longer term components to achieve these through co-design.
- The implementation plan has been cross-referenced with the current recommendations from the Disability Royal Commission coming out earlier in the year.

Members noted:

- General agreement that the policy is high-quality, which is a credit to the time taken to properly co-design.
- The implementation plan should identify short-term and long-term goals.

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- The need to address structural barriers to supported decision making. For example, people living in group homes with access to core supports only, not capacity building.
- The public advocate in Victoria has been pushing for people with disability to have their own voice and would like NDIA to be on board with this.
- Concerns the NDIA in the end makes the decisions in regard to planning, despite the policy.
- Choice and control means something completely different depending on if someone is from an individualistic or communal culture. NDIA needs to consider how a person has autonomy in context of their community.
- Supported decision making should start with intersectionality and allow for dignity of risk.
- The need to focus on allowing people who live in group settings to make their own decisions and have a voice, for example group homes and prisons.
- When a decision is being made for an individual, that person should completely understand the impact that decision has on their plan and their daily life.
- The importance of having different peer groups available so that people with disability can have options on who they wish to engage on different issues.
- Questioned what role the NDIS has to support people whose rights are challenged under guardianship mechanisms, like nominees and state trustees.
- There is a need to build up community knowledge of supported decision making so that participants and family feel it is realistic and achievable.
- When referencing the 'sector' in the policy and implementation plan it needs to be clear this includes providers.

4. Complex Support Needs Branch

4.1. The Complex Support Needs pathway

Ms Jodie Stangel, Branch Manager of the Complex Support Needs Branch provided an overview of the Complex Support Needs (CSN) Branch, noting:

- CSN is designed for participants with complex needs and people with interface with statutory bodies.
- Each CSN participant has a specialist planner with clinical and mainstream interface experience.
- A planner will have up to 55 participants that they support ongoing. The planner has a relationship with the participant and their support coordinator.
- CSN is not designed to be long term and most participants are supported 18 months to 3 years. Around 10% will require ongoing support.
- CSN sits in the branch along with Justice Liaison Officers. The new national justice planning team will also be put in place by August this year.
- There has been some dedicated recruitment of First Nations staff recognising the over-representation of First Nations people in the justice system.
- There is a small cohort of children and young people who sit under the CSN who are at risk of their parents relinquishing care.

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- There is a short-term response model for participants who have some identifying factor of complexity. This team will provide a specialist planner to support with intense intervention.

Ms Stangel noted regarding restrictive practice:

- Every participant with a behaviour support plan and restrictive practice has clinical oversight every 12 months.
- A key measure when a person leaves CSN pathway is to measure if they are leaving with less restrictive practices. This is measured monthly.

Ms Stangel noted Regarding supported Decision Making:

- Often participants in CSN make decisions that put them at risk and most have an appointed decision maker or plan nominee.
- With the high percentage of First nations participants, the CSN team recognises the need for culturally safe practice and having the right people involved to support decisions.
- The supported decision-making policy will be a challenge to implement for CSN participants. The team has regular case conferencing and implementation and monitoring processes that ensure the participant is always involved. However, the participant is usually not the decision maker.

Member noted:

- There has been noticeable improvement in the process of referring from the Local Area Coordinator (LAC) to CSN pathway.
- Data shows that some CALD communities are equally over-represented in the justice system.
- There is concern in the media about unauthorised restrictive practices and questioned what is known about kids in out of home care or at risk with unauthorised practices.
- There is a lack of safe places for young transgender kids and questioned whether the CSN team provides anything specific to this cohort.
- When participants make poor decisions in the past, or are being treated under the Mental Health Act, they shouldn't be excluded from being supported to have some control over decisions about their life going forward.
- There is a need to support to collaboration rather than paternalism.
- Where participants have decision makers who adult guardians or trustees, the Agency can only influence these.
- Trust is vital and takes time, and there is a need to recognise the trauma of a person's experience and that it will take time for a participant to build that trust with others. The ongoing changes in people providing supports means that trust often cannot be built.
- The need to consider the place for circles of support to provide some assurance to complex and vulnerable people.
- The positive outcome recently with a participant in the leaving custody after 20 years, and that a dramatic change in the man's behaviour is likely to be seen with his reconnection to land and culture.

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5. Session 5 Meeting Close

5.1. Other Business

There is a one hour out of session with Dr Chan on 14 July to discuss restrictive practices and behaviour supports.

Action 3: Secretariat to circulate list of questions for Dr Chan for final feedback

5.2. Next meeting

The Principal Member and co-Chair thanked members their participation, their patience dedication, truth and storytelling in each meeting.

The next meeting will be held on August 24 and will be an online meeting.

The meeting closed at 4.34pm.

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Meeting minutes for Equity and Inclusion Reference Group

Meeting 1 – 24 August 2023

12.30pm - 4.30pm via MS Teams

Reference Group members at the meeting

Leah van Poppel, Principal Member & Co-Chair

Jennifer Cullen

Tricia Malowney

George Taleporos

Mark Tonga

Barbel Winter

Judith Drake

Denton Bowles

Margherita Coppolino

Suzy Trindall

Clare Gibellini

NDIA staff at the meeting

Kathy ^{s47F - personal privacy} Director Strategic Advice

Gemma ^{s47F - personal} Assistant Director, Independent Advisory Council (IAC) Secretariat

Matilda ^{s47F - personal priv} Senior Communications Officer, IAC Secretariat

Also, at the meeting

2 Captioners

Reference Group members who could not come to the meeting

Kalena Bos

Words we use

- **Actions:** A list of things we need to do. In every meeting we make sure the list has all the things we still need to do on it and nothing we have finished working on.
- **Co-Chair or Co-Chairs:** the Chair of a meeting is the person who leads the meeting. In the Reference Group, we have two people who lead the meeting, so we call them Co-Chairs.
- **Co-design** is when the Agency will work together with people with disability and the broader disability sector to design policy.
- **Conflict of Interest:** Conflict of Interest Declaration is a document where you need to say all the different ways you are connected to the NDIS. This could include if:
 - your work is around the NDIS
 - you are a NDIS participant
 - you are part of other reference groups that talk about the NDIS

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This is because we all need to make sure your job in this Reference Group doesn't clash with other jobs you do. It is ok to have a conflict of interest, but you need to let the IAC Secretariat know.

- **Culturally and linguistically diverse (CALD):** Is a person who has a different culture or speak another language that is not English. For example, this can be someone who:
 - Is a migrant. They left their country by choice to live and work in Australia
 - Is a refugee. They left their country because it was not safe to live there anymore.
- **Diverse:** this means different in some way. Diverse people have personal features or experiences that make them different.
- **Employment:** having a job that pays you for your work.
- **Engagement:** people working together to share their experiences, thoughts, feelings and ideas on a project.
- **Equity:** everyone has the same chance to do or be part of something, no matter their background, identity, or experience.
- **First Nations:** people who identify as Aboriginal Australians or Torres Strait Islanders.
- **IAC Secretariat:** the team that organises the meetings, sends papers and pays members for attending.
- **Inclusion:** something is inclusive when everyone can take part.
- **Intersectionality:** happens when someone is different in more than one way and might be treated differently or poorly for all the ways they are different.
- **LGBTIQA+:** the letters LGBTIQA stand for lesbian, gay, bisexual, transgender, intersex, queer or questioning and asexual. The '+' is for people who are part of the LGBTIQA+ community but don't talk about themselves using a word from this list.
- **Matters arising:** things that are happening at the moment to do with the Reference Group.
- **Minutes:** notes of what happened in a meeting.
- **Participants:** these are the people that the NDIS helps.
- **Principal Member:** leads the Independent Advisory Council (IAC), and is one of the Co-Chairs of the Reference Group.
- **Psychosocial disability:** disability that affects how you feel, think and interact with others.
- **Reference Group:** is a group of people who know a lot about something. This group knows a lot about equity and inclusion.
Reference Groups work together to make a plan or find ways to make something happen.
- **Strategy:** planning a better future and how we are going to get there.
- **Transgender people:** people whose gender identity is different from the one they were given when they were born.
- **Work Plan:** is a document that says what the Reference Group will do in the next year, or two years.

Session One - Pink

1.1 Principal Member's welcome and open

Ms Leah van Poppel (Leah) opened the meeting and Ms Jennifer Cullen (Jennifer) Acknowledged Country.

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Leah noted Kalena Bos as an apology.

She also noted this meeting will not have a Co-chair. Leah will choose Co-chairs for each Reference Group once the Minister for the NDIS confirms the IAC's membership.

Session Two - Purple

2.1 Minutes, Actions and Conflicts of Interest and Terms of Reference

Members approved the minutes.

Members had no new conflicts of interest.

Leah noted there was an email last week about an action from the last meeting.

It was from the NDIA about what the NDIS does to check people who are lesbian, gay, bisexual, transgender, intersex, queer or questioning, asexual + (LGBTIQA+) are ok.

Leah told members if they are not happy with the response they should let the secretariat know.

Gemma explained that the LGBTIQA+ Strategy team are happy to have a follow up meeting. There will also be an out of session meeting in the next month about an LGBTIQA+ summit that is being planned. Representatives from this group and other IAC reference groups will be invited.

Action 1: Secretariat to set up meeting between Margherita and LGBTIQA+ Strategy team.

Session Three - Orange

3.1 Member introductions and 'What you've hear in your community'

Members said:

NDIS access and NDIS planning:

- Culturally and linguistically diverse (CALD) people, migrants and refugees need more help to understand and take part in the NDIS. Especially those who are also LGBTIQA+
- Pacific Islanders and other smaller CALD groups find it harder to get onto the NDIS because information is not in their language.
- Concerns that the self-management community is not culturally diverse and is mostly female. Self-management should be possible for everyone, including First Nations, CALD and people with complex needs.
- People who have neuromuscular conditions, for example stroke, need access and planning to happen quickly. If they get NDIS support early, they won't need as much support later on.
- People with disability are more at risk of scams. Participants need more help from the NDIS to understand technology and how to keep themselves safe online.
- Artificial intelligence could help make better NDIS plans by bringing together complex information in a consistent way. There would need to be good policy in place to support this.
- Continued concerns planners do not understand psychosocial disability.

NDIS services and supports:

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- Reports women with brain injury sometimes get less funding for things like cooking or washing clothes than men with brain injury.
- CALD parents who are getting older find it harder to support their children with Down Syndrome. They find it hard to understand NDIS home and living supports because of language barriers.
- School Leavers Employment Supports (SLES) is not working and pushes people into segregated employment, that is often for a few months only.
- There needs to be more opportunity for people with disability to get different types of work. For example, helping people with disability run their own business.
- Employers should look at customised employment, where a job is created that matches an individual's skills and needs.
- People who are First Nations, CALD or LGBTIQ+ are less likely to know what support they can get for work. They also might not have as much money to run their own business.

NDIS providers and the disability community

- Some SLES providers are focussed on making money, instead of helping people with disability get good jobs and careers.
- Support workers might leave disability support work if it takes too long to get their disability worker screening check.
- Some support workers talk about their participants with other participants. This might be because they don't have enough mental health support or peer support. This does raised concerns about confidentiality for participants.
- Some big support work platforms are asking for case notes. Many people with disability are unhappy about this as they don't want information shared on these platforms.
- Some participants, mainly in rural areas, do not think their providers can support them well in an emergency. Some providers seem unsure of how to help participants plan for an emergency.
- There will be a lot of work that comes out of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission) and NDIS Review. The disability community is worried about how much of this work NDIA will need to do and how NDIA will do all this work.

Other services that provide support

- There needs to be better psychosocial disability support outside of the NDIS.
- There is a need for services outside the NDIS who support people with disability. For example, someone who needs a mobility scooter because of cancer has no support.
- There is a lack of support for people with disability in an emergency in rural and regional areas.
- Concerns with supports provided by Disability Employment Services (DES).
- The NDIS should share more information on disability in communities, including local Councils. This will improve local support in the community.

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Action 2: Seek data on plan management type with a diversity split.

Action 3: Seek data on the average time it takes for a person with stroke to get access met, and a first plan.

Action 4: Seek further information on what is available through the Justice Transition Program

Session Four - Blue

4.1 Work planning – NDIA and IAC Work & Review of Reference Group priorities

There was a summary of the current Agency Strategy work that the is underway:

First nations strategy:

- The First Nations Advisory Council (FNAC) face-to-face for the first time in Sydney recently. The first day First Nations people met without people from government, to decide what would be told to government on the next day. Terms of Reference were also discussed.
- Erin b47f-personal the cultural facilitator, also helped First Nations people feel safe.
- There are First Nations people from all over Australia are included in FNAC.

The CALD strategy:

- The summit event in 2022 included people from small and big CALD communities and people of all ages taking part.
- Some were happy with the strategy. Some felt it didn't include enough of the co-design work.
- Some changes to the strategy were emailed out last week.

LGBTIQA+ strategy:

- This work was not a full refresh of the strategy. The activities to support the strategy were changed.
- Those who took part in work for this strategy would like to see more of outward focus.
- Members noted that the community felt that the final Strategy did not reflect what community talked about.
- Members noted that the document is ableist.
- Members noted that not all people will identify as part of LGBTIQA+ community. There needs to be a way to recognise these people in the Strategy and hear their voices.
- Sexuality is something that needs to be considered for all in the NDIS, not just in this strategy.
- The National Autism Strategy will talk about supporting LGBTIQA+ autistic people.

Leah gave a short summary of the IAC Advice:

- The 'Equity in the NDIS' advice is published. The IAC and this reference will track how the NDIA deliver the Advice.

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- The Voice of Children advice is finalised. The Agency is developing a response.

The Behaviour Supports advice will go to IAC for approval soon.

Members noted that:

- It may be good to be more pro-active in the reference group, and not focus too much on the Agency Strategy work going forward.
- The Equity in the NDIS advice notes the need for an intersectional approach to work, rather than dividing work up into different population groups.

Session Five – Red

5.1 Building the Workplan

The reference group considered what should be included in the workplan for the next 18 months.

Members noted some specific topics of concern:

- Employment
- Disability Royal Commission and NDIS Review
- How to apply intersectionality
- Ensuring people who cannot communicate verbally have a voice.
- People with complex medical needs, including those who need nursing care, intubation, or palliative care.
- How the NDIS supports people experiencing family violence.
- Sexuality and sex being recognised by the NDIS.
- Linking better to mainstream research.
- Ensuring access to health supports for people with disability and ensuring the voice of these people is heard in designing services.

