



NDIS REFORMS

PAUSE, RESET, CO-DESIGN

Summary Report of the NDIS Reforms Forum - Pause, Reset, Co-design

Forum held via Zoom

19 May 2021 4.00pm to 6.00pm



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FORUM PARTNERS

Queenslanders with Disability Network

Queensland Alliance for Mental Health

ADA Australia - Aboriginal and Torres Strait Islander Network of Queensland

National Disability Services

Community Services Industry Alliance

Queensland Advocacy Incorporated

Parent to Parent Queensland

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Executive Summary

A coalition of seven organisations hosted the NDIS Reforms "Pause, Reset, Codesign" Forum, representing the broad diversity of stakeholders in the disability services sector. The coalition arranged the Forum to gather direct feedback about proposed NDIS reforms from sector stakeholders; to inform the Queensland Government and Minister for Seniors and Disability Services in their stewardship role around the National Disability Insurance Scheme (NDIS).

The Forum had 250 registrants from all parts of the state, including north and western Queensland, coastal areas, and south-east Queensland. Participants represented the diversity of the disability sector, including people with physical, sensory, intellectual, cognitive, and psychosocial disability, family, carers, supporters, academics, advocacy organisations and service providers. People with disability from Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse background were also represented. Forum participants spent some time in eleven chat rooms where they discussed their perspectives around NDIS proposed reforms and some potential solutions.

Participant Quote: "We are at risk of going back in time when "one size fits all" services were acceptable."

Forum summary feedback

Forum participants gave positive feedback about the impact the NDIS has made in their lives —allowing access to individualised, funded supports that provide people with choice and control around meeting their disability needs and supporting their social and economic participation within the community, many for the first time in their life. However, overall feedback in regard to the proposed NDIS reforms was strongly negative, with participants calling for them to be stopped.

Participants gave feedback they felt the Commonwealth Government and NDIA had made decisions about reforms and designed a response without meaningful consultation with people with disability, families, service providers and the sector. Participants questioned whether Independent Assessors would be "truly independent" - *they are selected, contracted, and funded by the NDIA – they are servants of the NDIA, meeting the NDIA's expectations.*

Forum participants reported they do not trust proposed NDIS reforms, especially Independent Assessments. Participants saw the assessments as a tick a box process with strangers, many calling it a dehumanising process, utilising assessment tools that are not fit for purpose and assessors who know nothing about an individual's personal history, background, or condition.

Stories presented by NDIS participants at the Forum about their experiences in undergoing trial Independent Assessments demonstrated flaws in the Independent Assessment process.

Participant Quote: "Don't do anything that compromises the integrity of the original (NDIS) goals. Treat people with dignity, respect, and fairness. If a review is necessary, do it across the whole scheme, not just on one aspect – planning."

Forum participants overall were clear that it is time for the NDIA and Commonwealth to pause – reset – and commit to co-design; reinforcing that the people who know the impact of the NDIS best are people with disability, families, service providers and the sector. Feedback reinforced the way forward is to *truly* co-design any future NDIS improvements and reforms with people with disability, families, service providers and the sector. Additionally, it was stressed co-design is a bottom-up process rather than a top-down process, which would result in the delivery of outcomes that are more aligned with needs.

A key position on NDIS Reforms from participants and partner organisations

The following are provided as the key positions with regard to the proposed NDIS reforms, particularly with a focus on independent assessments from the forum participants and the seven partner organisations:

