
**Response to the Productivity Commission Position Paper on
National Disability Insurance Scheme (NDIS) Costs**



About Queenslanders with Disability Network (QDN)

QDN is an organisation of, for, and with people with disability. The organisation's motto is "nothing about us without us." QDN operates a state-wide network of over 1400 members and supporters who provide information, feedback and views from a consumer perspective to inform systemic policy feedback to Government and peak bodies. All of QDN's voting members are people with disability. QDN also provides information and referral support to people with disability.

QDN Consultation

QDN's submission is informed by the lived experience of QDN members with disability and key allies. QDN's work in providing feedback and input into systemic policy issues is based upon the organisation's core values (Appendix A) and the place of people with disability in an inclusive Australian society. In particular, this submission has been informed by the experiences of QDN's Group Convenors and members of 24 Local Support Groups (LSGs) around the State who meet regularly as part of QDN's work as a Disability Support Organisation (DSO).

Policy Overview and Introduction

QDN is pleased to provide feedback on the Productivity Commission Position Paper on NDIS Costs, in response to the current position and findings on the NDIS Costs study.

QDN and our members are committed to the success and sustainability of the scheme and support the intentions of the Commission to deliver better outcomes for people with disability and their families/carers in relation to the transition to the national scheme. QDN has many members in roll out regions across Queensland who have confirmed the benefits and changes in their life through accessing reasonable and necessary supports through the NDIS. People with disability are identifying that they are experiencing transformational change that comes from having more choice and control in the services and supports that people receive. However, QDN has also received feedback from participants and their family and carers about their less than positive experiences and poor outcomes that have negatively impacted upon people's lives at different stages of the NDIS transition.

QDN agrees that if the scheme is to achieve its objectives there needs to be a *better balance between participant intake, the quality of plans, participant outcomes, and financial sustainability*. The paper asserts that pressure on the NDIA to get numbers of people on to the scheme means that the quality of the care planning processes has decreased in some cases. This has resulted in confusion and poor outcomes for some participants. This has been reflected in feedback from members who have expressed concerns to QDN about the Queenslanders with Disability Network LTD www.qdn.org.au
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adequacy of the planning process and the need to seek reviews around a range of supports that they need to safely live their life that have not been included in their NDIS plan. Members have also raised issues about their experience of the planning conversations where questions asked do not necessarily enable a response that truly reflects the level of functional limitations a person has around a particular life domain. It is QDN's view that the structure of the planning conversation questions also lead to additional disadvantage for many vulnerable and marginalised people who may have their perception and understanding that they are performing particular tasks themselves, however, it is enabled through a range of supports in place in their life.

QDN also firmly believes that the full implementation of the scheme needs to be consistent with the original principles and intent of the NDIS and supports actions that deliver on this, however QDN does not support actions to slow down the roll out of the NDIS. QDN does not support actions that compromise the long awaited access to supports that many people with disability have been waiting decades for, particularly in Queensland.

QDN members have consistently raised the importance of the scheme to deliver continuity of support for all people with disability, particularly for people with disability over the age of 65 who require specialist disability funded supports that may not be provided to the same levels by My Aged Care.

People with disability need to have access to providers and support to deliver what is funded and approved in plans, as well as a level of skills and capacity to execute their plans. To date, QDN's feedback from members includes challenges with:

- Making the access request especially if they do not have current funded disability supports;
- knowing they have an approved plan and understanding how to access it via the online portal;
- having digital access and knowledge of how to use computers to access online portal;
- understanding what is in their plan,
- accessing suitable providers, and
- knowing what to do to start implementing their plan.

QDN is also aware of the challenges that some people with disability who experience additional disadvantage are facing poorer outcomes without the appropriate levels of access to independent support and advocacy to assist in the process.

People with disability are encouraged by the increase in rights, choice and control that the scheme brings, however, there has been limited focus and investment for participants in building capacity, knowledge and skills to be able to operate as customers in the new system. This is a transformational change from service recipient, to one of customer for people with disability and their families and carers. QDN believes that attention needs to be given to measures that give people with disability the support, knowledge and capacity building required to develop in this area. QDN also believes that this needs to be not only a

focus for the first year of a participant's plan but over a period of time as the scheme matures, along with participants knowledge and skills.