Intersectionality

In considering intersectionality members noted:

- Consider looking at best practice, eg. Australian Sports Commission
- This group should provide input into IAC advice about how intersectionality should be reflected in the advice and how it should be done.
- There is a need go consider intersectionality in participant planning.

The reference group should make a framework that will guide the Reference Groups and IAC to include intersectionality in their work.

- The framework can
 - Be applied to IAC advice and Agency questions.
 - Look at different life events or issues through the framework to see the different barriers different people might face.

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- Also be applied to what comes out of the NDIS Review and Disability Royal Commission.

IAC and Agency work

Members noted that current work that can be a focus for the group is:

- Informing the next IAC advice to be developed - participants who are ageing.
- Ensuring intersectionality is considered in IAC and other reference group work.
- Informing Co-design work
- Informing Reform for Outcomes

Next steps

Members agreed that they should delay committing to other work until after the recommendations from the NDIS Review and Disability Royal Commission come out.

Members agreed to move the next meeting to November so that there is an opportunity to discuss the Royal Commission and NDIS Review findings.

The Reference Group wants to be less involved in NDIA inclusion strategy work. They would just like updates at meetings, which could be written or a short verbal update.

Action 5: Next meeting pack to include any know informant from the current policy environment.

Action 6: The IAC Secretariat will move the next meeting to November.

Session Six – Brown**6.1 End of the meeting**

Leah closed the meeting and thanked Members for their participation.

Members thanked Leah for her inclusive Chairing today.

The meeting closed at 4.34pm.

Meeting minutes for Equity and Inclusion Reference Group

Meeting 2 – 8 November 2023

10.00am - 4.00pm

Hosted at NDIA Richmond office and via MS Teams

Reference Group Members

Leah van Poppel, Principal Member & Co-Chair

Jennifer Cullen

Tricia Malowney

George Taleporos

Mark Tonga

Judith Drake

Denton Bowles

Margherita Coppolino

Suzy Trindall

Clare Gibellini

Kalena Bos

NDIA staff

Gemma ^{s47F - personal} Assistant Director, Independent Advisory Council (IAC) Secretariat

^{s47F - personal privacy}, Assistant Director, IAC Secretariat

Matilda ^{PI}, Communications Officer, IAC Secretariat

Corri McKenzie, Deputy CEO, Service Design and Improvement (session 3.1)

Attending

Liz Reid, IAC Member (session 3.2)

James Manders, IAC Member (session 3.2)

Samantha Jenkinson, IAC Independent Consultant

^{s47F - personal privacy}

2 Captioners

Apologies

Barbel Winter

Session One - Pink

1.1 Principal Member's welcome and open

Ms Leah van Poppel (Leah) opened the meeting and Acknowledged Country.

Leah welcomed Samantha Jenkinson who is attending the meeting online. Samantha is the new IAC Independent Consultant [s47F - personal privacy](#)

Leah noted this meeting will not have a Co-chair and Co-chairs for each Reference Group will be chosen once the Minister for the NDIS confirms the IAC's membership.

Session Two - Purple

2.1 Minutes, Actions and Conflicts of Interest and Terms of Reference

Dr George Taleporos (George) noted that session 4.1 of the minutes need to record more clearly that members of the disability community may not identify themselves as part of LGBTIQ+ community and the NDIA need to ensure it also hears their voices.

Members approved the minutes with this update.

Members noted new conflicts of interest:

[s47F - personal privacy](#)

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Session Three - Orange

3.1 Reform for Outcomes - Overview

Leah welcomed Ms Corri McKenzie, DCEO of Service Design and Improvement in the NDIA. Corri talked about the NDIA's Reform for Outcomes (RFO) work. She noted:

- This work aims at to make the experience of being in the NDIS better for people with disability.
- NDIA is working in co-design with the IAC and Disability Representative Community Organisations (DRCOs) on what changes should be made to improve the participant experience.
- 6 co-design working groups have been set up to work on different parts of the RFO.
- RFO is focussed on what the NDIA can do now, not things that need change to government policy or the NDIS Act
- Through the RFO the NDIA is considering how the changes NDIA makes will impact different groups of people and communities. The NDIA must respect intersectionality when working with people and developing their plans. This means enabling NDIA staff to work with participants differently and be aware of issues.
- The Co-design Advisory Group is looking at how the NDIA does co-deign. The Advisory Group is helping the NDIA work out how co-design has been done in the past, how the co-design process is going now, and what needs to be done to make co-design better.

Members noted:

- There needs to be broad engagement with the community, so they can better contribute to co-design.
- There also needs to be support available to increase the ability of individuals when they start to work in co-design.
- The NDIA needs to respect intersectionality when working with people and developing their plans.
- It is important to think about intersectionality when support systems interface, such as disability and health. For example, an autistic person going into a planning meeting needing support for dentistry.
- It is positive to have an NDIA DCEO speaking in a positive way about an intersectional approach. This also needs to translate to a cultural shift with those on the ground, such as planners and Partners in the Community staff.

Action 1: The Equity and Inclusion Reference Group agreed to provide themes around intersectionality from reports from the ground to the different co-design groups.

Session Three - Blue

3.2 Reform for Outcomes – Talking about Reform for Outcomes topics

Fraud

James Manders (James) joined the meeting to talk about the topic of Fraud.

James said that the co-design working group on fraud is thinking about fraud on a scale from a deliberate criminal act through to softer forms of fraud such as misuse of funds, and misleading practices (sometimes called sharp practices).

James gave an update on the co-design working group to date:

- The current focus of the working group is creating a campaign that goes out to participants, plan managers and support coordinators to help identify fraud.
- The campaign will include communications agreed by the group and working with participants in sharing the support for decision making framework.
- Working with support Providers other than plan managers and support co-ordinators will be the next step.

Members noted:

- The NDIA should promote self-management and support participants' awareness on the appropriate and flexible use of their funding.
- Any NDIA communications campaign about fraud should provide information on the complaints process, with a view to prevent risk for participants who may unintentionally misuse funding.
- The NDIA should investigate the auditing process used by providers and continue to work closely with the NDIS Quality and Safeguards Commission as part of their co-design work on fraud.
- There is a need for a campaign for NDIA frontline staff, working in regional and remote areas about supporting First Nations participants to self-manage their funds.
- There should be a softer approach or 'circuit breaker' for participants who may unintentionally misspend funds.

Action 2: Members to send examples of good and bad practices from the provider community to Secretariat, particularly about plan managers and support coordinators.

Workforce Capability

Liz Reid (Liz) joined the meeting to talk about the co-design work on NDIA Workforce Capability.

Liz gave an update on the work of the Workforce Capability co-design working group so far:

- The aim is to design solutions and make an action plan for the NDIA.
- The work is just gaining momentum. The agreed themes are:
 - Planner specialisation
 - Training and support for partners
 - Improved guidance material for staff
 - Minimum standards for staff joining the NDIA

Members noted:

- Delegates also need to be better trained. Training should be customised to be very specific to a role. Skills need to include excellent communication skills, ability to have difficult conversations, and trauma informed practice.
- People with disability need to be delivering training and involved in the interview processes for new staff.

- HumanAbility are a resource to find out qualifications available to people with disability. For example, Holmesglen TAFE have a new disability qualification that does not have the requirements for any physical lifting etc. This makes the course accessible to some people with physical disability who otherwise couldn't do Certificate IV in Disability.
- The importance of customised employment and relaxing some education requirements.
- Concerns about the 'cultural load' carried by people with disability in the NDIA.
- The NDIA should implement the 'Sunflower Scheme' for people with hidden disability.

Action 3: Secretariat to give Liz's details to Denton for follow up discussion.

Action 4: Secretariat to collate all comments and forward to Liz. Particularly about what is working well and what can be done better.

Session Four - Orange

4.1 Issues Members have heard in their communities

NDIS access and planning

- Some NDIS planners seem to encourage participants aged 60 years and over to move to My Aged Care without letting them know they are ineligible to access the NDIS once they transition.
- Reports that asking for evidence from occupational therapists can delay the access and planning process. This is because there are not enough occupational therapists.
- A continued concern that assessments to access the NDIS can be expensive and are not refundable. This could mean that children are missing out on early intervention.
- Some families in the defence force find it harder to access the NDIS. This is because they move across Australia or overseas for work, making it difficult to gather evidence for access and to get support from local providers.
- There needs to be more NDIA staff who better understand people with intellectual disability and their needs for access and planning.
- Planners don't see self-employment through micro-enterprise as a vehicle for social inclusion. They only see success as financial independence, not building personal and social skills. Planners sometimes view micro-enterprise as a hobby, so they don't approve core supports.
- Some people with psychosocial disability are concerned that changes in the future to the NDIS will make it harder for them to gain access.
- NDIS letters about plan rollovers are confusing, and people think they need to use the funding they already have for another 12 months.

NDIS service and supports

- NDIA should improve the way it responds to accidental or minor misuse of plan funding by participants who self-manage.
- Some prisoners with disability find it difficult to access supports through their NDIS plan before they leave prison, to help them transition back into the community.

- There is a shortage of occupational therapists who specialise autism. Recognition this is also a problem for other disability types.
- Some LACs do not call back when participants contact them.
- Some people with intellectual disability don't feel like they are in control, the planner is.

The NDIA, disability community and other services

- The health system should better inform people with disability and those who help support them about getting important primary health checks.
- Some people in the community are confused about PACE, the new NDIA computer system. The NDIA should share clear information about PACE, including information in Easy Read.
- Concerns some participants are discharged from hospital with nowhere to go due delay in Supported Independent Living/ Specialist Disability Accommodation funding decision.

Action 5: Identify if PACE will improve the messaging going out to people regarding plan rollover.

Action 6: Identify what the NDIS is doing to support Defence families, including support for children.

Action 7: Identify what support is available to participants who have a microenterprise.

Session Five – Green

5.1 Participants who are ageing

Leah welcomed Samantha Jenkinson to lead this item. Samantha explained that she was just starting to plan the IAC advice about participants who are ageing.

Members noted:

- There needs to be a definition for 'participants who are ageing'. This also needs to consider that the ageing processes can be different for people from different cultural backgrounds and disability types. For example, First Nations people can access aged care at 50.
- There is a need for better coordination and communication between NDIS systems and My Aged Care.
- NDIS participants need support to make an informed choice about moving into aged care system.
- NDIA should make decisions based on a participant's needs, not their age.
- People with high support needs could be at risk of not having enough supports if they move into aged care, given that aged care funding is often less than funding through the NDIS.
- The elder abuse action plan has involved many organisations, for example FECCA, and LGBTIQ+ organisations. The advice should pick this up.
- Concerns about people with intellectual disability being pushed into aged care at a young age.
- There is a need for more equitable systems. My Aged Care is often viewed as a 'consolation prize'.
- People with disability who transition from the NDIS to My Aged Care may be unable to keep working without NDIS supports to work or run their business.

Samantha noted the next steps:

- Samantha will write a planning document which includes key questions, who to talk to, who would be in a steering group, and a timeline.
- A draft of this will be ready for the December IAC meeting.
- In March the draft advice will be tested with IAC and the Equity and Inclusion Reference Group.

Action 8: Secretariat to share Samantha's email address with reference group members.

Session six – Red

6.1 Feedback on Agency Strategy updates

LGBTIQA+ Strategy

Members noted:

- It was useful to connect to the new lead of the LGBTIQA+ Strategy team.
- There will be an LGBTIQA+ Summit on 18 March 2023.
- Concerned that stakeholders they are engaging with are mostly peaks, it would be good to have more representatives who have lived experience and those who are emerging leaders.

Action 9: Provide this feedback to LGBTIQA+ Strategy Team and make sure they are aware of the queer peer group.

First Nations Strategy

- The First Nations Advisory Council meeting was postponed due to the Referendum. Now is a time for healing but members are looking forward to reconnecting.

Cultural and Linguistic Diversity (CALD) Strategy

- No comments or questions.

Session Six – Brown

7.1 Other business

Margherita Coppolino gave recognition and support to the First Nations Members of the reference group, acknowledging the recent outcome of the referendum for a Voice.

7.2 End of meeting

Members said they were happy with the format and location of the hybrid meeting today. Suggested improvements are:

- Having people in the physical room dial in via a device so they can put their camera on when they talk. This helps people online see them.
- An Owl camera device can track people's faces when they talk.

Leah closed the meeting and thanked Members for their participation.

Members thanked Leah for her inclusive Chairing today.

The meeting closed at 4.00pm.

Words we use

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- **Co-design** is when the NDIA will work together with people with disability and the broader disability sector to design policy.
- **Conflict of Interest:** Conflict of Interest Declaration is a document where you need to say all the different ways you are connected to the NDIS. This could include if:
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 - you are a NDIS participant
 - you are part of other reference groups that talk about the NDIS

This is because we all need to make sure your job in this Reference Group doesn't clash with other jobs you do. It is ok to have a conflict of interest, but you need to let the IAC Secretariat know.

- **Culturally and linguistically diverse (CALD):** Is a person who has a different culture or speak another language that is not English. For example, this can be someone who:
 - Is a migrant. They left their country by choice to live and work in Australia
 - Is a refugee. They left their country because it was not safe to live there anymore.
- **Diverse:** this means different in some way. Diverse people have personal features or experiences that make them different.
- **Employment:** having a job that pays you for your work.
- **Engagement:** people working together to share their experiences, thoughts, feelings and ideas on a project.
- **Equity:** everyone has the same chance to do or be part of something, no matter their background, identity, or experience.
- **First Nations:** people who identify as Aboriginal Australians or Torres Strait Islanders.
- **IAC Secretariat:** the team that organises the meetings, sends papers and pays members for attending.
- **Inclusion:** something is inclusive when everyone can take part.
- **Intersectionality:** happens when someone is different in more than one way.
- **LGBTIQA+:** the letters LGBTIQA stand for lesbian, gay, bisexual, transgender, intersex, queer or questioning and asexual. The '+' is for people who are part of the LGBTIQA+ community but don't talk about themselves using a word from this list.
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- **Minutes:** notes of what happened in a meeting.
- **Participants:** these are the people that the NDIS helps.
- **Principal Member:** leads the Independent Advisory Council (IAC) and is one of the Co-Chairs of the Reference Group.
- **Psychosocial disability:** disability that affects how you feel, think and interact with others.

- **Reference Group:** is a group of people who know a lot about something. This group knows a lot about equity and inclusion.
- **Strategy:** planning a better future and how we are going to get there.
- **Transgender people:** people whose gender identity is different from the one they were given when they were born.
- **Work Plan:** is a document that says what the Reference Group will do in the next year, or two years.