1. The introduction of mandatory Independent Assessments for all new and all existing NDIS participants was not supported by forum participants. The one-size-fits-all approach does not work to retrofit people into tick boxes.
2. Forum participants felt that it was unfair that there is no right of appeal on assessment information used to determine individual plans, and does not afford individual NDIS participants their right to natural justice.
3. Participants identified the critical role that treating allied health professionals have in gathering vital information about an individual's needs and capabilities. Their position was that the information, professional assessment, and data from allied health professionals who are part of a participant's support team must form the basis of any plan review or assessment. They did not support an assessment being undertaken by a stranger who did not know the person, their disability, or their support needs.
4. Forum participants rejected the cessation of funds and a person's status as a NDIS participant if they did not undertake a mandatory independent assessment.
5. Some participants felt that reforms were like the Centrelink debt recovery process and asked to stop robo-planning.
6. Forum participants stated that planning must start from the basis of individual goals, and we cannot understand or look at functional needs without starting with dreams and aspirations to drive outcomes.
7. Participants were worried that this reform is about cutbacks and saving money, rather than having a focus on people with disability and their need for support to live ordinary lives like others in the community—impacting participants, their families, and service providers and the NDIS market.
8. Forum participants felt the evaluation of the current trial around Independent Assessments, currently being done with up to 4,000 NDIS participants, needs to be rigorous, externally reviewed and involve more engagement and data directly drawn from a range of trial participants. The report must be publicly available and used to inform the design and introduction of any future scheme changes.
9. Definition of reasonable and necessary - forum participants did not support the proposed changes to the definition of reasonable and necessary in terms of funding rather than supports within the legislation.
10. Governance and dual responsibility and decision-making - forum participants did not support arrangements to reduce State and Territory responsibilities, decision-making, and management within the NDIS.

Additional specific issues raised included:

- Rural and remote Queenslanders with disability and their families will not get adequate access to assessors due to a shortage of allied health professionals.
- Cultural barriers additionally impact people who will not trust a stranger in their house or in an online setting.

- Deaf community participants raised concerns that assessors will not understand the cultural context around their disability and as such, not assess their impairment/s appropriately.
- People with psychosocial disability face additional challenges due to the episodic nature of mental illness and impact of the condition upon their cognitive and communication abilities. As such, they need access to advocacy support to ensure the level of their impairment and support needs are fully understood and addressed in an assessment process.
- Concern was expressed by people from Aboriginal and Torres Strait Islander backgrounds in relation to understanding around cultural competency and being assessed by a non-indigenous person.

Forum participants put forward the following options for consideration as a way forward:

1. Meaningful, genuine consultation and co-design with people with disability, families, advocates, and providers to inform the new reforms beyond asking for feedback on pre-determined solutions.
2. Do not proceed with the introduction of the mandatory independent assessments for all new and existing NDIS participants and undertake the following key actions:
 - a. Review the mandatory function of Independent Assessments to enable new participants who need access to assessments and functional capacity assessments to assist with their NDIS application; to have choice and control re the assessor. Consider enabling this to be done in a similar process to Medicare. A person can choose their provider, and payment and funding for assessments are made via an established method and process.
 - b. Enable NDIS participants to continue engaging and utilising their trusted Allied Health professionals to provide essential information and data about individual functional needs and capacities to inform NDIS planning processes.
 - c. Undertake an external and broader evaluation of the current trial of the NDIS Independent Assessment process and publish this information in the public domain. This information to then be used as part of a co-design process to consider what worked in the trials, the challenges, and learnings to inform options and future action.
3. Access to advocacy for people with disability and families is a critical and ongoing need.
4. Queensland Government to continue to hold their current position that does not support the introduction of mandatory independent assessments for all new and existing NDIS participants.
5. Work with people with disability, families, carers, advocacy organisations and providers to ensure that the NDIS continues to be co-designed in order to deliver positive outcomes that make a difference in the lives of Queenslanders with disability.

“My concerns are around this independent assessment not being reviewable. How can we be certain that they are understanding our stories and will get it right? Even assessors who know us don't always understand what is happening.” Forum Participant

Quote

Introduction

The NDIS Reforms “Pause, Reset, Codesign” Forum was hosted by a coalition of seven organisations including Queenslanders with Disability Network, Queensland Alliance for Mental Health, ADA Australia, Aboriginal and Torres Strait Islander Disability Network of Queensland (ATSIDNQ), National Disability Services; Community Services Industry Alliance, Queensland Advocacy Incorporated, and Parent to Parent Queensland. These organisations represent the broad diversity of Queensland disability sector stakeholders.