QDN supports any actions to increase funding for Information, Linkages and Capacity Building (ILC) to the full scheme amount for each year during transition to assist people with disability to be able to build their capacity and be adequately connected with appropriate services both inside and outside of NDIS.

The Commission estimates that one in five new jobs created in Australia in the next few years will need to be in the disability care sector and current approaches to generating greater numbers of workers and providers are insufficient. QDN notes with interest the idea of allowing **formal and informal** carers to provide paid care and better price monitoring and regulation.

QDN also agrees with the interface issues highlighted in the paper between the NDIS and other disability and mainstream services including lack of clarity in terms of responsibilities of different levels of government and who should be providing which services. The Paper highlights that some people with a disability have lost access to supports they used to get as state government disability services close down. QDN members have particularly experienced this in the areas of transport, health and housing.

QDN's submission will focus on key areas in relation to:

- Governance
- Participant readiness
- NDIS and mainstream interface;
- Overall feedback

QDN's experience as the only Disability Support Organisation funded in Queensland, and our work in delivering NDIS participant readiness activities by people with disability for people with disability across the state has shown how effective peer leadership and peer support is to assist participants in building their knowledge and capacity to engage with the NDIS, their plan and implementation. QDN supports actions which provide participants with assistance to navigate their NDIS journey, focussing particularly on Productivity Commission recommendations concerning participant readiness, supports coordination and the role of Disability Support Organisations in supporting participants and the safeguards that are required.

Governance

QDN asserts the following feedback and recommendations in relation to governance issues:

- **Keeping on track with projected rollout through investment in activities that support participant preparation and access**

QDN notes that a consideration of the Productivity Commission Position Paper is to slow down the roll out of the NDIS. QDN agrees that the current poor outcomes that the Commission has highlighted in the paper are impacting upon the success of the scheme, and compromising the quality and access to basic supports that people with disability need to safely live their life. However, QDN is concerned that further delays to full scheme rollout will result in people who currently receive no supports waiting longer to receive the vital supports they need. QDN members have raised that this also affects people who are turning 65 in this period who will miss out on accessing the scheme if delays are made to the roll out schedule. QDN is also concerned that people currently in the service system will have to wait longer to exercise true choice and control in their services and supports.

QDN supports strategies that enable the rollout schedule to continue as planned, and ensure people can access the supports they need. QDN acknowledges the large scale of transition planned in Queensland in the final year of rollout with 60,000 participants to enter the scheme, and sees an important role for disability support organisations, peer support, advocacy and intermediaries to assist in readiness, and would support other ideas that assist participants. QDN would caution activities that rely on technology only, as many of the NDIS participants are challenged around digital access and digital inclusion. Additionally Queensland's vast geographic and demographic spread brings with it a range of digital connectivity issues, especially speed and access in rural and remote areas for internet.

Organisations that are peer led, yet not direct service providers could be trained and resourced to provide coaching, mentoring and supports to individuals to enable their preparation and the roll out schedules to continue as planned. It could also facilitate greater number of plans to be processed to accommodate the large numbers of people entering the scheme. An important safeguard would be to ensure that organisations that are not direct service providers, including organisations that are peer lead (of, by and for people with disability) are able to assist people to develop their NDIS plans with appropriate training and resourcing. This ensures there is no conflict of interest with a direct service provider gaining financially from plans they develop, for example, becoming the participant's direct provider. It also ensures the participant has access to independent advice and the full range of options under the NDIS and not just the services offered by a particular provider. Participants would also gain from the peer support and lived experience of peers who have already developed plans.

QDN supports any improvements to support coordination and believes this is an important ongoing function to assist participants to build their knowledge, skills and capacity as NDIS participants beyond 1 year.

QDN sees it is essential that measures are taken to increase the number of organisations that can assist potential participants with the planning process with a focus on organisations that are peer led, yet not direct service providers could be trained and resourced to provide planning supports to individuals.

