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| ADVOCACY STATEMENT |
| Rights and respect in multi-agency provision in the NDIS |
| Fitting providers together in your NDIS support puzzleJuly 2021 |

## Context

Queenslanders with disability want an NDIS that enables access to individualised, funded supports that meet people’s needs and is built upon the foundations of choice and control. A system that delivers quality and safe supports and services with disability and their families in the driver’s seat is critical. Importantly in being able to fit together the pieces of the puzzle is delivering a system that people can navigate, make informed decisions about the quality, capability and nature of their supports, work together with supports and providers in a way that people can exercise their personal agency and have effective monitoring and accountability measures in place to safeguard quality and safety.

With the introduction of the National Disability Insurance Scheme (NDIS), individual choice and control of participants is differentiating providers according to their contribution to an individualised plan. Yet, support for people with disability is a complex organisational task which requires coordination across multiple human service organisations. Fitting multiple supports together in an NDIS funded package can be challenging because of many providers involved and the different systems from where supports derive. What we know is that there are good examples of how to do this well such that everyone is working together in a safe and quality manner.

Effective, quality, and safe provision of funded supports, where there are multiple providers, is strengthened by four key components/pillars[[1]](#footnote-1),[[2]](#footnote-2): 1) systems for information and communication sharing; 2) clarity and integrity of roles and relationships; 3) discernible accountabilities of providers; and 4) capabilities of providers. The governing systems of the NDIS are critical in supporting these components and creating the conditions for cooperative working among providers.

## Forum on effective multi-agency working

Queenslanders with Disability Network (QDN), in partnership with Griffith University, recently held an online forum on 14 June 2021 to hear from NDIS participants and families about their experiences and challenges of fitting together multiple providers in their funded support plan. The forum was designed to address the question of how participants work with multiple providers and what contributes to quality and safety. Discussions focused on the four key components, and their influence and impact on quality and safety of provision. Key messages from forum discussants are presented in these four categories.

## Key messages – Information and Communication

* **Importance of access to clear, accessible, and timely advice and information to inform decision making** when implementing and managing complex plans which include multiple providers and personnel.
* **Information needs change with each stage of plan management.** Different kinds of information are required to support selection of providers, recruitment of workers, coordinating plan delivery, managing and tracking financial transactions, assessing the quality and appropriateness of service provision and when the need arises undertaking advocacy and/or complaints to address shortcomings and grievances. There is a preference for simple systems which they could access to obtain relevant information.
* **Getting the right balance of accurate, relevant, and timely information**. While information overload was not directly discussed, it was clear that some participants did not want excessive amounts of information. Too much information about complex topics could undermine confidence in making choices, and prompt some to relinquish responsibility to providers. This was resisted by other discussants who articulated concerns about plan managers and support coordinators who assumed too much responsibility over plan implementation without adequate consultation with the participant. All discussants were looking for access to accurate, relevant, and timely information.
* **There is a strong preference for respectful communication in plan implementation.** Discussants shared examples in which either providers or personnel made incorrect assumptions about their disability and their choices, failed to communicate with participants in a timely way or communicated without demonstrating respect for their will and preferences.
* **Being able to communicate in preferred language is important.** For discussants from a culturally and linguistically diverse background this was particularly important, as was the opportunity to identify the preferred method and medium for communication, and to be certain that providers and personnel would respect this. Additionally, discussants indicated a preference to control the flow of information about their conditions and circumstances to providers.

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| **Preferences for addressing information and communication:**   * Online systems that provide transparent information about plan progress, including financial transactions, which facilitate review and approval, and enable participants to query transactions * Regionally specific information forums about the type and quality of local providers to enable comparative analysis and foster the conditions for informed choices * Practical support to communicate effectively with providers and personnel, this may include advice about how to articulate expectations and the questions to ask to ensure that providers and personnel will communicate respectfully * Practical advice on how to maintain confidentiality and privacy when working with multiple providers * Practical support for self and supported advocacy to realise participant’s rights to clear, accessible, and timely information |