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Meeting minutes for Equity and Inclusion Reference Group

Meeting 3 – 25 March 2024

12.30pm to 4.30pm (AEDT)

Online via MS Teams

Reference Group Members

Leah van Poppel, Principal Member & Co-Chair

Jennifer Cullen, Co-Chair

George Taleporos

Mark Tonga

Judith Drake

Denton Bowles


Margherita Coppolino


Suzy Trindall


Clare Gibellini

Barbel Winter

NDIA staff

Marina  Director, Strategic Advice

Gemma  Assistant Director, Independent Advisory Council (IAC) Secretariat

Matilda  Communications Officer, IAC Secretariat

Corri McKenzie, Deputy CEO, Service Design and Improvement (session 3)

Aaron Verlin, General Manager, Co-Design and Engagement (session 5 and 6)

Attending

Lucy Testa, IAC Independent Consultant

Apologies

Kalena Bos

Tricia Malowney

Samantha Jenkinson

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Session One - Pink

1.1 Principal Member's welcome and open

Ms van Poppel opened the meeting at 12.33pm

Adjunct Associate Professor Cullen provided an acknowledgement of the Traditional Custodians and Owners of the lands on which Members and attendees were meeting.

Ms van Poppel noted apologies from Kalena Bos, Samantha Jenkinson, and Tricia Malowney.

Adjunct Associate Professor Cullen was welcomed back into the Co-Chair position.

Session Two - Purple

2.1 Minutes, Actions and Conflicts of Interest and Terms of Reference

Members approved the minutes from the meeting held on 8 November 2023 and noted the matters arising.

No new conflicts of interest were declared.

Session Three - Orange

3.1 Issues Member have heard in their communities

Leah led this session and welcomed all Members to share the most common issues they are hearing about in their communities.

Members noted:

NDIS Review and Disability Royal Commission (DRC)

- The proposed changes from the NDIS Review are causing a lot of fear, particularly for those relying on providers intensively.
- Concern that the NDIS Review has virtually nothing to offer in the intersectionality space and the NDIS is not genuine about this.
- Concern about what is in the new legislation that has been flagged by the Minister.
- Concern in First Nations community about the NDIS Review and DRC recommendations.
- Concern the government response to DRC recommendations will not be until middle of year and that this will mean further delay to the government response to the NDIS Review.
- There is fear in the autistic community about what changes will impact them, particularly around foundational supports.
- Concern about negative thinking about the autistic community, in regard to NDIS resources.
- Concern that the 3:1 funding model that is part of Home and Living recommendations will affect minority groups in particular.
- Concern amongst self-managed participants that respite may become less flexible.
- Concern that support coordinators are relabelling themselves as navigators.

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- Consideration should be given to the role of Local Councils in support or implementation of the navigator roles, given their knowledge of local community.
- In considering navigators for specific disability groups, it is also vital to recognise that people may have multiple disabilities.
- Concern that the requirement for provider registration will mean that some providers with a small number of NDIS clients may not go through the process, reducing the workforce.
- There is fear around the independent or assessment process being proposed by the review. It is stressful for people who are still traumatised by the independent functional assessment debate.
- More needs to be done in psychosocial disability and the Quality and Safeguards Commission needs to take an active role.
- Access to the scheme needs to remain based on individual functional capacity and not disability types.
- The NDIA needs to consult with the disability community and to keep the community well informed and engage every step of the process.
- There is reform fatigue in the disability community and there needs to be some clear assurance that any changes are what the disability community want, not what providers or others want.

NDIS services and supports

- Concern about people being forced into aged care facilities.
- The PACE system seems to be causing increased problems for participants, particularly when there is a need for change of circumstances.
- The messaging about the development of the First Nations Strategy is concerning. It is stated publicly and in the meeting papers that NDIA is partnering with First Peoples Disability Network to develop the Strategy. The role of the First Nations Advisory Council (FNAC) in co-design of the Strategy needs to be reflected. There also needs to be better communication with FNAC, including if there are any changes to their role.
- Frontline staff do not have quality of empathy in the National Contact Centre. This seems to be a culture issue and also about levels of delegation.
- Plan building is taking longer, and people are getting calls for unscheduled plan reviews out of the blue.
- Concerns participants are getting calls for a check-in and it turns into the planning meeting.
- Concern that planning meetings are based on 'worse day' scenarios and plans based on the views of one NDIS worker on one day.
- There is advertising for Supported Independent Living (SIL) everywhere and no quality assurance.
- There is a lack of choice and control for participants with Independent Living Options (ILO) and SIL.
- Concerns about disability workforce turnover, and how this will impact NDIS support quality and availability.

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- Encouraged to hear about the work Invespur is doing in auditing, where a consumer technical expert (CTE) who is a person with lived experience contributes to the audit process.
- Concerns the pricing survey was not set up to reflect that most people use multiple providers.

Action 1: Ms McKenzie to respond to Adjunct Associate Professor Cullen regarding concerns about messaging regarding the First Nations Strategy and FNAC.

Session Four - Blue

4.1 NDIS Review Recommendations

Lucy Testa, IAC Independent Advisor, led this session. Ms Testa asked the group what they considered the non-negotiable elements were in the review recommendations.

Members noted:

- Concern that NDIS participants who turn 65 will be pushed into Aged Care, and this is already happening. For people with disability, nursing homes are very unlikely to meet their needs.
- People with disability should have access to the supports they need regardless of which government agency funds these supports.
- People with disability must be included in the process of designing how foundational supports will work.
- There must be seamless transitions from the NDIS to foundational supports.
- Concerns what block funding foundational supports means for minority groups where there is less choice and control, and it may be more difficult to find trusted providers.
- Government needs to get better at supporting the intersections of a person. This means considering the needs of people and the best ways to support their quality of life.
- Mainstream supports need to have the capacity and necessary training and knowledge to support people with disability.
- It needs to be clear who funds different support needs, including palliative care disability needs.
- There must be real choice and flexibility with choice of a navigator.
- There must be skilled navigators who understand and represent the diversity of their community.
- Local Councils may be well placed to implement local generalist navigators, with existing community understanding and infrastructure.

Action 2: Ms Testa to have follow up discussion with Members about review recommendations regarding psychosocial supports and First Nations people.

Session Five - Green

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5.1 Update on the IAC Advice – Improving Equity in the NDIS

Aaron Verlin, General Manager Co-Design and Engagement provided an update on implementation of the IAC Advice Improving Equity in the NDIS.

He noted that there has been slow progress and highlighted the establishment of the Co-Design and Engagement Branch in late 2023. An intersectionality framework is one key piece of upcoming work which the group can be engaged on.

The NDIA's LGBTIQ+ Summit will be held on 25 July at the Victorian Pride Centre.

Members noted:

- It is encouraging that something is happening on developing the intersectionality framework. Members very keen to see early thinking. A lot of thinking and consultation with the sector has already been done, and there are complexities about intersectionality to ensure it is inclusive rather than exclusive.
- The importance to connecting with the Queer Peers group in the Hunter region.
- The LGBTIQ+ community is nervous about the religious Bill going to parliament. There is risk of discrimination, and the community will want to see how the NDIA responds to this.
- Highlighted the need for the Reform for Outcomes Workforce Capability co-design work to consider diversity.

ACTION 3: Schedule an Out of Session meeting to discuss the intersectionality framework once the inclusion team is in place.

ACTION 4: Mr Verlin to provide further detail on LGBTIQ+ Strategy development in regard to its structure, attendance, and final format, to be circulated by the Secretariat.

ACTION 5: Secretariat to circulate contact details for people working in inclusion team.

Session Five – Green

6.1 Co-Design update

Mr Verlin gave an update on Co-Design in the NDIA, including:

- There is significant co-design through reform for outcomes and six co-design working groups. This includes looking at the NDIS Review recommendations and where they fall amongst the co-design groups.
- The intersections for co-design with IAC and different IAC reference groups will be mapped out.
- There is a need to be careful about how the term co-design is used. Not everything will be co-design and the processes need to be transparent.
- There will be some clear communication about what approaches the NDIA is taking for specific tasks.

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Members noted:

- There is a need to get more diversity on all co-design groups.
- There should be consultation with community for good advice, to help them feel involved, and also help people feel updated with current information.
- There is deep engagement that can come from groups that don't have access to 'co-design' itself.
- It is a high anxiety environment and this needs to be acknowledged,
- The co-design process can be a capacity building opportunity for participants. There are also peer training opportunities in co-design.
- When groups are formed for engagement or co-design opportunities they shouldn't be completely disbanded once a job is done.
- Local Councils are an asset to use in co-design.
- There is resentment when people are pulled into co-design groups without remuneration.

Session seven – Brown

7.1 Other business

- Ms van Poppel noted there is lots of work to do to work out how IAC and its reference groups consider and engage on all the NDIS Review recommendations.
- At the next meeting the IAC and reference groups will be identifying what is most important, and how to do it.

7.2 End of meeting

- The next meeting of the reference group will be the combined IAC and reference group meeting on July 3 and 4 | Melbourne.
- Ms van Poppel and Adjunct Associate Professor Cullen thanked Members and those who supported the meeting.
- Meeting closed at 4.30pm (AEDT)

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Draft Minutes March 2024



Minutes of Home and Living Reference Group

Meeting 4 – 26 June 2023

12.30pm – 4.45pm, MS Teams videoconferencing

Reference Group Members:

Ms Leah Van Poppel, Principal Member & Co-Chair
Dr Leighton Jay, Co-Chair
Dr Sharon Boyce
Adjunct Associate Professor Jennifer Cullen
Mr Mark Tonga
Mr Peter Gregory
Ms Grace Mills
Associate Professor Mary-Ann O'Donovan
Ms Pat Sutton
Dr George Taleporos
Mr Peter Tully
Mr Robbi Williams
Ms Leanne Pearman
Ms Rebecca Evans

NDIA Representatives:

Mr Tim Stork, Branch Manager, Performance Management and Quality (Session2)
Mr Ed Duncan, Branch Manager, Operations and Housing Support (Session 2)
Dr Sam Bennett, General Manager, Policy, Advice and Research (Session 4)
Mr Ross ^{s47F - personal privacy}, Director, Agency Policy (Session 4)
Ms Penelope McKay, DCEO Market Stewardship and Home and Living (Session 3 and 4)
Ms Kathy ^{s47F - personal privacy}, Director, Strategic Advice, Policy, Advice and Research
Ms Gemma ^{s47F - personal privacy}, Assistant Director, Independent Advisory Council (IAC) Secretariat
Ms ^{s47F - personal privacy}, Assistant Director, IAC Secretariat

Attending:

Ms Anna Burke, acting as IAC's Independent Consultant

Apologies:

Ms Liz Dutton
Mr Alan Blackwood

1. Co-Chair's welcome and open

1.1. Principal Member's welcome and update

Dr Leighton Jay opened the meeting at 12.30pm as Chair of today's meeting, noting [s47F - personal privacy](#)

Ms Jennifer Cullen provided Acknowledgement of Country.

Dr Jay noted apologies from Liz Dutton, Leah van Poppel and Alan Blackwood.

Dr Jay noted that the update to the Reference Group membership will be confirmed soon and thanked members for their patience.

Dr Jay noted Penelope McKay, Deputy CEO Market Stewardship, and Home and Living, will attend the meeting from 2.30pm. The agenda has been adjusted so Ms McKay can be in attendance for member reports.

1.2. No co-chair welcome.

1.3. Minutes confirmation and Declarations of interest

Members confirmed the minutes from the previous meeting – Meeting 3 – 17 May 2023.

Matters arising from the previous meeting were noted, and there were no new Declarations of interest.

2. Intraplan inflation in relation to Supported Independent Living (SIL)

2.1. Intraplan inflation in relation to SIL

Dr Jay welcomed Ed Duncan, Branch Manager Operations and Housing Support and Tim Stork, Branch Manager Performance Management and Quality to the meeting.

Mr Stork provided an explanation of the inflation that can occur in existing plan (intraplan) or between plans (interplan). A written brief was provided with data from the Scheme Actuary.

Mr Stork noted:

- The Agency has been looking these issues over last two years.
- Intraplan inflation often occurs with spending on core supports, or on quotable items. It is more commonly seen when a plan is reduced.
- With core supports intraplan inflation often happens when provider changes the number of hours of support or ratio of support.
- Interplan inflation is more common with section 100 requests and Administrative Appeals Tribunal.
- Intraplan inflation is less predictable so potentially harder to understand or control. It may not always be a bad thing, but the Agency needs to understand the cause.

- Participants who have a complete change of circumstance will likely fall into this data.

Members noted:

- Questions about where most inflation is occurring. For example, if it is for legitimate reasons such as degenerative condition or change in informal supports, or other issues, eg. provider activity.
- There is a need for the Agency to address the indexation element in a better way.
- Concerns that the Agency often provides additional funds in the next plan when inflation occurs.

In regard to SIL Mr Duncan noted:

- When a person requires additional supports in their home, or they need to move to short-term SIL due to change in circumstances, plan funds are used up much quicker than expected.
- There is intraplan inflation occurring in 38% of plan reviews.
- Impacts of previous plan decreases is a significant cause of inflation.
- The Agency has seen a 41% increase in home living, and many requests are due to change of circumstances.
- The current housing crisis is potentially driving some of this as SIL is an opportunity to have a home.
- Ratios in SIL supports can cause inflation, eg, when funded for 2:1 but receiving 1:1 support.
- The better planning initiative (Reform for Outcomes) should aim at identifying issues early and addressing issues early.

Members noted:

- The need to make plan managers more accountable for managing plan funds over the plan period.
- NDIS Quality and Safeguards Commission is a significant stakeholder in this work. However, there is a lack of follow up when complaints are made.
- The need to link this work with other areas of the Agency, such as those leading the hospital interface and Justice work.
- Also need to consider homeless, those at risk of homelessness and those requiring palliative care.
- Questions about the methodology of how the Agency decides reasonable and necessary supports.
- Concerns that it is not fully understood what it takes to support people with complex needs.
- Providers are charging for a large range of non-face to face activities. For example, not providing 'back of house' supports that should be expected (eg. team meetings) without the participant incurring additional costs.
- There is a need to provide information in accessible formats and easy read. It is vital the participant fully understands their plan.

3. What you've heard

3.1. Issues Members have heard in their communities

Members noted:

NDIS access and planning

- The need for future care planning, particularly among people with disability who have ageing parents. There is a need to consider supported decision making, reliable supports and information about supports for these people.
- Reports that planning does not encourage independent living, especially for those with psychosocial disability.
- There is inconsistent information about how people can and cannot use their NDIS plan funding. The disability community require clear information, in accessible formats, for equal information access.
- There needs to be consistent decision making about SIL and SDA.