Legislative definitions and direction of reasonable and necessary

The NDIS is underpinned by a broad range of human rights conventions and treaties to which Australia is a signatory and contemporary disability social policy. Additionally the intent of the NDIS is underscored by core principles and values, and the legislative framework regulates the implementation of the scheme, including ‘reasonable and necessary supports.’

QDN highly regards the values and principles that underpin the NDIS, however QDN has received feedback from members concerned that some of the original intent and principles are at risk of being rolled back or compromised. QDN has had feedback from members in rollout areas where plan reviews have resulted in support packages decreasing, particularly in reference to the allocation of supports coordination. QDN acknowledges that many people with disability, family members, allies, and the disability service sector as a whole have worked tirelessly to ensure a fair system that took into account people’s needs for support across the lifespan was implemented. While the scheme needs to maintain economic viability it would be disappointing for many people to see the original intent and principles rolled back to reflect what the old system.

Clarity around how the legislative criterion of “reasonable and necessary” and its application in practice, is important, otherwise it remains subjective to the knowledge, skills, value judgements and information collected by an individual person. QDN supports a strategy that delivers consistency of outcomes to people that does not put at risk the financial sustainability of the scheme, nor put people with disability at risk of their safety or going back to an old system approach.

- **Different bilateral agreements across each state/ territory**

QDN is aware through speaking with our national allies that the scheme is at risk of not delivering a nationally consistent approach in the delivery of disability services and supports as each State and Territory has signed different bilateral agreements with the Commonwealth government.

This results in variations and inconsistencies across States and Territories regarding the availability of mainstream supports. For example, in Queensland the Taxi Subsidy Scheme (TSS) has been cashed in for NDIS participants as part of the Queensland-Commonwealth Bilateral Agreement. The Queensland Government announced on 15 July 2017 to suspend this arrangement during scheme transition while a workable solution is found that is consistent and delivers continuity of service for people with disability, and does not leave people in a worse off, or more vulnerable position.

QDN believes it is important that there is a nationally consistent approach in the delivery of disability services and supports and other essential mainstream services, which currently is not in place with the different State and Territory Bilateral Agreements variations.

- **NDIS Rules**

In regards to the Commission's inquiry with regards to NDIS rules and current governance arrangements, QDN believes that there is benefit to all jurisdictions having input and agreement for changes to fundamental rules and principles of the scheme to ensure the interests of all contributors and investors across all jurisdictions is considered. Whilst QDN acknowledges that this has had implications for timeframes for decision-making and agreements by all parties, it is essential for transparency, stewardship and a bi-partisan approach given the financial investment is provided by Commonwealth, State and Territory money.

Participant Readiness

QDN provides the following feedback and recommendations in relation to participant readiness:

- **The importance of building people's capacity as participants**

QDN agrees with points in the Position Paper about the importance of peer led processes in building people's capacity as NDIS participants. While QDN acknowledges the importance of the Participant Readiness work that has occurred to date we also acknowledge more broadly, the need to build people's capacity to shift from service recipient or consumer to the place of participant and customer. QDN believes there has been a lack of investment and focus on this to date as the majority of the focus has been on pre-readiness, with very little focus on what people need to do once they have their plan. This is a new environment for people with disability to be in. QDN is concerned about an underlying assumption that people can automatically move into high levels of responsibility and have the necessary skills for coordination, financial acumen and an ability to navigate a complex system.

QDN supports the development of a suite of activities aimed at building participants capacity, pre and post entry into the NDIS, including information, support, resources and activities based on:

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- Coordinating services and supports: including ensuring everything is in place, managing support staff, coordinating rosters, service brokerage arrangements, managing complex decisions, managing support staff, industrial relations issues.
- Financial accountability and management processes: adhering to financial requirements, managing invoices, managing budgets to meet support needs within available resources, decision-making, getting the best value for money.
- Navigating the system: using the NDIS portal, planning for your review, navigating the Pricing Guide, communication skills, key contacts, troubleshooting.