The Commonwealth Government and the National Disability Insurance Agency (NDIA) announced a range of legislative and operational reforms for implementation during 2021. Following feedback from across the disability sector, Senator the Honourable Linda Reynolds, Minister for the National Disability Insurance Scheme, announced a pause to the rollout of the reforms stating she would consult with a range of stakeholders, including people with disability, their families, providers and the States and Territories before finalising the reforms.

The Queensland Government has a stewardship role as co-funder of the NDIS. Queensland contributes more than \$2 billion to the scheme. This Forum was arranged to gather direct feedback about the proposed NDIS reforms from disability sector stakeholders, to inform the Queensland Government and Minister for Seniors and Disability Services as stewards of the scheme for Queenslanders with disability.

This report summarises the keynote speaker's critical points, forum participants' feedback about the key issues, potential solutions, and themes from the 11 discussion rooms.

This report is provided to Minister Crawford and the Queensland Government for their consideration.

Agenda

1. Introduction, welcome and housekeeping
2. Acknowledgement of Country
3. Minister opening of Forum – Hon Craig Crawford MP Minister for Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships
4. Setting the Scene – Kirsten Deane (Melbourne Disability Institute) and Jean Cotchin (Every Australian Counts)
5. Panel - Queensland perspective – Byron Albury, Jennie Duke, Valmae Rose, Liz Sutton
6. 11 Breakout Rooms – Participant discussion in breakout rooms
7. Feedback from breakout rooms
8. Close

Participants

The forum was held virtually on Zoom with 250 people registered from throughout Queensland, including the Far North, Western Queensland, coastal areas, and South East Queensland. The participants were a diverse group, including people with physical, sensory, intellectual, cognitive, and psychosocial disability, families, carers, supporters, academics, advocates, and service providers. People with disability from Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse backgrounds were also represented.

Participant Quote: “Co-design is the way forward to reform the NDIS.”

Acknowledgement of Country

Willie Prince, founding member of the Aboriginal and Torres Strait Islander Disability Network of Queensland (ATSIDNQ), undertook the acknowledgement of country and an acknowledgement of people with disability.

Opening

The Honourable Craig Crawford MP, Minister for Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships, opened the Forum. He outlined Queensland's involvement in the NDIS and its position on the proposed reforms.

The Minister welcomed participants and advised he looked forward to hearing of their deliberations and receiving a report from the Forum.

Keynote Speakers

Setting the scene were keynote speakers Kirsten Deane – General Manager Melbourne Disability Institute (MDI) and Jean Cotchin – Representative, Every Australian Counts (EAC). Their joint presentation outlined the proposed NDIS reforms, including how Independent Assessments are intended to work, their impact on NDIS participants and people with disability trying to access the scheme, and their effects on NDIS processes.

Background

EAC is a grassroots member-based campaign that worked hard to introduce the NDIS and continues this work to make sure the NDIS delivers on its promise to people with disability and the intent of the scheme. It has been involved in the NDIS since the developmental stages of the scheme.

MDI is a multidisciplinary Research Institute at Melbourne University. Professor Bruce Bonyhady AM is the Executive Chair and Director, and one of the original architects of the scheme.

In opening this section, the keynote speakers highlighted that the proposed reforms are the most significant changes to the NDIS since its inception and are a divergence from the original intent of the NDIS. They noted three key issues are:

1. independent assessments
2. changes to the definition of reasonable and necessary
3. changes to the whole of access and planning.

The Planning Process

The table below provides a summary of the keynote presentation talking about how processes will change if reforms are implemented.

| Now | After Changes |
|-------------------------------|--|
| Planning meeting with LAC | Three hour assessment with a stranger |
| The draft goes to the planner | Assessment assigns one of 400 boxes |
| You get a plan | Then have a planning meeting to talk about goals |
| You can appeal it | Not appealable |

Impact of Changes

The Melbourne Disability Institute highlighted three key concerns in relation to the proposed reform:

1. Independent Assessment tools are not designed to determine funding
2. the proposed New Planning process doesn't consider goals
3. Assessment is not appealable, resulting in a breach of rights.

Nine hundred people supported a submission about NDIS reforms to the Joint Standing Committee on Independent Assessments by EAC. MDI also submitted to the Joint Standing Committee, referring to the proposed reforms as robo-planning.