NDIS service and supports

- The significant impact that circles of support around a person can provide to a person, particularly for people with complex needs and ageing parents.
- Concerns around safety and quality of supports with reports that some people with disability are sleeping in their mobility chairs even though they have multiple service providers.
- In relation to hospital discharge, there is a need for the various support roles to work in a more coordinated way. For example, hospital liaison officers, aged care, planners, navigators etc., should work together to provide streamlined supports.
- There is a lack of appropriate accommodation, particularly core and cluster, for people with psychosocial disabilities.
- There is a need for NDIA to acknowledge the risk of homelessness for people with disability and work closely with states and territories and mainstream services to address the issue.
- Concerns around the power imbalance and sense of intimidation a person with disability feels when they go to the Administrative Appeals Tribunal.
- Calls for NDIS and NDIS Quality and Safeguards Commission to do more to stop service providers who overcharge participants for services, above the NDIS Pricing Arrangements and Price Limits. For example, misconduct in charging for crossover shifts, SIL supports, assistance with daily living.
- Calls for the more clarity around the recently released [NDIS SDA Pricing Review 2022-23 Final Report \(2.3MB DOCX\)](#). Particularly for people with disability who have SDA and want to update existing housing or want to live in a one-bedroom house.
- The information in the appendix to the SDA Pricing Review report needs to be accessible.
- Current individualised living options (ILO) are not being applied the Consumer Price Index. The ILO price brackets have not changed as far as members are aware. There has been no increase in the guidelines.
- There seems to be a disconnect between different parts of Agency about how home and living is operationalised.
- There is a need for a navigator position for people with psychosocial disability or cognitive impairment. This person can provide accountability to ensure the support allocated is properly provided to the participant.
- There is a lack of flexibility in NDIS plans, in shifting core and capacity building funding in particular.

- In regard to the pathway out of SIL, people find themselves trapped into what we would have referred to previously as forced co-tenancies.

SDA AND SIL practices and quality

- Concerns about quality of supports in SIL and SDA.
- Reports the NDIA tells some people with assistance dogs that they need to live in SDA, despite wanting to rent appropriate properties through ILO supports.
- Reports there is a lack of choice and control and supply in supported independent living (SIL) dwellings.
- The short-term nature of property leases in the open rental market means it is very difficult to obtain long term rental accommodation for participants who qualify for SIL funding. Every time a participant moves and is removed from a familiar environment it often significantly impacts their quality of life.
- Providers are using inappropriate practices and advertising techniques to fill vacancies in SIL.
- Concerns that SDA providers are only focussed on money. Some companies build SDA apartments as a means only to get people into that space, however there is no community resources around them.
- Lack of flexibility around the use of core supports, particularly where a person is in a 1 to 3 SIL arrangement and funding for behaviour support plans.
- Some participants are having a positive experience, for example a family member has interstate and is receiving SDA funding to live independently in and SDA apartment for the first time.

Action 1: Identify any work or communication the NDIA is doing with others in the sector to address the issue of lack of long-term rental options for participants who qualify for SIL funding.

4. Home and Living Framework

4.1. Update on the Home and Living Framework and Implementation

Ms McKay was welcomed back, along with Ross s47f - personal privacy Director Agency Policy, to present on the Home and Living Framework (the Framework). Ms McKay first responded to questions raised in the previous session in relation to the SDA Pricing Review:

- As ILO is not priced as a package the cost is made up of the priced items that are included for the participant.
- An SDA owner can have a property reclassified as a new build if over 45% of the new build price is spent on renovations.
- The SDA price guide does not include one-bedroom homes as they are not readily available, they are villas and apartments. There is a gap where the dwelling has one participant living with others who are not participants, this still needs to be reviewed.

Ms McKay provided an update on the Framework, noting:

- The Framework document is comprehensive, and the co-design work that has gone into creating it is commended.
- The Framework has been to the Senior Leadership Team (SLT) who made the decision it should go to Board.
- The NDIS Review team Agency had been in discussion as the release of the Review outcomes gets closer, and there is no indication that Framework is out of alignment with the Review.
- Regarding timing of release of the Framework, considering the Review and the Royal Commission, it is not about priority but the sequencing that is significant.

Mr [REDACTED] noted that:

- The new framework includes some minor changes regarding housing supply, language and formatting.
- Following the SLT outcome, the business ownership of the Framework will move into Ms McKay's group, Market Stewardship, and Home and Living.
- When the Agency talks about legacy stock, this is the 6+ bedroom housing that is being transferred from States. The next element is how do we work to ensure participants have access to inclusive housing.

Members praised the co-design approach of the NDIA to finalise the Home and Living Framework and Implementation Plan.

Members noted concern that if the NDIA waits on outcomes from the NDIS Review and Disability Royal Commission this work may be lost. There is a need to ensure the group can continue to co-design and walk alongside the Agency in implementation.

In regard to the SDA Price Review report members noted:

- Concerns you cannot live alone in a one bedroom home according to the SDA price guide. The house option is only there if you are sharing with other people. You need to live with another person to qualify for SDA.
- Concerns this is a supply and demand issue, if it was priced these dwellings may be available.
- This is an issue for people in criminal justice system who are required to live alone.
- When putting in evidence for reasonable and necessary support, is it clear that there are certain dwelling types and living arrangements that suit different people. For example, a single person dwelling with overnight assistance.
- Robust housing should not be a housing option, only a short to medium term support.

5. Meeting close

5.1. Other Business

N/A

5.2. Next Meeting

The Chair thanked Reference Group members for their participation today, acknowledging that this will be the last meeting for some members.

The next meeting is scheduled for 14 September and is online. **

The meeting closed at 4.45pm.

** Meeting date later changed to 18 September 2023



Minutes of Home and Living Reference Group

Meeting 1 – 18 September 2023

12.30pm – 4.30pm, MS Teams videoconferencing

Reference Group Members:

Leah Van Poppel, Principal Member & Co-Chair
Patricia Sutton
Leighton Jay
Peter Tully
Rebecca Evans
Luke Nelson
Grace Mills
George Taleporos
Peter Gregory
Mary-Ann O'Donovan
Jennifer Cullen
Sharon Boyce
Leanne Pearman

NDIA Representatives:

Kathy ^{s47F - personal privacy} Director, Strategic Advice, Policy, Advice and Research
Gemma ^{s47F - personal} Assistant Director, Independent Advisory Council (IAC) Secretariat
Matilda ^{s47F - personal priv} Senior Communications Officer, IAC Secretariat
Sam Taylor, acting General Manager for Policy, Advice and Research
Chris Faulkner, Branch Manager for Home & Living and Home & Living Innovation

Attending:

^{s47F - personal privacy}

Apologies:

Robbi Williams
Kelly Cox

Words we use

- **Circles of Support:** a group of people built around a person with disability. They meet regularly to help the person think about, plan and achieve their goals and make decisions.
- **Co-Chair or Co-Chairs:** the Chair of a meeting is the person who leads the meeting. In the Reference Group, we have two people who lead the meeting, so we call them Co-Chairs.
- **Co-design** is when the Agency will work together with people with disability and the broader disability sector to design policy.
- **Conflict of Interest:** Conflict of Interest Declaration is a document where you need to say all the different ways you are connected to the NDIS. This could include if:
 - your work is around the NDIS
 - you are a NDIS participant
 - you are part of other reference groups that talk about the NDIS

This is because we all need to make sure your job in this Reference Group doesn't clash with other jobs you do. It is ok to have a conflict of interest, but you need to let the IAC Secretariat know.

- **Cultural change:** changes to the way a group of people think and act about something.
- **First Nations:** people who identify as Aboriginal Australians or Torres Strait Islanders.
- **Homelessness:** people who do not have a home or place to live.
- **IAC Secretariat:** the team that organises the meetings, sends papers and pays members for attending.
- **Independent Living Options (ILO):** supports people with disability to live the way they want to, for example with a host or housemate.
- **Informal support:** unpaid support a person with disability gets from their friends and family.
- **Intellectual disability:** disability that affects how someone thinks and understands information.
- **Intersectionality:** happens when someone is different in more than one way and might be treated differently or poorly for all the ways they are different.
- **Matters arising:** things that are happening at the moment to do with the Reference Group.
- **Minutes:** notes of what happened in a meeting.
- **Participants:** these are the people that the NDIS helps.
- **Participant Service Guarantee:** The [Participant Service Guarantee](#) is a document that tells participants how long the NDIS will take to make decisions. The NDIS must meet these timelines.
- **Policies:** rules for how an organisation is run.
- **Principal Member:** leads the Independent Advisory Council (IAC), and is one of the Co-Chairs of the Reference Group.
- **Psychosocial disability:** disability that affects how you feel, think and interact with others.
- **Reference Group:** is a group of people who know a lot about something. This group knows a lot about home and living supports for people with disability. Reference Groups work together to make a plan or find ways to make something happen.
- **Supported Independent Living (SIL):** support to live in your home, usually for people with higher support needs who live with others with disability.

- **Strategy:** planning a better future and how we are going to get there.
- **Work Plan:** is a document that says what the Reference Group will do in the next year, or two years.

1. Co-Chair's welcome and open

1.1. Principal Member's welcome and update

Ms Leah van Poppel (Leah) opened the meeting and Acknowledged Country. Ms Jennifer Cullen (Jennifer) also acknowledged First Nations people as traditional owners of the lands we met on.

Leah asked that members be accessible in the words they use and, be allies by asking others to explain any hard words they use.

2. Minutes and Declarations of interest

2.1. Minutes confirmation and Declarations of interest

Members noted they would contact the secretariat to correct a couple of spelling and clarity errors in the previous meeting's minutes. This includes making sure there is no jargon in the minutes.

Members told us about their new conflicts of interest:

- [s47F - personal privacy](#)

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

3. What you've heard

3.1. Issues Members have heard in their communities

NDIS access and planning

- Reports some participants have thought of ways they can live independently but are told by NDIS planners that living with others with disability is best for them.
- Members recommended NDIS home and living decision makers work more closely with participants and the people who support them.
- Reports of long delays for home and living decisions that sometimes result in the participant going to hospital or aged care.
- Home and living supports are not part of the [Participant Service Guarantee](#). Members reported this leaves participants and their support workers unsure of when decisions will be made.

- Reports the NDIA takes too long to approve Independent Living Options (ILO) funding. The wait can be stressful for participants, and it can be difficult to complain or try to speed up the process.
- People with intellectual disability, brain injury and psychosocial disability do not always realise they need support or that the NDIS can support them. Members suggested creating a NDIS service to help people navigate the NDIS, including accessing the NDIS.
- Calls for more flexible NDIS plans where participants can swap core and capacity building supports and use behaviour support funding on other things if they are already well supported.
- Concerns for public and participant safety if home and living plans come to an end without a plan for keeping at risk participants from homelessness or crime.

NDIS service and supports

- Reports self-managing participants find it difficult to understand home and living supports.
- Members reported ILO does not always fit a person's needs. This can move participants into ill-suited Supported Independent Living (SIL) or mean they need more [informal support](#).
- [NDIS supports have price limits](#). Members reported these price limits aren't always used the same and are not always high enough to support people in rural and remote areas.
- Continued reports of limited housing for people with psychosocial disability, particularly core-and-cluster housing. This model builds independent homes around core support and service centres.
- Members want the NDIA to support more creative thinking around home and living supports by sharing more information with the community on innovative home and living models.
- Reports it can be difficult for parents to support their children with disability to buy a home that suits their needs because of challenges in the NDIS and builders' concerns about cost.
- Members highlighted the importance of building [Circles of Support \(external\)](#) for people without many informal supports, especially First Nations people and people leaving prisons or hospitals.
- Members advocated for better funding for Circles of Support. Members reported the NDIS rarely funds these important social networks which are usually grant, self and community funded.
- Members also noted funding Circles of Support could make them a target for fraud if not managed properly.

NDIS providers and disability community

- Members highlighted the importance of forming partnerships between providers and participants when designing and building home and living supports.
- Concern current practices, policies and pay for home and living support workers are not flexible enough to allow creativity and collaboration in how they support people with disability.
- Members reported fear in the disability community about what changes will come from the [NDIS Review](#) and [Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#) (Royal Commission).

- Members suggested brief and positive messaging without jargon for the NDIS Review and Royal Commission and connecting with the disability community to see how they react to information.

Action 1: Seek data from the Agency on backlog of home and Living decisions.

Sam Taylor, acting General Manager for Policy, Advice and Research and Chris Falkner, Branch Manager for Home & Living and Home & Living Innovation provided general responses and feedback including:

- The Royal commission will give hard recommendations, in accordance with the Terms of Reference. The Agency will be responsible to act on what is in its remit.
- The NDIA Home and Living Framework is on hold until the Review and Royal Commission reports are released. The NDIA will come back to the group once more is known.
- Hospital discharge decision is now set at 5 days, but there are sometimes delays in availability. The NDIA doesn't know about a person being in hospital unless they tell them.
- Acknowledged the feeling in community about being worried about Review and Royal Commission.
- Recognised the need to shift the NDIA culture.

4. Workplan

4.1. Workplan

Members highlighted that many of the home and living issues are because people with disability are not able to understand and make decisions about how they live. The Reference Group want their workplan to focus on changing this attitude into one that values and listens to people with disability.

The Reference Group identified 3 issues they want their work to address through education and cultural change:

- How people navigate the NDIS, including:
 - Creating NDIS Navigators to support those most in need.
 - How the NDIS Navigator role relates to the work of local area coordinators (LACs) and support coordinators.
- NDIS planning, including:
 - Creating NDIS plans in the participant's voice in language they understand.
 - Ensuring people centred planning for home and living supports.
 - How the NDIS can help participants understand planning.
 - Improving transparency around how home and living decisions are made.
 - How PACE, the NDIA's new computer system, relates to planning changes.
 - How cultural differences are considered in planning.
- How the NDIS works with other government agencies and community services. For example in addressing homelessness and housing shortages for people with disability.

Members agreed the workplan would cover these 3 areas by focusing on fostering values of listening and inclusion of people with disability in the NDIA. A goal should be to change the culture in

the NDIA so no one assumes people with disability cannot make good decisions about how they live.

The Reference Group decided their workplan will include working with the independent living and plan flexibility co-design [Reform for Outcomes initiatives](#). Members agreed most of their work will be on navigating the NDIS and NDIS planning. The Reference Group plan to do smaller targeted pieces of work on how the NDIS works with other systems to address homelessness.

The overarching principles of Sustainability, Community, Self-reliance, and Interconnectedness were highlighted.