QDN believes it is essential to build the capacity of individuals not only as NDIS participants but as leaders in their own lives, and within communities, as citizens, as employees, as owners of businesses, as members of clubs, as volunteers, as customers of services, and as members of committees and boards. The functions of the ILC are two-fold:

1. Personal capacity building – this is about making sure people with disability and their families have the skills, resources and confidence they need to participate in the community or access the same kind of opportunities or services as other people.
2. Community capacity building – this is about making sure mainstream services or community organisations become more inclusive of people with disability.

Early release investment of full ILC funding would support the development and capacity of people with disability, to have the skills, resources and confidence they need to participate as well as the essential work that is required to deliver mainstream services or community organisations that are more inclusive of people with disability. It is an essential missing piece of NDIS transition at the moment, and the work that is required to achieve the outcomes of the NDIS and the National Disability Strategy.

QDN supports the benefits that can be achieved through peer led processes. QDN has supported the development of group leaders in 24 local peer networks that are spread across Queensland as part of the Disability Support Organisation initiative, and modelled peer leadership. This work has had a focus on ensuring that everyone is included, including people with disability who are more marginalized. It is critical that there is equity of access to supports for all participants, including those who experience additional disadvantage and need different types of support in the learning, capacity building and practice.

QDN peer leaders and group convenors have given the following feedback on the importance of peer led approaches to building people's capacities as participants:

"It is important to get access to reliable information about the NDIS"

"Without the support of others we don't seem to have a voice On your own no one listens because we are seen as insignificant especially those with intellectual disability because you can't see our disability. Peer leaders can really understand what group members want and need. Peer leaders can learn a lot from leading."

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QDN sees that the investment in building the capacity of people with disability to engage well in the NDIS, and navigate the system through initiative's such as the DSO is vital to the ongoing success and viability of the scheme, and the goals of the National Disability Strategy.

A range of strategies are required in the coming 18 months in Queensland given the high volume of 60,000 people transitioning to the NDIS. QDN sees the value and opportunity that peer led support provides participants, however, consideration needs to be given regarding the best strategy. It is essential that adequate resources to undertake the preparatory work to ensure people go into their planning meeting prepared for engagement with planner, and can leave without a need for review and changes. This current inadequacy of participant's preparation of planning is impacting upon participant safety and well-being with plans not adequately reflecting basic needs for support, potential impacts upon and increased time and resources required to rectify this both from the Agency and the participant.

QDN believes it is essential that Disability Support Organisations are funded to provide peer support and information resources to participants in the pre-planning, planning and implementation stages of their NDIS journey: this capacity building exercise involves training peers to assist participants in preplanning activities and also attending planning meetings in an informal capacity to provide support to the participant.

- **Support Coordination**

The Position Paper asks for specific feedback on the use of Support Coordination funding. QDN members in Townsville have told us of incidences where people's budgets have been recalculated to not include funding for support coordination once people attend their 12 month plan review. The reason given for this is the recent availability of Local Area Coordinators (LACs) in the Townsville area. Yet when members have asked LACs what supports they provide, they were told that LAC's provide support with Supports Linking, not Supports Coordination. For the scheme to be successful, participants need appropriate and adequate levels of support to transition to the changed environment, for the time that is needed. Supports coordination is a vital function, however, it needs to be delivered in a way that focuses on building individual capacity, not just a provider 'coordinating' supports as they would have done under the previous system. Supports Linking provides information (contact details) of services in a person's area and requires the individual to follow up whereas Supports Coordination coordinates a person's funded supports. Many participants will be left in a vulnerable position without appropriate levels of support to coordinate their plans and implementation of this. This has led to confusion and anxiety for people in roll out areas with challenges in accessing follow up support.

QDN believes it is essential that the function of Supports Coordination is a requirement in participant plans, and is needed to continue to be in place over time as the Scheme matures

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so that participants have the opportunity to learn, practice and develop their skills as customers. QDN recommends that this safeguard needs to be in place for more than one year and it needs to have a dedicated skills development focus.