The submissions raised the impact of the proposed reforms for people with disability. Fear of the reforms has resulted in outright anger and uncertainty around participants' NDIS supports, created negativity throughout the sector regarding the scheme. The greatest impact is for participants with the perceived loss of an individualised approach to their NDIS plans and supports. The proposed Independent Assessment process has signalled a fundamental shift which has created negativity and uncertainty in relation to the continuation of the NDIS as an enabling and empowering scheme.

Alternate approaches:

The keynote speakers concluded the presentation by outlining some alternate approaches to the proposed reforms, including:

- different forms of assessment should be trialled and evaluated
- any scheme process must be reviewable – NDIS participants need to be afforded the right of appeal
- planning should begin with a person's goals and remain individualised.

Participant Quote: "I wonder where the evidence is that what we are doing now is not working!"

Panel Presentation

A diverse panel comprising an NDIS participant, family member/carer, allied health professional and service provider answered questions and helped set the scene for discussions by forum participants.

Case Studies

Byron Albury – NDIS Participant

Byron felt that the proposed changes are fraught with danger, not only for people with disability from Aboriginal and Torres Strait Islander backgrounds but also for non-Indigenous Australians and their families. Byron's feedback included that:

- He has had 12 plans in 18 months and needs to tell strangers his story repeatedly, resulting in significant emotional impact
- People may be "left out in the cold" without the NDIS if they refuse to have an independent assessment and their plan is stopped
- Independent assessments would be challenging for people in places such as Cherbourg and Woorabinda.

"People are going to say we're not doing this, and we don't understand it, so we will keep doing what we've been doing because that's how we support the family. We don't need an algorithm to tell us how to look after our auntie or uncle. "

- The proposed changes will result in the loss of people's dignity, and the proposed reforms will be dehumanising.

Jennie Duke – Family member of a Person with Disability

Jennie gave feedback that she felt families with people with disability are diverse - they all are different. Jennie's feedback included:

- She has a 34-year-old son with autism, and his support team are qualified and know him well, His allied health professionals can assess him accurately, and he is currently on his third NDIS Plan
- Under the reforms, the assessor will not be familiar with Jennie's son or his family
- Families are fearful of reforms because they will be dealing with strangers and people not familiar with their family member. Their professional background and expertise align with their work and understand their family member's disability.

"We worked hard to ensure we have a multidisciplinary team supporting my son. These professionals, after many months and years, are familiar with him and he with them. I don't expect that the psychologist will assess my son's ability to prepare a meal. I want them to work within their field and share each other's findings."

- Families are anxious to let strangers in the house
- An inaccurate report may result in the change of funding to their plans. She said her family should have a choice of who enters their life. "The word I keep hearing from families is 'fear'. Many fear that it won't be the NDIS based on choice and control for people with disability and their family."

Valmae Rose - Allied Health Professional

Valmae provided the following critical feedback and commented about her experiences in supporting someone in who participated in one of the trial Independent Assessments:

- The Independent Assessment tools were not designed to determine funding yet that is how they are proposing to use them

"On the positive side, the tools that are being used themselves are fine for determining functional capacity and adaptive behaviours, and so on, but they're only useful in the context of a person's story. They're a pretty blunt instrument for the purpose that they're being used for at the moment in independent Assessment trials."

- Valmae sat in on Wendy's assessment. It consisted of making tea and turning on the computer. However, it did not take into context her history and overall physical functioning, in particular changes to her swallowing and the fact that she would not be able to drink the cup of tea, even if able to make and lift the tea, because of her changed swallowing capacity.
- Valmae felt the proposed Independent Assessments reforms would not work as they do not focus on the personal context of a person's life and needs.

Liz Sutton Service Provider – Ingham Disability Support Services

Liz gave feedback that she felt service providers would be affected by the proposed reforms. If NDIS participant funding is reduced, this will impact the market. Service providers will need to increase their client base, and this could affect the quality of service.