Members also noted:

- The Reference Group would like an overview of what the NDIS Review is thinking about a navigator role in their next meeting.
- The disability community need clear information on changes that affect them, and their reactions to change should be brought into the decision-making process. This includes the outcomes of the NDIS Review and Royal Commission.
- The narrative around the NDIS Review and Royal Commission should focus on how the information they collect will be used to help people with disability. It should explain that government will implement changes in collaboration with the disability community.
- Some participants and their carers have worked hard to get home and living supports that work well and are worried changes to the NDIS could take them away.
- People with disability need time and simple language to understand and take part in planning.
- Intersectionality should be considered in all reference group work, and how some people with disability experience more barriers than others.
- The NDIA have not done much work on Circles of Support but this topic covers more than home and living supports. The Reference Group should not step outside its focus but want to consider Circles of Support where they are relevant. For example, a NDIS navigator role could include building Circles of Support for their participant.
- Over the past few years the NDIA has not wanted to do co-design. There has been a shift towards co-design. It is good to remember how far things have come and that they can continue to improve.

Action 2: Agency to provide paper and discussion on draft work they have done on the navigator role at next meeting.

5. Meeting close

5.1. Other Business

- N/A

5.2. Next Meeting

- The next meeting is scheduled for 9 November and is online.
- The meeting closed at 4.23 pm.



Minutes of Home and Living Reference Group

Meeting 2 – 9 November 2023

12.30pm – 4.30pm, MS Teams videoconferencing

Reference Group Members:

Leah Van Poppel, Principal Member & Chair
Patricia Sutton
Leighton Jay
Peter Tully
Rebecca Evans
Luke Nelson
Grace Mills
George Taleporos
Peter Gregory
Mary-Ann O'Donovan
Jennifer Cullen
Sharon Boyce
Leanne Pearman
Kelly Cox

NDIA Representatives:

Andrew Parsons, General Manager of Markets Priority Projects (session 3)
Ed Duncan, Branch Manager Operations and Housing Support (session 4)
Craig ^{s47F - personal privacy} Director Reform for Outcomes (session 4 and 5.1)
Maria Gold, Acting Branch Manager Reform for Outcomes (session 4)
Olivier ^{s47F - personal privacy} Director Technical Advisory Branch (session 4)
Gemma ^{s47F - personal privacy} Assistant Director, Independent Advisory Council (IAC) Secretariat
^{s47F - personal privacy}, Assistant Director, IAC Secretariat

Guest:

Gavin Burner, IAC Member

Attending:

^{s47F - personal privacy}

Apologies:

Robbi Williams

1. Co-Chair's welcome and open

1.1. Principal Member's welcome and update

Ms Leah van Poppel (Leah) opened the meeting and gave an Acknowledgment of Country.

Leah noted there is no Co-chair for the meeting and advised that the IAC will appoint Co-chairs for each Reference Group once 6 IAC member vacancies are resolved through the government decision-making process.

Mr Andrew Parsons, General Manager of Markets Priority Projects, NDIA was welcomed as a guest today to hear member reports.

Leah noted apologies from Mr Robbi Williams and Ms Samantha Taylor (NDIA).

2. Minutes and Declarations of interest

2.1. Minutes confirmation and Declarations of interest

Members approved the minutes of the last meeting.

Members noted the actions log. Leah noted the 'Navigator' discussion paper was circulated this morning. This is not on the agenda, but members may want to discuss it in other business.

The following Conflicts of Interest were noted:

s47F - personal privacy

[Redacted]

s47F - personal privacy

[Redacted]

3. What you've heard

3.1. Issues Members have heard in their communities

NDIS access and planning

- Concern that older participants are encouraged to leave the NDIS. This seems to be particularly when they start experiencing age-related health issues.
- Face to face meetings are really important for NDIA staff to understand participants, and are preferred by a majority of participants.
- Calls for a greater focus on social connection in conversations about home and living supports.

- Reports that delays in home and living decisions are impacting participants whose circumstances have changed.
- Calls for better long-term planning to help people with psychosocial disability move out of their parent's home and into housing that suits them.

NDIS service and supports

- Concern that operating guidelines (Our Guidelines) are unclear about Specialist Disability Accommodation, particularly in relation to eligibility.
- Reports that some families with children approaching the upper age limit of the early childhood approach are not well supported to understand the process required for eligibility reassessment for the NDIS.
- Recommendations for core and cluster style housing for people with psychosocial disability as a cost-effective way to support their independence. This is housing with fully independent living quarters with private bathroom and kitchen facilities.
- Reports that some people with intellectual disability feel unsafe in Supported Independent Living (SIL) accommodation. Calls for more support to help these people decide where they live and who they live with.
- Continued reports of state guardians making decisions that appear to be without taking into consideration what the person with disability wants.
- Reports that people feel pressured by NDIA staff and SDA providers to share their home.
- Concerns the NDIA does not have appropriate frameworks in place to evaluate outcomes that reflect the core principles of the UN Convention of Rights of Persons with Disabilities.

Providers

- Reports that some providers build accessible housing where it suits them, which can make it hard for people with disability to find a home somewhere close to their family and community.
- Concern that some participants' choice and control over who they live with in SDA is limited.
- Reports some providers stop participants from using other providers in their SDA and don't allow visitors.
- Concern people with disability are not involved in finding and choosing their SDA housemates. SDA providers advertise and fill vacancies without any concern for what the person with disability wants.
- Reports that people with disability in remote communities may not apply for the NDIS because there are limited providers in their area.

Community and other government services

- Reports that people with disability are not being able to access appropriate palliative care.
- Calls for the NDIA to work closely with the health and aged care system to find solutions for people in palliative care needing disability support.
- Reports that some people with disability who leave the justice system are having difficulty finding a home that meets their needs. This may contribute to them reoffending.

- Calls for the NDIA to advocate for improvements to [Special Disability Trusts](#) so the legislation better reflects the current cost of accessible housing.

Action 1: Seek response from the NDIA about what the current and future approach is to giving participants the option of face-to-face meetings.

Action 2: Hold out of session meeting to discuss issues with Our Guidelines for SDA (Ms Leah van Poppel, Mr Peter Gregory, Mr Peter Tully, Mr George Taleporos, Mr Leighton Jay and Ms Kelly Cox)

Action 3: Seek Scheme Actuary presentation on what participant outcomes are being measured, particularly home and living outcomes in relation to UNCPRD.

4. Home and Living Decisions

4.1. Home and Living Decisions

Leah welcomed Mr Ed Duncan, Branch Manager Operations and Housing Support, Ms Maria Gold, Acting Branch Manager Reform for Outcomes, and Mr Craig S47F - personal priva, Director Reform for Outcomes and Co-Chair of the Independent Living co-design group.

Mr Duncan talked about the current issues with home and living decisions and what the agency is doing to make better quality and faster home and living decisions. This includes:

- The new process of having a Complex Assessment Meeting when a participant is new to SIL or SDA, to check the quality of decisions.
- Employing more people and having them trained in home and living supports and decision making.

Members noted:

- Concerns about the recent trend with reports of participants 65+ who are being forced to residential aged care.
- Concerns that plans for those aged 65+ are 'cut and paste' do not account for a person's unique needs.
- Ageing in place for people with disability is not discussed in the way it is for the general public.
- Concerns that the NDIA expects to meet most home and living decision-making improvement targets in 6 months, which is a long time for people who are waiting for a home and living decision.
- Questions about what external communications are being provided to people about the delays in home and living decisions.
- Calls for more education and information for occupational therapists and other people who provide evidence for home and living decisions.
- Concerns about planners messaging to participants that the home and living team is overloaded and a reassessment will take too much time.
- Concerns that decisions are being made without meeting with participants or their families.

- Some people with disability need help to use their home and living supports, especially to understand the recent price changes to SDA.

Action 4: Mr Ed Duncan to seek data on what trends are occurring for participants with home and living supports who are 65+ or approaching 65.

Action 5: Hold a future meeting to discuss the trends for participants who are 65+ or approaching 65.

5. Reform for Outcomes

5.1. Reform for Outcomes – Independent Living

Mr George Taleporos, IAC representative on the Independent Living co-design working group gave an update and asked a series of questions about this topic. They are now calling this group 'Home and Living'. He noted the co-design work that has already gone into the Home and Living Framework, and said the group has a focus on:

- How people identify need and apply for home and living.
- How decisions are made about need for home and living supports and the level of funding.
- How funding is used to implement a plan to achieve outcomes.

Members noted:

- Concerns about the language of markets and providers viewing people with disability as commodities.
- Planning discussions need to be participant focussed and participants need clear information about their options. The conversation should be about what is required for me to participate and live safely in my home.
- Participants and their families need more opportunity to collaborate with providers and planners on innovation in home and living supports.
- The focus should be on participant outcomes and upholding the rights of people with disability.
- People with psychosocial disabilities appear to be remaining disadvantaged. Many potential participants do not have access to the NDIA and those who do gain access don't appear to have enough support.
- There is a need to understand what the return on investment would be for genuine social and economic participation and participant focused planning and support.
- If participants have more flexible funding there needs to be better guidance, navigators, or other supports. This will help sustainability with better informed decisions.
- Need to extend the concept of co-design with community organisations from design to implementation.

5.2. Reform for Outcomes – Better Planning

Gavin Burner, IAC representative on the Better Planning co-design working group gave an update and asked a series of questions about this topic.

Members noted:

- Planning conversations should be longer to allow for supported decision making.
- Specialised navigators are needed, especially for people with cognitive or psychosocial disability.
- There are too many people involved in planning meetings, and they should be face to face.
- All documents need to be available in accessible formats, including Easy Read.
- Planning should be more like storytelling. It should be a personal process with an appropriately skilled person collecting all the information.
- The NDIA can help peer led and disability-led organisations to develop information for participants, noting people trust these organisations.
- Participants and their families should get a contact phone number or email address so they can contact the same person every time they need information.
- Local Area Coordinators and planners need more training, and this should be delivered by people with lived experience.
- Plans should be more flexible and recognise supports like navigators and peer supports have a role in helping people make good choices with their funding.

Action 6: Secretariat to provide detailed notes from session 5 to the presenters.

6. Meeting close

6.1. Other Business

- Members would like to talk about the Navigator role in more detail. This will be an item for discussion at the first meeting of 2024.

6.2. Next Meeting

- The next meeting will be in 2024.
- The IAC Secretariat is currently finalising the 2024 schedule of meetings.
- The meeting closed at 4.40 pm.

Words we use

- **Circles of Support:** a group of people built around a person with disability. They meet regularly to help the person think about, plan and achieve their goals and make decisions.
- **Co-Chair or Co-Chairs:** the Chair of a meeting is the person who leads the meeting. In the Reference Group, we have two people who lead the meeting, so we call them Co-Chairs.
- **Co-design** is when the Agency will work together with people with disability and the broader disability sector to design policy.
- **Conflict of Interest:** Conflict of Interest Declaration is a document where you need to say all the different ways you are connected to the NDIS. This could include if:
 - your work is around the NDIS
 - you are a NDIS participant
 - you are part of other reference groups that talk about the NDIS

This is because we all need to make sure your job in this Reference Group doesn't clash with other jobs you do. It is ok to have a conflict of interest, but you need to let the IAC Secretariat know.

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- **Homelessness:** people who do not have a home or place to live.
- **IAC Secretariat:** the team that organises the meetings, sends papers and pays members for attending.
- **Independent Living Options (ILO):** supports people with disability to live the way they want to, for example with a host or housemate.
- **Informal support:** unpaid support a person with disability gets from their friends and family.
- **Intellectual disability:** disability that affects how someone thinks and understands information.
- **Intersectionality:** happens when someone is different in more than one way and might be treated differently or poorly for all the ways they are different.
- **Matters arising:** things that are happening at the moment to do with the Reference Group.
- **Minutes:** notes of what happened in a meeting.
- **Participants:** these are the people that the NDIS helps.
- **Participant Service Guarantee:** The [Participant Service Guarantee](#) is a document that tells participants how long the NDIS will take to make decisions. The NDIS must meet these timelines.
- **Policies:** rules for how an organisation is run.
- **Principal Member:** leads the Independent Advisory Council (IAC), and is one of the Co-Chairs of the Reference Group.
- **Psychosocial disability:** disability that affects how you feel, think and interact with others.
- **Reference Group:** is a group of people who know a lot about something. This group knows a lot about home and living supports for people with disability. Reference Groups work together to make a plan or find ways to make something happen.
- **Special Disability Trust:** are set up to help family members with the funding for their current and future care and accommodation needs.

- **Specialist Disability Accommodation (SDA):** types of housing that suit people with high support needs.
- **Supported Independent Living (SIL):** support to live in your home, usually for people with higher support needs who live with others with disability.
- **Strategy:** planning a better future and how we are going to get there.
- **Work Plan:** is a document that says what the Reference Group will do in the next year, or two years.

Minutes of Home and Living Reference Group

Meeting 3 – 16 April 2024

12.30pm – 4.30pm, MS Teams videoconferencing

Reference Group Members:

Leighton Jay (co-chair)
George Taleporos (co-chair)
Patricia Sutton
Peter Tully
Rebecca Evans
Luke Nelson
Grace Mills
Peter Gregory
Mary-Ann O'Donovan
Jennifer Cullen
Sharon Boyce
Leanne Pearman
Robbi Williams

NDIA Representatives:

Penelope McKay, Deputy CEO, Partners, Providers and Home and Living
Kathy ^{s47F - personal privacy} Director Strategic Advice
Gemma ^{s47F - personal} Assistant Director, Independent Advisory Council (IAC) Secretariat

Attending:

^{s47F - personal privacy}

Apologies:

Leah van Poppel
Mary-Ann O'Donovan
Kelly Cox (attended briefly)

1. Co-Chair's welcome and open

1.1. Principal Member's welcome and update

Dr Leighton Jay opened the meeting and said that he would be co-chairing with Dr George Taleporos today. [s47F - personal privacy](#)

Mary-Ann O'Donovan also noted as an apology.

Adjunct Associate Professor Jennifer Cullen gave an Acknowledgment of Country.

Dr Jay noted this is the first meeting of the Home and Living Reference Group for this year.

Dr Jay introduced Lucy Testa as the new Independent Advisory Council (IAC) Independent Advisor working alongside Samantha Jenkinson.

2. Minutes and Declarations of interest

2.1. Minutes confirmation and Declarations of interest

Members approved the minutes of the last meeting on 9 November 2023.

The following Conflicts of Interest were noted:

- [s47F - personal privacy](#)

Members agreed that action 1 from the meeting on May 2023 regarding leaving hospital or nursing homes could be closed, noting the Secretariat is following up on some additional data.