NDIS and Mainstream Interface

QDN asserts the following feedback and recommendations in relation to the NDIS and mainstream interface:

- **Information Linkages and Capacity Building (ILC) – access to funding dollars and the need for the DSO**

The Productivity Report recommends that the full ILC funding be available in each jurisdiction during transition phase. QDN supports this and believes that this funding could be used to assist in transition and pre-planning work with participants, especially in Queensland.

Earlier access to ILC supports will have numerous benefits including making sure people with disability and their families have the skills, resources and confidence they need to participate in the community or access the same kind of opportunities or services as other people and ensuring a large volume of people successfully transition across to the NDIS.

- **Transport, health and housing interface**

Queenslanders with disability have also told us that accessible quality mainstream services are critical to meeting peoples' basic human needs and rights, as well as key to being able to participate socially and economically in the community. QDN, our members and advocacy allies are noticing some interface issues with the NDIS and other mainstream supports such as transport, health and housing. Members in rollout areas have expressed their distress regarding their ineligibility for the TSS scheme once they become NDIS participants. This combined with the loss of Mobility Allowance is seeing some people, particularly in regional areas, significantly struggling to meet their transport costs.

The role and function of Community Transport Operators (CTO) also remains ambiguous in the NDIS landscape. Many are struggling to meet demand in regional areas and also feel obliged to continue to offer service to people who are not NDIS eligible. While QDN acknowledges the positive move forward taken by the Queensland Government's on 15 July 2017 to reinstate the TSS for NDIS eligible participants during the transition phase, it is essential that a long term viable solution is found to ensure people's rights to accessible public and private transport options. QDN also raises the importance of any access to Taxi Subsidy Scheme solutions for the future have a national focus and implementation to ensure that a participant's human right to access public transport within their community.

QDN's members and advocacy allies have also shared concerns regarding essential health supports that go unmet once a person becomes an NDIS participant. One systems advocate

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shared the story of a woman who was getting regular pressure area care and catheter changes through community care. However, once the woman had a registered NDIS plan, Community Care told her they could no longer provide services to her. NDIS did not fund the support for pressure area care and catheter changes as at the time of her planning meeting this was being funded through another provider. The case awaits a decision in the Appeals Tribunal.

Disability is a whole of government responsibility and never the sole responsibility of one government department or program. This is a sentiment that has been clearly expressed through the National Disability Strategy and the CRPD. Yet, since the NDIS rollout participant's report they have seen a gradual rollback of services, subsidies and programs that were previously offered to people with disability by other government departments. Clearly further work is needed between State, Territory and Commonwealth governments and relevant departments and the NDIS to address these service interface issues. QDN supports the Productivity Committee recommendations regarding addressing these interface issues.

Overall Feedback

QDN asserts the following overall feedback and recommendations

- **Communication**

While QDN members are generally pleased with the speed at which NDIS Plans are being rolled out and funded, there have been some gaps identified with communication. Some members have found out they have been successful in attaining an NDIS funding package through their current support provider, not the NDIA when they receive feedback that the provider can no longer provide supports to them as they have an approved NDIS Plan. QDN members have also reported a gap in communication around the implementation phase of their plans, many saying they didn't know how to progress implementation as there were no clear instructions or communications. QDN believes the implementation phase is another area where peers could provide invaluable support and assistance. This could include sharing stories of how people have implemented plans in small groups and one-on-one peer support with plan implementation (see earlier recommendation on DSO/ Peer Support being extended to pre-planning, planning and implementation stages of the NDIS journey).

QDN members have also been highly supportive of the opportunity to have face-to-face planning meetings, and state this as a clear preference to meetings held over the phone. QDN welcomes the return of this approach.

- **Importance of access to advocacy**

The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:

- promoting their independence and social and economic participation; and
- promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and
- maximising independent lifestyles of people with disability and their full inclusion in the community.

Many people with disability remain extremely vulnerable and their success in negotiating the NDIS landscape relies on them having access to independent advocacy. QDN strongly asserts that alongside the NDIS there needs to be effective, independent advocacy and funded programs with a dedicated focus on peer support and leadership, awareness raising and assertiveness training to support people with disability to identify and assert their rights or have their interests represented.