Assessment may be used to give less money to a service user. So it means then that the less income you've got, the more clients you have to have, the less quality service that you can provide to people, and at the end of the day, we want to make sure that the people who we support get the best out of their support services. Whether it be those people who live with their families still or whether they're living in a SIL accommodation. Quality is the thing that we all pride ourselves on doing.

- Service providers need to be flexible and responsive to need, which will be challenging in the proposed reforms
- We should not cut funding, and people with disability need access to reasonable and necessary supports.

"If you've got an independent assessment taking a very narrow view on an individual's capacity or life, you can't be responsive to meet their needs if they're only allocated minimal amounts of money to help somebody live a life."

Summary of discussion in chat rooms

Participants were divided into 11 Chat Rooms with a facilitator for each group discussion. They considered three questions around how Independent Assessments would work, issues around the reforms, and alternatives. The detail of each Chat Room discussion is at Appendix 1; however the main points are:

- The current reforms are tinkering only with some parts of the NDIS, and if reforms are needed, they should review the whole program and organisation
- NDIS reforms should be co-designed with people with disability so that outcomes are consistent with needs, and families and service providers need to be included and at the table
- Independent Assessments are not an accurate representation of the full context of life – they are a tick-a-box moment in time that does not include essential information and context about the person and their disability needs
- People consider that no access to the right to appeal is a loss of natural justice and that it is a fundamental right to appeal Government decisions
- The NDIS Quality and Safeguards Commission has more robust powers to deal with and respond to complaints with the NDIS
- The overall feedback from the forum participants to the Queensland Government was to support their current position, which is not to support the introduction of mandatory Independent Assessments. Queensland should maintain and pursue its opposition to Independent Assessments.
- Talking to NDIS participants about their goals and aspirations as part of their planning conversations should be the starting point for the assessment and planning process
- Planning should be individualised as no one size fits all
- Participants asked decision-makers to "spend a day in my life"
- Some participants fed back that they felt that reforms were like the Centrelink debt recovery process and asked to stop robo-planning
- Forum participants gave feedback that they are not comfortable dealing with strangers in undertaking Independent Assessments
- Participants were worried that this reform is about cutbacks and saving money, not about people with disability and their need for support to live an ordinary life like others in the community
- People identified that the way forward involves better and improved training, better listening and respect for the voice and views of people with disability
- Participants identified the critical role that treating allied health professionals have and the extensive critical and historical assessments and information they hold about an individual's needs and capabilities

"Don't disregard treating professionals' reports. Build on them, so we don't have to keep telling our story over and over."

- Participants identified they were concerned about the changes to reasonable and necessary definitions and questioned how the NDIA would make these decisions
- Some participants raised the importance of “Nothing about us without us”
- Forum participants focused on the impact that the NDIS has made in their lives, the positive change it has brought through delivering participants supports that meet their needs, with many people receiving funded support for the first time in their life

“NDIS has helped us do things we couldn’t before.”

- The work in the future needs to include people with disability, families, providers, the Commonwealth, States and Territories and the NDIA working together to make NDIS work
- Participants felt it is essential to rethink reforms – redesign – codesign
- Some participants raised the question of why one independent assessment should shape your future life and support needs
- Some participants felt the NDIS reforms didn’t trust them and their assessing/treating professionals
- The body of participants reiterated “co-design; co-design; co-design” as a way forward.

Recommendations

1. That the Honourable Craig Crawford MP, Minister for Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships:
 1. note the contents of this report and the feedback from this representative forum
 2. provide the report to the Palaszczuk Government and Cabinet for their consideration
 3. continue to raise these issues as Queensland Minister for Disability Services with Commonwealth and State and Territory Disability Ministers.

Appendix 1

Chat Room Discussion Summary

Chat room 1: Discussion

- Independent Assessments will disadvantage marginalised people.
- Rural and remote residents will not get adequate access to assessors due to a shortage of Allied Health professionals.
- Cultural barriers can mean people don't trust a stranger in their house.
- The change proposed should include the co-design process in the legislation.
- The deaf community concerned that assessors will not understand the cultural context around their impairment and people may not be adequately assessed.
- Health professionals not biased.
- Co-design
- Co-design
- Co-design

Chat room 2: Discussion

- The reforms are dehumanising because they take away choice
- I am uncomfortable letting strangers in the house.
- It's inappropriate to ask older people how long they think they will live during an assessment.
- When questions didn't fit answers, the assessor chose the nearest answer.
- How can we understand function without goals and aspirations?
- Independent assessment causes uncertainty and fear.
- Who decides reasonable and necessary?