3. What you've heard

3.1. Issues Members have heard in their communities

NDIS Services and supports

- The accommodation shortage means that people who should be leaving hospital are unable to be discharged as they have nowhere to live.
- Concerns that many people with mental health and psychosocial disability are not having access to the NDIS.
- Concerns about statements made by Mental Health Australia (MHA) that people with psychosocial are now well set up with supports for living and recovery. MHA has also (incorrectly) said the NDIS doesn't support recovery.
- The Administrative Appeals Tribunal (AAT) process is incredibly difficult for participants and their families and lacks empathy. There is not transparent decision making.

Disability Community

- Concern about recent media commentary about people involved in justice system.

- Concern that inappropriate accommodation with 4 bedrooms or more is still being registered, and there are areas where rows of SDA houses are being built.
- There is a lack of outcomes from the extensive Information Linkages and Capacity Building (ILC) funding that has been spent on projects.
- People who are incarcerated and have an NDIS plan are waiting a long time to get any communication or support.
- Concerns about general lack of housing and the skilled worker shortage in the community.
- There needs to be work done so that people can invest in Specialist Disability Accommodation (SDA) and do SDA themselves.

NDIS Review and Disability Royal Commission (DRC)

- It is hopeful that that specifically trained navigators will help people with psychosocial disability. Navigators will be able to assist when people have fluctuating conditions and changing support needs.
- Concerns in the community about the NDIS Review recommendations regarding the 1:3 funding model for supports. It seems inevitable that this will lead to more decision making that moves participants into group homes.
- Concerns about the NDIS Review recommendation to remove the improved liveability category from SDA.
- Concern about the NDIS Review recommendation re- mandatory registration and the likely impacts on self-managers.
- Amendments to NDIS legislation is causing distress and people are worried about seeing a return to previous forms of funding.
- There is a lack of communication with participants. This is creating fear as they are aware there is a lot going on in the background.

3.2. NDIA Update

Dr Jay welcomed Ms Penelope McKay, Deputy CEO of Partners, Providers and Home and Living to respond to the key issues raised in Member reports and provide an update from the NDIA.

Ms McKay noted:

- The concerns about funding supports on a 1:3 ratio are acknowledged but this is not a recommendation from the Agency. The Agency's approach hasn't change, it determines funding on what is reasonable and necessary.
- The Agency provides its own advice to government and will make sure the views of the community and reference groups are heard.
- Regarding lack of housing, this is an all of community problem, but it is recognised that the most vulnerable people are impacted the most.
- The Agency has prioritised making sure there is better data on SDA.
- Once there is a government response to the NDIS Review and DRC recommendations the Agency will be able to move forward.

- Regarding the Home and Living Framework (the Framework), this work has been held up. The NDIA is looking at what impact DRC recommendation 7, NDIS Review recommendations 8 and 9 have on the Framework.
- Following the government response, the NDIA will return to co-design and progressing the Framework.
- NDIA is committed to co-design and working with the sector, and recognises that people with home and living supports are some of the most vulnerable.

Action 1: Schedule future session to talk about the SDA enrolment processes and issues. Discussion to include what levers the agency has to give guidance to the sector about what is built.

Action 2: Schedule future discussion to talk about the 3:1 ratio for funding and funding decisions that only allow for living in group supported settings.

4. NDIS Review Recommendations

4.1. NDIS Review Recommendations

Ms Samantha Jenkinson, Independent Advisor to the IAC led the discussion on the NDIS Review recommendations related to Home and Living.

Ms Jenkinson explained that recommendation 8 is about funding being calculated at a 1:3 ratio for support, a flexible budget for home and living, and specialist navigators. Recommendation 9 is about sharing more information about the market and increasing the focus on participant outcomes.

Members noted:

- The wording is unclear, and people need to understand what 'average' funding of 1:3 means.
- Concerns that the 1:3 reflects old thinking and does not consider the rights of people with disability or self-determination for First Nations participants. It suggests that for some people shared living is their only option.
- The Agency needs to research and construct a funding approach that genuinely looks at the individual needs of a person who needs 24/7 supports.
- There is significant work to do to work with people in closed Supported Independent Living (SIL) services.
- Concerns about what stated support plus flexible budget can possibly look like.
- For flexible supports to work, there needs to be clear outcomes. There also needs to be consequences, tracking, and accountability.
- Concern that if Home and Living is attached to SIL and is a stated support, the only flexible budget will be community participation.
- Stating a ratio in government policy is a risk to innovation.
- When exploring what home might look like and be available to people, there needs to be enablers. Legislative frameworks do not allow for flexibility or creativity.
- There are support coordinators, Hospital Liaison Officers (HLOs), Justice Liaison Officers (JLOs), system wranglers and support coordinators. It is not clear who will still have a role to play.

5. The Navigator role

5.1. The Navigator role

Samantha Jenkinson gave an overview of how the navigator role has been represented in the NDIS Review recommendations and noted that the possible role of future navigators has also been part of the Home and Living Framework discussions. Ms Jenkinson asked the group to think about two questions related to the navigator role:

- What do we think are the skills required for this role?
- What are the points for transition – what does a person get from a specialist navigator as opposed to a general navigator?

Members noted:

- That having multiple navigators should not add to the complexity of the NDIS.
- If there is a need for navigators, does that say that the system being built is too complex? How can the NDIS be made more simple?
- Thinking needs to be done about how a home and living navigator can help to simplify things for a participant.
- The disability community are frustrated that the independent support coordinators will be removed, and concerned these will be replaced by a navigator who is an NDIS or partner staff member who is not trusted.
- Concerns a non-independent support coordinator will stop innovation.
- When home and living navigators were discussed previously, they were not replacing support coordinators.
- Navigators should not be put in place with block funding or large contracts. There should be diversity and people must have choice of what navigator they use.
- The role includes understanding the individual disability of the person.
- The navigator needs to have the skills to help the participants overcome difficulty to engage.
- The navigator needs to be working with the participant from the start, not after a personal budget is allocated.
- The navigator's work is about being a strong ally and helping people on their journey, and the role should not be fractured across authorities.
- Concerns the NDIA says it will design the training and skill set for navigators. This should be embedded in a co-design process.
- The agency of the participant needs to be supported. The plan is owned by the person. The NDIA's job is to decide on the funding for the person's plan.

6. Reform for Outcomes

6.1. Reform for Outcomes – Home and Living co-design working group

Dr Taleporos led this session. Dr Taleporos noted:

- For the first 3 months the working group tried to identify the key issues for Home and Living.

- Much of what was done was to help the government meet its 8% target.
- A short-term initiative the group completed was to streamline the process for a home and living request and change the guidance on the website.
- The group also reviewed and improved website messaging on different home and living products, to make the messaging more individualised.
- The next step is for the Home and Living co-design working group to move under Penelope McKay's area, Partner, Providers and Home and Living.

Dr Taleporos asked members what they think are priorities for co-design. Members noted:

- Navigators
- Variation of legislation
- Assessment and needs
- What constitutes reasonable and necessary support
- What needs to be done to achieve social and economic participation (funded and non-funded)

In regard to improving the co-design processes Members noted:

- People who don't have a voice need to be included in co-design.
- Information that is collected needs to be shared in accessible formats, eg. Easy Read and video.
- NDIA needs to make sure people know how the co-design is being done. This needs to happen from the beginning to end so the community is taken on the journey.
- Co-design should include face-to-face, local strategies, alongside online strategies.
- There is a lot of links between this work and the evidence-based support co-design and the 2 groups should collaborate.
- Concern that there was a lack of coordination and process design done when the co-design work was first starting.

7. Meeting Close

7.1. End of meeting

The next meeting will on July 3 and 4. This will be a joint meeting with IAC and all the reference groups. Members will have the option to come in person to Melbourne or join online.

A big focus of the meeting will be the NDIS review and strengthening the way IAC and its reference groups work together to deliver on the IAC workplan.

Meeting closed 4.30pm

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- **Strategy:** planning a better future and how we are going to get there.



PURPLE SESSION – AGENDA ITEM 2.1

ATTACHMENT A

Minutes of Intellectual Disability Reference Group (IDRG)

Meeting 2 – 1 June 2023

9.30am to 4.00pm, ParkRoyal Melbourne Airport.

Members

Ms Leah Van Poppel, Principal Member
and IDRG Co-Chair

Ms Sam Paior, Co-Chair

Dr Leighton Jay

Ms Paige Armstrong

Mr Gavin Burner

Ms Marissa Carlyon

Mr Nathan Despott

Mr Angus Graham OAM

Mrs Judy Huett

Ms Leonie McLean

Mr Jim Simpson

Ms Sarah Sutton

Mr Justen Thomas

Ms Catherine Viney

Ms Angela Yee

NDIA Representatives

Ms Rebecca Falkingham, Chief Executive Officer

Ms Corri McKenzie, Deputy Chief Executive Officer, Service Design and Improvement

Mr Sam Bennett, General Manager, Policy Advice and Research

Mr Daniel ^{s47F - personal privacy} Strategic Advisor, Policy, Advice and Research

Ms Kathy ^{s47F - personal privacy} Director Strategic Advice, Policy, Advice and Research

Ms Jaklin ^{s47F - personal privacy} Assistant Director (a/g), Independent Advisory Council Secretariat

Ms ^{s47F - personal privacy}, Assistant Director Communications, Independent Advisory Council Secretariat

Ms Karyn ^{s47F - personal privacy} Project Officer, Independent Advisory Council Secretariat

Attending

Ms Alisa Chambers, Acting General Manager, NDIS Quality and Safeguards Commission

Dr Jeff ^{s47F - personal pi} Senior Practitioner, NDIS Quality and Safeguards Commission

Ms Belinda Epstein-Frisch, Independent Consultant

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Apologies

Professor Sally Robinson, Member

Mr Brodie McElroy, Member

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- **Work Plan:** is a document that says what the Reference Group will do in the next year, or two years.
- **Secretariat:** the team that organises the meetings, sends papers and pays members for attending.
- **Priorities:** things that are important to us, and to people with disability, and that we want to make better.
- **Information, Linkages and Capacity Building (ILC) program:** this is an important part of the NDIS. ILC gives support to all people with disability, including those in the NDIS and those who are not in the NDIS. ILC help make Australia more accessible and inclusive of all people with disability. It can help you do what you need to do to be part of the community. The Department of Social Services (DSS) is in charge of ILC.
- **Department of Social Services (DSS):** DSS is a government department that is in charge of making Australia fair and improving the wellbeing of all Australians.

Session One – Pink

1.1 Co-Chairs' Welcome and Open

The Principal Member Ms Leah Van Poppel (Leah) and Co-chair, Ms Sam Paior (Sam) opened the meeting at 9.35am.

Leah acknowledged the Traditional Owners of the lands where Members and attendees were meeting. Mr Justen Thomas (Justin) also personally delivered an Acknowledgement to Country.

Leah said Professor Sally Robinson and Mr Brodie McElroy were unable to attend the meeting.

s47F - personal privacy

Leah welcomed everyone to the meeting and said it was good to have everyone face to face again. She also said Sam and Belinda would attend online because they weren't able to come in person.

Leah welcomed Ms Rebecca Falkingham (Rebecca), Chief Executive Officer and Ms Corri McKenzie (Corri), Deputy Chief Executive Officer who were joining the meeting today.

Leah also said Ms Alisa Chambers (Alisa) and Dr Jeff s47F - personal (Jeff) from the NDIS Quality and Safeguards Commission will join the meeting. They will talk about what they've heard from participants on Behaviour Supports.

Sam said it was going to be a big day and it was ok if people needed to take a break or have a rest.

Sam said that Easy Read documents were available for this meeting and if people have feedback to let the Secretariat know.

Session Two – Purple

2.1 Minutes, Actions and Conflict of Interest Declarations

Leah explained the:

- Conflict of Interest Declarations (this is where you tell us other jobs you do that relate to the NDIS).
- Actions list (this is a list of actions from earlier meetings, and we update this every meeting)

Leah noted new updates received from Mrs Judy Huett (Judy) and Justen. The Secretariat will update the register.

Members:

- approved the minutes from the last meeting, with one small change.
- noted the actions list.
- had no new conflicts of interest to declare.

Session Three – Orange

3.1-3.3 What members have heard in their community and discussions with the CEO.

Members raised issues they have heard in their communities, including:

- Reports people with intellectual disability need to repeatedly give evidence to prove their disability to access the NDIS.
- Younger people with intellectual disability find it harder to access the NDIS.
- A need for fairer and quicker access to the NDIS for people with intellectual disability. Especially for people in the justice system, First Nations and culturally and linguistically diverse (CALD) people.
- NDIS information and plans need to be in accessible formats, like Easy Read. This will help participants:
 - make sure they understand the supports in their plans.
 - make decisions about things that affect them.
 - have flexibility in how they use supports.
- Plan decisions are not consistent, especially for innovative supports like circles of support. These supports provide peer support and build people's capacity to make decisions. This is important for people with intellectual disability.
- Some support coordinators are charging for phone calls they make for participants.
- Support workers need to have better training to help people with intellectual disability.
- Lack of specialist support coordinators negatively impact participants.
- Justice Liaison Officers have really helped people with disability in jail. But people accessing the court system should be able to use justice liaison services too. This may help people prove their eligibility for the NDIS.
- Access to services is hard for people with disability living in regional and remote areas.

- Reports people with intellectual disability have restrictive practices without their consent.
- Some people with intellectual disability face issues with housing. Some people get little support to help them find a home.
- There is not enough available housing for people with disability. This includes supported independent living (SIL) and specialised disability accommodation (SDA) options.
- Issues with conflicts of interests when a service provider is also the accommodation owner.
- Mixed feedback about the PACE trial in Tasmania. Some people say it is working well and that they welcome improvements to the role of local area coordinators. Others say that it is causing sector disruption.
- The NDIA needs to have better information, training and tools that help people with intellectual disability to report fraud.
- Concerns NDIS behaviour support practitioners are making behaviour supports plans without meeting a participant.
- Concerns about inconsistent service quality. And there is no oversight or accountability of workers.
- Clinicians need more training around how to better support people with intellectual disability. For example, dentists could use an oral health pathway to inform people with intellectual disability about connected services and consent.
- People with intellectual disability have rights and want to use them. This includes: the right to vote, and to review programs and services they get.
- Recent budget announcement about the NDIS not well explained to the disability community.
- Issues about how the NDIS works alongside other support services. This includes health, education, housing, and justice.
- Confusion about what the NDIS does and what the NDIS Quality and Safeguards Commission (the Commission) in putting a behaviour support plan in place.