QDN believes that alongside the NDIS there needs to be effective, independent advocacy and this is vital to the success of Scheme navigation with vulnerable participants.

- **Positive outcomes of the NDIS**

QDN would also like to take this opportunity to acknowledge the positive outcomes of the Scheme. QDN has heard first hand experiences from people who have finally benefited from much needed services and supports in their life. If the principles of choice and control, equity and economic and social participation are adhered to, the scheme promises to deliver the most transformational social policy change since the introduction of Medicare.

Under the NDIS people with disability will have more choice and control in how and what services they receive and their use of those services. People with disability will have greater opportunity to participate as citizens and both the public and private sectors, and decision makers will need to better engage with, and listen to, all citizens.

- **Targeted Strategies to ensure people don't miss out on the NDIS**

QDN believes that there needs to be targeted strategies in Participant Readiness activities (including pre-planning, planning and implementation phases) for specific groups so they don't miss out on the NDIS. These groups include:

- Aboriginal and Torres Strait Islander (A&TSI) people with disability
- Culturally and Linguistically Diverse (CALD) people with disability
- Women with disability
- Children with disability
- People with intellectual and cognitive disability
- People with serious mental health issues
- People with disability living in institutions, hospitals, aged care facilities, supported accommodation facilities, caravan parks

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- People with disability who are homeless or at risk of homelessness
- People with disability/young people who are exiting the child safety, criminal justice and juvenile justice systems
- People with disability from lesbian, gay, bisexual, transgender and/or intersex communities.

Conclusion and Recommendations

QDN is pleased to provide this feedback to the Productivity Commission Position Paper on NDIS Costs. QDN's submission has focused on number of key issues that have been raised by members based upon their lived experience of the transition, and supports the Commissions actions going forward that deliver a better outcome for people with disability, involving people with disability in the design, development, implementation and evaluation of solutions.

QDN firmly believes that the full implementation of the scheme needs to be consistent with the original principles and intent of the NDIS and supports actions that deliver on this. There are a large number of people in Queensland who have been waiting decades for access to the supports they need to live their day to day life. QDN does not support any actions to slow down the timing and roll out that would jepordise people's access to support, nor deny people who are currently under 65 access to the scheme should timing be changed.

QDN supports the early release investment of full ILC funding that could assist in increasing the capacity of a range of disability support organisations, advocacy, and intermediaries that can assist potential participants with access and planning preparation, outside of direct service providers. QDN believes it is essential to resource participants to participate well in the scheme as customers in the market.

The Scheme is delivering positive outcomes in people's lives, however there are a number of critical points raised within this submission that QDN members recommend serious attention is given to. It is essential that people with disability have positive outcomes as a result of their access to the scheme and can access the day to day supports they need to live their life, safely, and be able to participate socially and economically in their community.

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Appendix 1. QDN's Value Statement on People with Disability

QDN's work in providing feedback and input into systemic policy issues is based upon the organisation's core values and the place of people with disability in an inclusive Australian society.

QDN believes that:

- all people with disability have a right to a place in the community and have contributions to make to community. This is as empowered, free citizens who are as valued, present, participating and welcomed as members of any dynamic and diverse society
- the place of people with disability in the community is not just about people with disability having a house in the community. Core to this is that they are welcomed in the community as ordinary citizens, where they are genuinely given opportunities to contribute and actively participate. People with disability need to be in communities where their individuality, their talents and their lived experiences of disability are recognised and acknowledged
- culturally and historically, people with disability are not afforded the same value, opportunities or access to community life
- any inclusion in community for people with disability is conditional and vulnerable to withdrawal
- many people with disability in Queensland are excluded from the most basic experiences of ordinary lives
- current exclusionary practices are unacceptable and must be challenged
- these issues affect not only people with disability but the whole community
- the responsibility is shared. It lies within government (federal, state and local) and the community at large, to ensure that people with disability have a place and are resourced to belong in community.