## Key messages - Roles and Relationships

* **Strong partiality for respectful relationships which are structured around the participant’s expectations and preferences**. Discussants included NDIS participants living independently with daily facilitative care and access to additional allied health services and participants living with family, receiving funding for more discrete categories of support. The structure of the support package had a direct impact on the kinds of relationships which participants developed with providers and personnel.
  + Some discussants recalled incidents in which they felt very vulnerable when personnel entered their homes to provide funded services. Managing relationships on these occasions required significant assertiveness, and, consistent with the above observations, the quality of communication had an influence on the quality of the relationships.
  + The NDIS had provided an opportunity to manage relationships in ways that were consistent with personal preferences: participants who had, through a process of trial and error, identified personnel who were willing and able to work with them according to preferences regarding scheduling and task allocation. These successful team-based approaches were based on clear roles, supportive team processes to enable participants to achieve their goals, and effective communication between team members to secure this outcome.
* **Participants’ agency in configuring relationships and scoping roles of personnel in their support plan can depend on access to plan management and/or support coordination.** Even when this was the case, discussants indicated a strong preference to have their agency with respect to this topic recognised, respected, and facilitated
* **Experiences with support coordinators were varied.** There was strong opposition to support coordinators who acted to limit participants’ discretion in developing relationships, and desire for coordinators to facilitate personal capacity to make selections and develop a shared understanding of the role of providers and personnel in their lives.

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| **Preferences for addressing roles and relationships:**   * Respect of participants’ expectations and preferences * Opportunity and support to exercise personal agency in determining relationships and roles in support plans * Relationships that enable personal capacity to manage relationships and roles |

## Key messages - Accountability

* **Contracts, reporting portals, and the NDIS Quality and Safeguards Commission were three accountability mechanisms identified**. Contracts functioned to delineate the scope and structure of service provision, explaining the roles and responsibilities of providers and personnel. Reporting portals facilitated the review of plan implementation, in particular financial transactions. The complaints mechanisms of the NDIS Quality and Safeguards Commission allowed participants to address problems and rectify grievances.
* **Participants had varied experiences of the accountability mechanisms:**
* Contracts varied considerably in terms of structure and content. The absence of consistent clauses coupled with limited access to expert legal advice meant that some discussants felt vulnerable and uncertain when signing contracts. Additionally, discussants mentioned examples in which they considered clauses to limit their rights and discretion, which were justified by providers from a “risk management” approach. Discussants recommended the development of standard clauses that addressed issues of risk management but preserved the best interests of participants; and a clear preference for contracts that were transparent in the allocation of rights and responsibilities, with consistent clauses that prioritised and protected the rights of participants.
  + Satisfaction varied regarding information on expenditure and plan implementation accessed through reporting portals. Very different levels of satisfaction were reported with the amount of information provided and sense of control of their plan with the capacity to challenge expenditure/allocations.
  + Some had made recourse to the NDIS Quality and Safeguards Commission when difficulties were encountered.

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| **Preferences for addressing accountability**   * Transparency and consistency in allocation and protection of rights and responsibilities * Consistency in contracts to address risk management while preserving best interests of participants |

## Key messages - Capability

* **Assessing the capability of providers and personnel was an ongoing task.** Generally, assessment of the capability of providers occurs at the outset of the relationship and informs selection and recruitment, although this was ongoing. Discussants shared examples in which they needed to replace personnel and either renegotiate with or change providers when they were dissatisfied with the quality of their service provision.
* **Different stages of plan implementation require different kinds of support:** 
  + Initial assessments of the capability of providers and the competency of specific personnel are contingent on accessing information about the quality of services and the qualifications of individuals Discussants relied on peer networks to provide advice or referral networks between providers with established relationships, and some did not have access to either source of advice. Nonetheless, neither approach was considered wholly satisfactory.
  + There is a need for practical support when recruiting staff directly. Discussants indicated the online platforms which could be helpful in this regard but also indicated that it was important to meet with potential personnel because beyond qualifications it was important to know if the individual was the right fit.
  + Ongoing assessment of whether providers and personnel were capable of meeting expectations for quality and safe service provision is complicated. Practical support is required to enable individuals to understand and assert their rights, how to access complaints mechanisms and renegotiate contracts or change providers.