Leah thanked Members for their reports and handed over to Rebecca to speak.

Rebecca thanked Members for the opportunity to attend the meeting. She said this group is very important to the NDIA and it was great to meet everyone.

Rebecca noted the issues raised and gave comments back to the meeting.

- Having information and plans in accessible formats is very important. This is a high priority to the NDIA.
- The NDIA is currently looking at ways to simplify the paperwork.
- Work is underway on market development in regional and remote areas. This is to look at ways to improve access to support services for participants.
- The budget announcement is about making sure participants get better outcomes.

Rebecca said the NDIA wants better outcomes for participants. This is the main thing that motivates and guides the NDIA's work.

Lastly, Dr Sam Bennett (Sam B) thanked Members for their help and input into the Supported Decision Making Policy. He said it was released publicly in May.

Session Four – Dark Blue

4.1 News about Behaviour Supports from NDIS Quality and Safeguards Commission

Dr Jeff [REDACTED] said he was pleased to be at the meeting. He told Members what the Commission has heard from participants about behaviour support. He also gave an update on the Commissions' work to make behaviour supports better. This included:

- increasing skills training for behaviour support practitioners
- reducing the use of restrictive practises

Members said:

- Behaviour support plans should be in Easy Read. This will make sure everyone understands their plan.
- Behaviour support plans should use strong processes, checks, and authorisation. This should be using a co-design approach that includes participants.
- Panel meetings for behaviour support plans need to include the participant, not only family members and service providers.
- Better understanding of behaviour support plans and restrictive practices and how to use them. More discussion between people with disability, family members and community are needed.
- A need to understand why people have these behaviours. And understand the trauma behind them.

Session Five – Green

5.1-5.3 News about Behaviour Support Advice

Ms Belinda Epstein-Frisch (Belinda) gave an update on the Behaviour Supports Advice since the meeting in June 2022. Belinda asked Members to break into groups, talk about each recommendation and answer the below questions:

- Do you support this recommendation?
- Are there any changes needed?

Members said:

- best-practice behaviour supports need to use a strong co-design process.
- improved training is needed for practitioners.
- making behaviour support plans and other information easier to understand is important.
- including people with intellectual disability at every stage is necessary and very important. This makes sure the person with disability gives consent and has choice and control.

Members were pleased with the Advice and thanked Belinda for all her hard work. They endorsed the Advice to progress to the IAC for final approval, noting the inclusion of their feedback.

Session Six – Brown

6.1 End of Meeting

Leah asked members for feedback about the meeting.

Members said:

- The Easy Read documents are great, and everyone would like to receive the easy read version.
- The dinner was a good chance to talk with everyone in a personal setting.
- Everyone was respectful when talking about difficult and uncomfortable topics. It was really good to see everyone come together and find the right words to use.
- A Member with intellectual disability needs to be in each small group.
- The meetings are so much better and more inclusive than they were when the group first started in 2016, thank you.

Leah thanked everyone for their time, wisdom and respect to all Members. She said the next meeting will be in August and looks forward to seeing everyone.

Leah closed the meeting at 3.55pm.

Minutes of Intellectual Disability Reference Group (IDRG)

Meeting 15-17 August 2023

Pullman Adelaide, South Australia

IDRG members at the meeting

Ms Leah Van Poppel, Principal Member and
IDRG Co-Chair
Ms Sam Paior
Mr Gavin Burner
Ms Paige Armstrong
Ms Brooke Canham
Mr Angus Graham OAM
Ms Judy Harper

Ms Judy Huett
Ms Catherine McAlpine
Ms Sarah Sutton
Mr Justen Thomas
Ms Angela Yee
Professor Sally Robinson
Mr Leighton Jay

NDIA staff at the meeting

Ms Rebecca Falkingham, NDIA Chief Executive Officer (CEO)
Ms Corri McKenzie, NDIA Deputy CEO of Strategy and Service Improvement
Ms Kathy ^{s47F - personal privacy} Director Strategic Advice, Policy, Advice and Research
Ms Jaklin ^{s47F - personal privacy} a/g Divisional Support Officer, Policy, Advice and Research Division
Ms ^{s47F - personal privacy}, Assistant Director Communications, Independent Advisory Council Secretariat
Ms Karyn ^{s47F - personal privacy} Project Officer, Independent Advisory Council Secretariat

NDIA Observers (on line)

Mr Daniel ^{s47F - personal privacy} Strategic Advisor, Policy, Advice and Research
Ms Louise ^{s47F - personal privacy} a/g Senior Project Officer, Independent Advisory Council Secretariat
Ms Matilda ^{s47F - personal privacy} Communications Officer, Independent Advisory Council Secretariat

People also at the meeting

^{s47F - personal privacy} Support
^{s47F - personal privacy} Support
^{s47F - personal privacy} Support



People who could not come to the meeting

Ms Leonie McLean

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- **Action list:** A list of things we need to do. In every meeting we make sure the list has all the things we still need to do on it and nothing we have finished working on.
- **Participants:** these are the people that the NDIS helps.
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- **Secretariat:** the team that organises the meetings, sends papers and pays members for attending.
- **Priorities:** things that are important to us, and to people with disability, and that we want to make better
- **Restrictive Practices:** This is when something is put in place for a participant that reduces a participant's freedom, or their ability to do something that they would normally be able to do. An example of a restrictive practice might be a locked cupboard in the kitchen.
- **Reasonable and necessary:** These are supports the NDIS pays for in a participant's plan. The NDIS pays for supports that are reasonable and necessary. They help you work towards your goals, be more independent and take part in the community.



Session One – Pink

1.1 Co-Chairs' Welcome and Open

The Principal Member and Co-chair, Ms Leah Van Poppel (Leah) opened the meeting at 10:30am.

Leah acknowledged the Traditional Owners of the lands where the IDRG met. Mr Justen Thomas also acknowledged the Kaurna people as Traditional Owners of the lands now known as Adelaide.

Leah welcomed new and returning members to the meeting. She said that the voices of people with intellectual disability are the most important. IDRG will support them to be heard.

The IAC Secretariat gave everyone Easy Read documents for this meeting. Members said that:

- The videos given to us at the last meeting were good, but we need information in Easy Read
- We need the Easy Read documents a week before the meeting, so we have enough time to read them.

Leah gave Members an outline of the meeting. She said to let the Secretariat know of any feedback.

Leah told members that Ms Rebeca Falkingham (Rebecca) and Ms Corri McKenzie (Corri) from the NDIA are at the meeting. They will listen to the important things members have to say. They will tell members what the NDIA is doing about the things they raise.

All of the members and the IAC Secretariat staff introduced themselves.

Session Two – Purple

2.1 Minutes, Actions and Conflict of Interest Declarations

Leah explained the Conflict of Interest Declarations and Actions list. Members:

- approved the minutes from the last meeting
- noted the actions list
- had the opportunity to report any conflicts of interest.

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Session Three – Orange

3.1 What you've heard in your community (including small group discussions)

Members said that:

NDIS access and planning

- NDIS plans in should be offered in Easy Read so people with intellectual disability can understand their plans.
- There should be less planning meetings over the phone.
- Some adults with Foetal Alcohol Spectrum Disorder (FASD) can't get a diagnosis for FASD. This means they can't always get the NDIS and supports they need.
- Some behaviour support practitioners create behaviour support plans without spending much time with the person the plan is for.
- There needs to be a plan how the NDIA Supported Decision-Making Policy will work in real life. People with intellectual disability should be part of this work.

NDIS service and supports

- The NDIS needs to understand that people with speech and language disorders need speech pathology for a long time.
- Some NDIS participants are told they can't spend their flexible funding on other therapies.
- People with intellectual disability are often vulnerable to scams and need more support to understand technology linked to their services and supports.
- People with disability who are very sick need their NDIS supports. Their NDIS supports help make the end of their life more comfortable.
- The Justice Liaison Officers (JLO) are doing a really good job. The NDIA should think about participants who lose JLO supports when they leave the justice system.
- It would be good if there are planners with special training in things like home and living.
- The NDIS has changed some rules about employment supports. Some people are not getting employment supports in their plans.
- People in the Northern Territory have a hard time finding a provider.



- Some plan managers are telling people they can't buy things, Plan managers can't make reasonable and necessary decisions.
- Participants who have restrictive practices should be involved in decisions and they must agree to the restrictive practice.

NDIS home and living supports

- Reports that some home and living providers in Queensland, who also offer other services/supports, pressure participants to get all their NDIS supports from them.
- The NDIA should look at apartments as part of home and living supports.
- Houses for people with disability should have good facilities nearby, like shops and gardens.
- There should be more information on what 'shared supports' means for people with intellectual disability, autism and psychosocial disability living in group homes.
- Reports some planners ask people with intellectual disability leading questions about their home and living supports to nudge them towards choosing supported independent living (SIL).
- The NDIS recently helped some people move out of a long stay health facility in Queensland. This was really good. Now these people live in a more suitable place.

Other services that work alongside the NDIS

- There should be a more accessible and Easy Read option for reporting fraud on the NDIS Quality and Safeguards Commission's website.
- Public transport and airports need to be more accessible for people with intellectual disability.
- Services outside the NDIS might refer people with disability to the NDIS because they don't know what other services outside of NDIA do. For example, family violence workers referring children with disability to the NDIS even though they need family violence support.
- People with disability leaving the justice system are often vulnerable to exploitation and they seem to have an overuse of restrictive practices.
- Some people can't get back into their houses after the flood in NSW. This is causing them a lot of stress.

3.2 Rebecca responded to what members said

- Participants, the NDIS, and their aging parents should be able to plan what supports they need to be more independent before their parents are no longer able to provide as much support.
- We will be co-designing an implementation plan for the supported decision-making policy.
- The same Local Area Coordinator (LAC) should guide a person with disability on their journey. The NDIS Review are looking at why this often doesn't happen.
- We will have specialist planners in the future. They could be for certain disabilities or a topic like home and living supports. We are also looking at having employment specialist planners.



- The NDIA is looking at how it can make it hard to do the wrong thing. This includes fraud and unethical practices.
- Supported decision making – the NDIS need to think about how we will put the policy into practice.
- The Agency is committed to increasing the number of first nations staff members including at leadership level. We want to listen to and think about first nations people when we make decisions.
- The NDIA is thinking about how we can do a better job of supporting people with Foetal Alcohol Spectrum Disorder.
- The NDIA is looking at how we can do a good job of supporting participants who are in prison or are coming out of prison.
- The planners at the NDIA should know where a person can get support, if it can't be funded by the NDIS.
- We need to understand and partner with organisations people trust, like First Nations organisations.
- Emergency management frameworks currently do not have any disability practice.
- There is a shortage of behaviour support practitioners.
- We should always ask participants how they want to talk to us instead of assuming we know.
- The NDIA should make plans in Easy Read.
- The NDIA should work more closely with other services to make sure that participants who are very sick or dying get the supports they need, and their disability supports can continue.

Session Four – Dark Blue

4.2 News on employment of people with disability at the NDIA

Rebecca told the Reference Group about how the NDIA are working to hire more people with disability. The NDIA is also looking at how it can become a better work place for people with disability, and how it can support people to give a good experience when they apply for a job at the NDIA.

4.2 What good employment looks like for people with intellectual disability

The Reference Group told us about things which help people with intellectual disability have a good work experience and outcomes.

Things that help people with intellectual disability get good work:

- Employers who value people with disability and will build the job around the person's skills.
- Job interviews should be led by people with intellectual disability who ask questions which are easier to understand.



- Information about the job and/or interview in Easy Read.
- Support to make choices that suit them and help with their career, not business goals.
- Paying a fair wage.
- Help them understand what employment might mean for the disability support pension.

Things which help people with intellectual disability do good work:

- Regular (weekly) individual or team check ins.
- Having a workplan for each day.
- Accessible online working and being able to work part time if they want.
- A word list explaining big words is useful, but it is better if people use words that everyone can understand.
- Accessible human resources processes like Easy Read timesheets and leave forms.
- Understanding, valuing, and including people with intellectual disability, for example at team lunches.
- Mentors who know the job well and make the person with intellectual disability feel safe to ask for help.
- Stable work and jobs that hire people with intellectual disability for a long time and have a career pathway.
- Using performance reviews to plan their goals and gives required training.

Day 2

Session Five – Green

5.1 South Australian Council on Intellectual Disability (SACID) presentation

SACID gave a presentation on what helps people with intellectual disability get work and be supported to work. Members said that:

- People with intellectual disability should enjoy their work, whether they are self-employed or part of a team.
- What is happening in someone's home life can make it harder for them to work.
- People with intellectual disability might look for and find jobs in different places, like Facebook.
- The workplace needs to be designed or redesigned to support people with intellectual disability.
- Running the organisation with a trauma informed model is important for keeping staff safe.
- Employees with intellectual disability need support based on their strengths and individual needs.
- A fair wage gives someone with intellectual disability more choice and freedom.



Session Six – Red

6.1-6.3 Making our work plan

The Reference Group started planning what they would do over the next 18 months. Leah talked about some of the things that the IDRG has worked on in recently. For example behaviour support. The IDRG had an idea for advice that is going to go to Council.

Some of the big topics that the groups talked about were employment, planning and justice.

Some of the things they thought about were:

- The work the NDIA is already doing that relates to intellectual disability.
- What intellectual disability advocacy groups like Inclusion Australia are working on.
- What recommendations might come from the NDIS Review and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.
- What work the Reference Group and IAC have already done.
- Focusing on problems that impact people with intellectual disability more than people with other disabilities.
- Thinking about different groups of people when we suggest something. For example, we should ask if this will work for participants in rural or remote areas, or First Nations participants.
- Employers need to be taught how to support employees with intellectual disability. The disability industry should be leaders in this and an example of how to employ people with disability.
- People with intellectual disability need to understand and have a say in their supports, particularly in restrictive practices and guardianship orders.

There is still some more thinking to do on the Workplan but members said:

- We want to keep working with the NDIA to employ more people with disabilities especially intellectual disabilities.

We want to do some more thinking about:

- governments and services working together to support people with intellectual disability across all parts of their life.
- People with intellectual disability in the justice system. Both as victims of crimes and people accused of them.
- Preparing and inspiring people with intellectual disability to get real jobs and careers from age 15.



Things we need to do

Leah and the NDIA will update the Reference Group on how the NDIA has been using the IAC's advice on supporting parents with disability.

The IDRG will check the intellectual disability engagement guidelines and think about how other IAC Reference Groups could use them.