Chat room 3: Discussion

- Incomprehensible that a person can't appeal assessments.
- How will someone be assessed if the assessor doesn't know them?
- A 3 ½ hour assessment process exhausts participants.
- A friend participated in the trial assessments, and he answered questions erroneously because he didn't understand the question.
- Talking to strangers with no existing relationship is difficult.
- Stranger (assessor) doesn't know medical conditions or history.
- (NDIS) If not broken, don't fix it

- If you qualify under Centrelink, that should be used as an assessment.
- I have fought for 25 years to be independent; I don't want to lose choice and control.
- Please don't take my choice away!
- Co-design
- Independent assessment is a loss of natural justice – because there is no appeal process.

Chat room 4: Discussion

- What is the quality of boxes being ticked?
- Mental illness might minimise a person's perceived disability at a particular time because of the episodic nature of the condition. As such, people need advocates to support their telling of the overall impact of the disability upon their life; otherwise they would get an inadequate assessment.
- People are scared of Independent Assessments.
- Not Independent Assessors as selected and funded by Government and working for Government.
- An assessor should review medical history documents.
- Assess in a safe way based on historical information, not just through a 3 ½ hours tick a box interview.
- There needs to be access assessment but should include history, medical and other health information.
- Some people didn't get access to the NDIS because they couldn't afford medical assessments.
- Changes to reasonable and necessary not really defined.
- QLD Government should hold their position opposing Independent Assessments.
- Independent Assessments are standardised, not individualised.
- Strengthen Quality and Safeguards Commission – this is the body that can deal with complaints regarding the NDIS.
- Move forward - co-design.

Chat room 5: Discussion

- Decrease the price of health professional assessments.
- Changes to reasonable and necessary will justify focusing on the funding level rather than supports, which will remove choice and control.
- Give people a quantum of funds and let them allocate as needed.
- Indigenous people are concerned to be assessed by a non-indigenous person.
- The uncertainty and anxiety created by Independent Assessments, especially if deciding a person's level of funding without the ability to appeal, will impact on the mental health of people with disability being assessed and/or their family member.

- Independent assessment creates anxiety instead of trust.
- If review of some parts of NDIS is necessary, do a whole study of the NDIS program, not just parts of its operations.
- Maintain scheme integrity.

Chat room 6: Discussion

- Independent assessments are not a good idea.
- Present system works.
- Improve cost of getting an assessment for people needing one to assess the NDIS re proving their eligibility.
- Aboriginal and Torres Strait Islander people still have trouble accessing the NDIS.
- Reforms won't improve the NDIS.
- Should focus on abilities rather than inabilities.
- The state should uphold their position of opposition to Independent Assessments.
- Privacy is critical.
- The State Government needs to engage with the Commonwealth as a pivotal contributor to the NDIS and argue that the Commonwealth drop Independent Assessments.

Chat room 7: Discussion

- The Government has shifted the NDIS goal posts - don't consider participant. The proposed assessment process will take away choice and control.
- Tick a box won't work when all individuals have different needs.
- Independent Assessments will cause stress and mental health problems for participants.
- Most blind people are concerned about the definition of functional capacity. To determine available capacity is complex and a tick a box assessment doesn't do this.
- Assessors not trained in vision impairment.
- Waiting 16 weeks for reports post an assessment, as it currently happening to people participating in the trial, is absurd.
- The planner had a vision-impaired mother and translated the mother's situation into the plan. Therefore, the participant did not get their support needs met and funded.
- Won't let strangers into their life over who we work with
- Reasonable and necessary won't meet people's needs.
- The goals of a person should be a starting point.
- No one size fits all
- Spend a day in my life!
- Stop robo-planning.