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| **Preferences for addressing capability:**   * Access to reliable information and practical support to assess the capability of providers * Practical support in recruitment which included how to design interview questions and articulate expectations * Practical support to access complaints mechanisms and to assert rights if change is required |

## Priorities for action going forward:

The NDIS is an evolving and maturing scheme that needs ongoing support, education, and capacity building directed not only to individual NDIS participants and their families but also services, providers and the market. It is critical that we work together to ensure people with disability and their families can operate as empowered customers, in a thriving market that is responsive to their needs and delivers quality and safe services with appropriate safeguards, monitoring and accountability in place. The preferences and solutions to improve the complex interface issues identified by participants during this forum are supported and endorsed by QDN. They provide a range of key actions that can deliver improvements to participant experiences and drive much needed change as the NDIS continues to evolve and mature.

QDN acknowledges the importance of the leadership of people with disability and their families in informing and co-designing actions moving forward to achieve these and address key issues raised during this forum. QDN identifies the following priority actions at the individual, service and systems levels:

## Priority actions for people with disability and families

1. **Provision of independent services to deliver peer support, self-advocacy and targeted services for capacity building.**
2. **Continued access to independent individual and citizen advocacy services** that includes provision of support to access complaints mechanisms and assert rights.

Independent advocacy exists to ensure that people with disability have a voice and support to overcome barriers and challenges. We all want to be included in our communities and have access to the same opportunities, but for people with disability it can be a whole lot harder. We need continued and long-term commitment by both state and federal governments to provide the funding that disability advocacy organisations need to keep serving people with disability.

Disability advocacy can make a critical difference in a person’s life. It can be the difference between getting a disability support worker to help you at home or struggling on your own; living comfortably in your rental home or becoming homeless; having your child attend the local school versus a special school which is further away; being part of a local club or being isolated at home.

There are so many areas were disability advocacy matters. For example, provider expos, practical information, and support to develop communication skills in negotiating with services and support workers, recruiting staff, coordinating multiple services, managing contracts, complaints and changing providers to ensure mutually respectful conversations and relationships; and access to technology including devices, affordable data and the skills and knowledge in how to use them.

Independent services to deliver peer support, self-advocacy and targeted services for capacity building could include key information, forums and activities about:

* Access to quality services and determining/identifying provider quality
* Assessing and undertaking comparative analysis of different services to make informed decisions
* NDIS consumer rights
* Accessing NDIS services of LAC/ECEI,
* Plan-manage and self-manage
* Charges and transactions and individual plan
* Confidentiality and privacy when working with multiple providers

## Priority service and workforce actions

1. **Support to develop a local information hub to deliver clear, impartial, and accurate information about what services and providers are available in local communities:**

* Develop a function/service at the local level where NDIS participants can access support from independent experts to assist participants to undertake comparative analysis of what is available and what fits with their needs for services and supports. This could be achieved by enhancing the function and skills of supports coordinators and putting parameters in place for supports coordination to only be delivered by a service that is not the same service delivering their individual NDIS supports and services to avoid conflict of interests.
* Consideration would need to be given to the role and function of the Local Area Coordinator (LAC) and how this intersects with what they currently do in provision of lists of options of providers and services for NDIS participants.

1. **Improve professional development options for supports coordinators, planners and LACs to ensure quality workforce** with necessary skills, knowledge, attitudes, and values to deliver person-centred services centred on choice and control:

* Accountability and transparency with regards to the delivery of the roles in community:
  + Understand and access the NDIS
  + Create a plan
  + Implement your plan
  + Review your plan
  + Learn about support available in your local community
  + Understand how the NDIS works with other government services – this is supports like education, health, and transport
  + Sustain informal supports around you – this is family, friends, and local community members.

1. **Increase workforce capability, knowledge, and skills.** This would include:

* Working effectively with NDIS participants to ensure their choice, dignity and risks, and how participant expectations and preferences are understood and respected.
* Working with NDIS participants in a practice that acknowledges the inherent power imbalances in the relationship and delivers support that is empowering to the individual and their personal agency.