Session Seven – Brown

7.1 End of the meeting

Leah thanked the group:

- for attending the meeting for a long time
- giving valuable feedback and insights.

Leah closed the meeting at 2:30pm Thursday 17 August 2023.

Minutes of Intellectual Disability Reference Group (IDRG)

Meeting 2 – 22 and 23 November 2023

Pan Pacific Melbourne

Reference Group Members

Ms Leah Van Poppel, Principal Member and
IDRG Chair
Ms Sam Paior
Dr Leighton Jay
Ms Paige Armstrong
Ms Judy Harper

Mr Gavin Burner
Ms Brook Canham
Ms Sarah Sutton
Mr Justen Thomas
Ms Angela Yee

NDIA staff

Ms Corri McKenzie, Deputy Chief Executive Officer, Service Design and Improvement (sessions 1-3)

Ms Carolyn s47F - personal p Assistant Director, Service Guidance and Practice (session 5)

Mr Daniel s47F - personal privacy Strategic Advisor, Policy, Advice and Research

Ms Jessica s47F - personal priv Acting Director Strategic Advice, Policy, Advice and Research

Ms Sarah s47F - personal privac Assistant Director, Independent Advisory Council (IAC) Secretariat

Ms Gemma s47F - person, Assistant Director, IAC Secretariat

Ms s47F - personal privacy, Assistant Director Communications, IAC Secretariat

Ms Matilda s47F - personal priva Communications Officer, IAC Secretariat

Attending

Mr Kurt Fearnley, NDIA Board Chair

Ms Samantha Jenkinson, Independent Consultant to IAC

Dr Geoge Taleporos, IAC member (session 6.4)

Mr James Manders, IAC member (session 6.2)

Ms Sylvana Mahmic, IAC member (session 6.4)

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s47F - personal privacy Support

Apologies

Professor Sally Robinson, Member

Mr Angus Graham OAM, Member (due to connectivity issues)

Ms Catherine McAlpine, Member

Day 1, 22 November - 10.00am to 3.00pm

Session One – Pink

1.1 Co-Chairs' Welcome and Open

The Principal Member Ms Leah van Poppel (Leah) opened the meeting.

Leah acknowledged the Traditional Owners of the lands where Members and attendees were meeting. Mr Justen Thomas also gave an Acknowledgement to Country.

Leah said Professor Ms Sally Robinson, Ms Catherine McAlpine and Mr Angus Graham could not come to the meeting.

Rebecca Falkingham, CEO of the NDIA, could not come to today. Deputy CEO Corri McKenzie, Service Design and Improvement is attending until midday to hear member reports.

Kurt Fearnley will attend the second day of the meeting.

Leah said a Co-Chair for IDRГ will be appointed soon. Congratulations to Leighton and Sam for reappointment to the IAC. Congratulations to Gavin who is also appointed to IAC.

Leah welcomed Samantha Jenkinson who is the new Senior Independent Consultant to IAC and acknowledged the work of Belinda Epstein-Frisch.

Leah said Ms Leonie McLean has retired from IDRГ due to personal circumstances and Leah acknowledged and thanked Leonie for her tireless contributions.

Leah said Ms Judy Huett has resigned from IDRГ as she has found the meetings not accessible. Judy has given good feedback about this for a long time. Leah thanked Judy for her contribution, dedication, and patience.

Leah introduced the traffic light card system and noted the House Rules.

Session Two – Purple

2.1 Minutes, Actions and Conflict of Interest Declarations

Members approved the minutes of the August meeting.

Members noted new conflicts of interest:

- [s47F - personal privacy](#)

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Members noted the actions list.

Session Three – Orange

3.1 What members have heard in their community and discussions with the CEO.

Members raised issues they have heard in their communities, including:

Access and planning

- There is not consistent funding for people with similar disability, this is unfair.
- Getting a plan review can take a very long time. Funding can run out while participants wait for a review.
- Access is difficult for people in youth justice, as it is hard to provide things such as ID.
- Concerns that if you are in justice system, you now need to apply to NDIS through the Local Area Coordinator (LAC) rather than direct to the NDIA. LACs understand justice issues.
- Concerns culturally and linguistically diverse (CALD) people do not know how to get into the NDIS.

NDIS Services and Supports

- It is too hard to get in touch with the NDIA.
- When a participant passes away people are not sure who to tell.
- People who turn 65 need more information about what they can get from the NDIS, or aged care.
- People who need help with ageing issues, before they are 65 need more information. For example, people with Down syndrome who get early onset dementia.
- Concerns people with intellectual disability do not always have the chance to stay in the home of their choice when they get older.
- There is not much housing or respite available for people whose parents are getting older and can no longer care for them.
- When an accommodation provider is also providing community participation during the day a participant may have no access to community.
- Concerns people in remote communities do not access the NDIS because there are no providers.
- Concerns people can't find support workers who are right for them so are not accessing supports.
- Concern the design of the NDIS is making some people with disability dependent on their support worker.

Providers and the disability community

- The public are negative about the NDIS because people think people with disability are getting free supports and money.
- Concern that some support workers see their job as watching over the person with disability and do not try to engage with them.
- Reports it is difficult to complain and hold providers accountable when they have done the wrong thing.

- Concern that providers are building Specialist Disability Accommodation (SDA) close together and that this will isolate people with disability from the community. This is called 'intentional communities'. There needs to be rules about this.
- Some SDA providers have lease terms of 3 years and this does not work for people who need stability in their housing.
- Calls for better long-term funding for peer and self-advocacy organisations so they can help with supported decision making.
- Concern some organisations are seeking guardianship orders for young people when they take over management of their plan at 18 years old because they don't have other support.

Action 1: Ms McKenzie to share information on what to do if a participant passes away.

Action 2: Ms McKenzie to respond by video to any Member reports she missed when she had to leave the session.

Session Four – Dark Blue

4.1 and 4.2 Engagement Guide for IAC meetings

Leah introduced this topic and noted that the group has already talked about some things that have been hard with this meeting.

The Engagement guide is going to be updated to make sure it includes all the information needed to make things accessible for Members.

Members said some things that are hard are:

- There are too many emails, and they are not in Easy Read.
- The Easy Read documents are too big.
- The don't get documents with enough time before the meeting.
- Getting late travel bookings makes people anxious.
- Two-hour sessions in the meeting are too long.
- Information about travel and late notice of travel arrangements is not accessible.

Members said some good things are:

- The traffic light cards introduced today.
- The hotel location in the city, because members can get out and walk in the city and be independent. This is good for mental health and more culturally appropriate.
- Breaking into small groups is helpful for sharing stories and giving feedback.

What would help make things better:

- Having a PowerPoint presentation on screen to help keep track of where the meeting is up to. Not lots of words, just a visual or a word.
- 1 hour sessions followed by a 10 minute break.
- Easy Read papers only, and up to 20 pages.
- Some members prefer images to be photos instead of cartoons.
- An agenda for pre-meeting would help keep things on track and help people be ready for the next day.

- Items from the pre-meeting need to be added to the agenda for the meeting.
- Ice-breakers and informal chats are really important to have a bit of fun and get to know other people.
- People should introduce themselves with what First Nations Country they are from.
- Having more people with disability in the group, not just intellectual disability. Because it is good to think about all lived experiences.
- Emails should be shorter, with only one topic. They should be followed up with a phone call.
- Emails shouldn't ask for quick answers as members need time to talk to support people.
- A summary video by Leah after the meeting would be better than a written report.
- Secretariat and other NDIA staff to do training in Easy Read and make more Easy Read information.
- Trial different ways to communicate between meetings. For example, a video update or short online meeting.
- Make travel bookings early and avoid other events happening at the same time.

Members agree the Engagement Guide should be used all across NDIA, not just IDR. The Guide should have some principles at the start and an explanation of why the Guide was made.

Day 2, 23 November – 9.30am to 2.30pm

Session Five – Green

Easy Read plans

Ms Carolyn Tetaz, Assistant Director, Service Guidance and Practice, shared an update on work the NDIA is doing to offer NDIS plans in Easy Read. Members shared:

- Easy Read plans should:
 - be no more than 12 pages (6 double sided printed pages).
 - use colour coded sections.
 - use culturally safe pictures and icons.
 - have the NDIS planner and a way to contact them on the front.
 - include the participant's strengths at the start.
 - include how much funding and supports the person is getting up front.
 - clearly show how funding has changed from the old plan to the new plan.
- Participants and their family should be able to write or edit the 'About you' section.
- NDIS planners should ask participants how they want to get their plan and have some options for presenting plans. These should be designed for different circumstances, backgrounds, and disabilities.
- Community groups have developed many creative resources for engaging vulnerable people in NDIS planning that the NDIA could use.
- Letters are not always the best way to communicate with a participant. This might be because of their disability or other personal circumstances.
- NDIS welcome letters need to better explain what SDA is.

- Participants should be able to use the NDIS without needing to understand details of NDIS support categories.
- The NDIA should engage people with disability, including First Nations and CALD communities, and Disability and Carer Representative Organisations (DCROs) on this work.
- More planning meetings should be in person to give NDIS planners a better understanding of the participant. This should reduce errors.
- In person meetings are important for vulnerable participants. The new PACE computer could help identify these participants.

Action 3: Ms Armstrong to share a copy of a board game planning tool with Ms Tetaz.

Action 4: NDIA to share the summary 'What we've heard' about Easy Read plans with the IDRG in 2024.

Session Six – Red

6.1 Reform for outcomes

IAC representatives shared their work on the NDIA's [Reform for outcomes co-design activities](#).

6.2 Reforms for Outcomes – Better Planning and Fraud

Mr Gavin Burner led the session about Better Planning. Members shared:

- When things change, participants often need more support coordination.
- The NDIA should share more information on what good service providers look like.
- The NDIA should do more to help participants track their NDIS spending.
- The NDIA should ask participants when and how they want to receive information.
- Communication with participants should be culturally safe and trauma informed.
- People with disability should be involved in training NDIS planners. This will help grow them understand disability.
- NDIS planners should give more time when helping participants set their goals.

Mr James Manders led the session about Fraud. Members shared:

- Some CALD people have difficulty understanding what a support coordinator does. This can put them at risk of fraud.
- Support coordinators should all be registered, and they should share their specialisation with participants.
- There should be harsher punishments for providers who do the wrong thing.
- Some support coordinators charge the highest fee but pay their workers the minimum rate. This often leaves the participant with poor quality support.
- There should be accessible information about fraud and the price guide.
- The NDIA's new computer system PACE might identify conflicts of interest.
- NDIS plans should show what money is spent and how much funding is left.

6.3 Reforms for Outcomes – Workforce Capability and Evidence Based Supports

A group talked about Workforce Capability. Members shared:

- There should be a clear strategy on how the NDIS will help participants build their capacity in addition to funding therapy.
- NDIS needs more planners, especially planners with disability, specialist planners in ageing and disability, and planners based in rural areas.
- NDIS planners need to better understand supported decision making.
- NDIS planners need a lot more training to understand intellectual disability and be able to work with people in a safe and supportive way.
- NDIS planners could be tested by creating plans for fake participants, without knowing they were test examples. Trainers can look at these to give feedback and make improvements.

Ms Leah van Poppel led the session on Evidence-Based Supports. Members shared:

- NDIS website should have important information easy to find and in plain English and accessible formats (including Easy Read). More detailed information should be available through expandable headings.
- Sometimes participants in rural areas do not leave bad providers. This is because there are no other providers, or they are afraid of how the community will react.
- Many participants trust providers who listen to them and do what they say.
- NDIS planners should look for evidence for if a participant is meeting their goals.

6.4 Reforms for Outcomes – Independent Living and Plan Flexibility

Dr George Taleporos led the session on Independent Living. Members shared:

- People with intellectual disability may not look at different options to a group home because they are afraid and do not understand the other options.
- Trialling independent living before moving out of their parent's home can help people with intellectual disability decide how they want to live.
- Moving back into shared living is not always a sign someone with disability cannot live independently.
- Hearing stories of people with intellectual disability living independently inspires others to do the same.
- NDIS planners do not always want to include a participant's goal to live alone in their NDIS plan, perhaps because of the time it will take or a bias they have.
- Planners should work with the participant with intellectual disability and the people around them to help them understand what it takes to live alone.

Sylvana led the session on plan flexibility: Members shared:

- The NDIA should list what each piece of funding is and explain how to spend it.
- A participant should meet with a support coordinator to plan how they will use their budget and implement their plan.
- Participants need more help to implement their first plan.
- The [NDIS budget calculator](#) is good but not all participants have digital access.
- LACs and support coordinators need to support participants to use their plan flexibility, especially around health issues or uncertain housing arrangements.
- Participants need to be able to get funding within 24 hours in emergencies.
- There should be funding to support participants while they wait for plan reassessments.

Session Seven – Brown

6.1 End of the meeting

Leah noted that she will do work now to fill gaps in the IDRG membership.

The group shared ideas for thinking about what new members would be good for IDRG.

Leah thanked everyone for sharing their ideas at the meeting.

Words we use

- **Bias:** attitudes people have about a group of people that they may or may not be aware of. Bias can guide what people do.
- **Reference Group:** is a group of people who know a lot about something. This group knows a lot about intellectual disability. Reference Groups work together to make a plan or find ways to make something happen.
- **Co-design:** is when the NDIA will work together with people with disability and the broader disability sector to design policy.
- Culturally and linguistically diverse (CALD)
- Disability and Carer Representative Organisations (DCROs)
- **Conflict of Interest:** Conflict of Interest Declaration is a document where you need to say all the different ways you are connected to the NDIS. This could include if:
 - your work is around the NDIS
 - you are an NDIS participant.
 - you are part of other reference groups that talk about the NDIS.

This is because we all need to make sure your job in this Reference Group doesn't clash with other jobs you do. It is ok to have a conflict of interest, but you need to let the Secretariat know.

- **Participants:** these are the people that the NDIS helps.
- **Co-Chair or Co-Chairs:** the Chair of a meeting is the person who leads the meeting. In the IDR, we have two people who lead the meeting, so we call them Co-Chairs.
- **Principal Member:** is the Chair of the Independent Advisory Council (Council), and one of the Co-Chairs of the IDR.
- Specialist Disability Accommodation (SDA)
- **Secretariat:** the team that organises the meetings, sends papers and pays members for attending.
- **Information, Linkages and Capacity Building (ILC) program:** this is an important part of the NDIS. ILC gives support to all people with disability, including those in the NDIS and those who are not in the NDIS. ILC help make Australia more accessible and inclusive of all people with disability. It can help you do what you need to do to be part of the community. The Department of Social Services (DSS) is in charge of ILC.