Chat room 8: Discussion

- NDIS answers will be given by assessors because they are funded by the Government.

- People are frightened when trying to get the NDIS.
- The reform process is a cost-cutting exercise.
- People won't use assessment history with Independent Assessors.
- Independent assessments need to be genuinely independent not done by assessors funded by Government.
- The Commonwealth Government should humanise the reforms. Proposed reforms impact real people.
- Co-design is the way to reform the NDIS.
- Independent Assessments retrofit people into boxes.
- This reform is about cutbacks and saving money, not about needs. When the NDIA changes policy, people are impacted by it.
- Need better training, better listening, better respect.

Chat room 9: Discussion

- IA tools intimidating to participants.
- NDIS has helped people come out of their shells and they will go back into their shell!
- The NDIA need to better define reasonable and necessary as these terms are not well understood.
- Senator Reynolds said it would be further defined and this has to happen.
- If these terms are being redrafted to mean 'appropriate and necessary', the funding allocated to participants will disadvantage them regarding their range of supports; thus limiting their ability to continue to build their capacity re economic and social participation.
- Please keep it simple rather than tie up the NDIS in red tape.
- Assessors should not be strangers.
- Better training for NDIA and LAC staff would improve NDIS processes.

Chat room 10: Discussion

- Concern about no appeal process.
- IA is a tick box process.
- NDIA should not mistrust people with disabilities.
- IA should consider historical medical reports.
- Nothing about us without us - co-design!
- Don't throw away all that has been done – the history - build on it.
- Reasonable and necessary, who makes the decision?
- Co-design is the way to go to improve the NDIS.
- NDIS has been great in supporting people with disability to live 'an ordinary life' in the community – something previously impossible for many!

- I want to work with the NDIA and Commonwealth to make it work.

Chat room 11: Discussion

- Assessments should be done by qualified persons - the treating professional who knows best.
- Independent Assessors do not have the context around a person's life and their history.
- NDIS should pay for assessments from treating doctor and allied health professionals instead of funding independent assessments by third parties.
- State Government needs to listen and voice these arguments to the Federal Government.
- The Commonwealth Government should know people with disabilities are frightened by reforms.
- Pause, rethink and redesign scheme changes.

Case Studies

Case Study 1

Young Girl in a wheelchair assessed as having no mobility concerns by Independent Assessor.

A nine-year-old girl who sometimes uses a wheelchair was described as not having mobility concerns in a report prepared for the national disability insurance scheme trial of independent assessments.

Mary said her daughter Sara, who lives with physical and intellectual disabilities, took part in a January trial assessment. The family then waited 16 weeks for a copy of the report. "It said that she doesn't have any mobility issues," Mary said. "And this is a child with brittle bones and who uses a wheelchair. I'm not quite sure how they arrived at that conclusion."

The five-page "participant interaction notes" included a question, "Does the participant have any mobility concerns?" and the listed response is "no". The answer was baffling to Mary given the previous question notes Sara uses a manual wheelchair, while other reports generated from the assessment also referred to Sara's mobility issues.

Mary said she was only aware of the inaccuracy because she had specifically requested to see the report. She was worried it could have affected her daughter's funding if the assessment were not a trial.

"I would imagine if I'm asking for a new wheelchair for Sara because she grows out of the current one, they're going to look at the independent assessment, and it says she doesn't have any mobility issues," Mary said.

Case Study 2

John, a man with vision impairment.

As a man with vision impairment John believes his Independent Assessment did not consider his full range of support needs and functional capacities in different environments. John was asked to make a cup of tea in his house – an environment set up to meet his practical needs, however this did not reflect his ability to do this task and the challenges involved in other different and unfamiliar community environments.

Additionally, John was asked to turn on the computer as part of assessing his communication needs, however this task in itself does not reflect the complexities around John's need for specialised equipment such as a Braille Display, special software, Colour Coding devices and a particular computer, in order to communicate effectively both in the home and broader community.

Participant Quote: "Why aren't Independent Assessments reviewable? How can we be certain Assessors will understand our story when even Assessors who know us well don't always understand what is happening."

Identity of people in both stories has been changed.