1. **Expansion of programs such as the NDIS Training and Skills Support Strategy (NTSSS),** which is the largest project delivered by WorkAbility Qld. The NTSSS is leading industry-focused, multi-faceted approach to developing a quality NDIS workforce that can deliver services which are reflective of the needs of NDIS participants across Queensland. The project has been developed in partnership with the Department of Employment, Small Business and Training (DESBT) and is delivered in collaboration with the disability services industry, key government agencies and people with lived experience. The project aims to:

* Provide VET Industry advice to the Department to maximise opportunities under the VET Investment Plan and respond to the skilling workforce needs to support NDIS recipients
* Promote uptake of the Annual VET Investment Plan
* Promote industry leadership in the co-design and delivery of NDIS training
* Development of advice around NDIS workforce development

## Priority system actions

1. **Review current settings in place that enable supports coordination and direct service provision to be delivered by the same organisation** to address the issues of conflict of interest.
2. **Increase funding for supports coordination and specialist supports coordination** in individual plans, especially for first plans.
3. **Support ‘thin markets’** particularly in regional, rural and remote communities to grow options and deliver a thriving market for NDIS participants and their families.
4. **Review current technology and systems for NDIS** **participants** to manage their plans to ensure people can have access to transparent information about plan progress, financial transactions, review and approval mechanisms and process for inquiry on transactions.
5. **Ensure enforceable transparency and accountability under the outcomes of the National Disability Strategy** so that all governments are committed to a national approach to supporting people with disability to maximise their potential and participate as equal citizens in Australian society.
6. **Review how the current regulatory environment is undertaking monitoring and reporting on the implementation of contractual arrangements and services** to ensure a balance the rights and interests of the individual with service risk management and risk mitigation.
7. **Adopt Terms of Engagement from the NDIA.**
   1. People with disability must be at the centre of decision-making as partners in the NDIS.
   2. People with disability must be represented in NDIS governance, in the leadership of the National Disability Insurance Agency, and in the delivery of the NDIS.
   3. Engagement must be honest, transparent and respectful.
   4. Changes to the NDIS need to be co-produced in collaboration with people with disability, our families and our representative organisations.
   5. Australia’s obligations under the United Nations Convention on the Rights of Persons with Disabilities underpin engagement.

## Background to the Forum

QDN in collaboration with The Hopkins Centre, Griffith University, hosted an online forum on 14 June 2021 on *Fitting providers together in your NDIS support puzzle*. The purpose was to engage in open discussion with NDIS participants and their families about experiences, challenges and solutions of managing multiple providers in a support plan, and perspectives on how to ensure quality and safety of these supports. The forum attracted 74 registrations from people with disability, families of people with disability, advocates, academics, providers, and government, with a 78% attendance rate. The largest attendees were people with disability (29%). Discussions were preceded by three invited presentations, which provided perspectives from an NDIS participant, a family member of an NDIS participant, and a disability advocacy perspective. Five small discussions groups were held with people with disability and families of people with disability to openly share thoughts and experiences of support provision involving many providers and suggestions for improvements at both local and scheme levels.

The forum and its focus on effective multi-agency working, originated from the findings of a three-year ARC Discovery project (ARCDP190102711), led by Griffith University, The Hopkins Centre, in collaboration with University of New South Wales and University of Birmingham, UK. **The ARC project: *Making complex interfaces work for the NDIS***, examined the online and offline relationships of organisations working in the NDIS; and explored how funded supports were being constituted and coordination from three perspectives: organisational, support coordinators and frontline workers, and NDIS participants. Online relationships of 216 organisations were mapped and analysed using web metrics and social network analysis. A combination of qualitative interview data and survey data on coordination of supports was collected from 67 organisational managers and frontline workers/support coordinators: and 51 participants. These components specifically focused on understanding the local practices of coordination of supports involving multiple providers and services, with a view to highlighting challenges and best practices examples and the key features of good local governance of disability support.

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1. Greer et al. 2016 Strengthening health system governance. Open University Press.

   Exworthy et al. 2017 The governance of integrated health and social care in England since 2010. Hth Policy, 121. [↑](#footnote-ref-1)
2. [↑](#footnote-ref-2)