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Research for Rehabilitation and Resilience

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SUBMISSION to the Queensland Productivity Commission Inquiry into the National Disability Insurance Scheme Market in Queensland

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Submission to the Queensland Productivity Commission

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ARC Discovery Project (ARCDP190102711) Making Complex Interfaces Work for the NDIS
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Introduction

Established in 2017 and co-located at Griffith University and Metro South Hospital and Health Service, the Hopkins Centre is Queensland's premier research agency examining rehabilitation and resilience for people with disability. With over 200 research affiliates, including both academics and clinicians, the Centre's approach to research involves a distinctive coupling of the voice of lived experience with systems and policy analysis. The Centre's work transcends traditional disciplinary boundaries to investigate how to drive improved outcomes for people with severe disability through translating research into effective policies and practice. Our research is organised in three streams: positive environments and communities; therapeutic interventions and practices; policy, governance, and service systems.

The Hopkins Centre welcomes the opportunity to contribute to the Queensland Productivity Commission's inquiry into the operation of National Disability Insurance Scheme (NDIS) markets in Queensland. The inquiry is timely not just because of the full establishment of the NDIS in Queensland, but because the period of transition has revealed some of the challenges of delivering services and supports to people with disabilities within a newly created service system, which has some market features, but also extensive regulation and is structured by public funding and fixed pricing. Indeed, in the following analysis, the challenges of working in a hybrid system—a quasi-market with fixed prices—that activates competition between providers to enable choice for people in receipt of funding packages to purchase services, are apparent for both providers and purchasers. The ongoing importance of government's role in stewarding the market to ensure the availability and quality of service provision, addressing market failures and deficiencies is likewise evident.

In drafting this submission, we have drawn upon some of the preliminary findings of a current research project, *Making complex interfaces work for the NDIS* (2019-2021), which is funded by an Australian Research Council (ARC) Discovery Project (ARCDP190102711) grant. The project is described more fully in the Appendix to this submission. The initial phase of research involved 28 interviews with selected organisational representatives providing services under the NDIS in Queensland, and with seven NDIS Participants and one parent of an NDIS participant, all living in South-East Queensland.

Key Findings

At this early stage, key findings of the research into the impact of the transition to the NDIS on providers include:

- *Disruption to governance*: Service providers who transitioned to the NDIS experienced significant, if anticipated, disruption that required investment in developing the administrative, technological and commercial skills and infrastructure necessary to operate in the NDIS environment. This has ongoing effects with increased staff required to manage

the load of administering the scheme. Providers also reported increased levels of reporting and thus clinical oversight.

- *Financial vulnerability*: Providers reported increased concerns about financial viability. Reasons for this sense of financial exposure included that the costs of provision were inconsistent, mostly greater than, the price guide; participants could change providers and withdraw from service, and as already noted the costs associated with administration had increased. In some instances, this has led to greater risk aversion and thereby less willingness to innovate, in other examples increased financial vulnerability has led providers to expand corporate partnerships and leverage philanthropic investment.
- *Organisational culture:* An impact on organisational culture was also apparent, with providers indicating that their core philosophies have not changed, but their ways of working have had to adjust to reflect financial uncertainty and competitiveness.
- *Capacity to collaborate:* This has diminished, reflecting both the absence of margins that would otherwise enable staff to allocate time to the development of collaborative relationships. Market competition and the influx of new providers makes organisations less willing to share information and work together to improve outcomes for participants.
- *Staffing arrangements*: These changes also have an impact levels of staffing. Increases in administrative workload have already been noted. Some providers reported that employment contracts are now less secure because participants can change providers at short notice. Financial pressures have meant that some organisations are deploying staff with fewer qualifications, whose wages are thereby lower, to perform services. The decreased margins have also meant that there is less investment in staff training and development.
- *Service models*: Providers have had to make decisions about their competitive advantage and whether to occupy specialised niches within the service sector. This is having a number of effects with some providers narrowing the scope of their provision, and others prioritising participants willing to invest their entire funded package with a single agency. In most instances, providers are aligning service provision with business strategy and are thus becoming more selective about who they work with and in what ways.

The above findings suggest that agencies that had been providing disability services prior to the full establishment of the NDIS have undergone significant changes with implications for all aspects of their operating and business models. Some of these changes can be slated to the “market” aspects of the scheme, including less collaboration between providers and changes to service models. The price guide which effectively places a ceiling on cost recovery has driven many of the noted changes in organisational structure and service provision.

In addition to the direct impact of the changes to the way that disability services are funded, the research has confirmed that other aspects of the scheme have had a profound effect on service provision within emergent markets. Some organisational changes reflect the governance and administrative requirements of registration with the NDIA and the requirements of the NDIS Quality and Safety Commission. The quality of plans and the implementation process were also highlighted as constraints on service design and market provision.

Providers were consistently critical of the skills and capacities of both Local Area Co-ordinators (LACs), who undertake the plan development with NDIS participants, and Support Co-ordinators who facilitate the implementation of complex NDIS plans. Similar themes emerged, with providers concerned that the workforce often lacked specialised knowledge of disability and service provision. Providers strongly advocated for intervention to improve the quality of the workforce and thus of plan development and implementation. The quality of plan development and implementation has a direct effect on the market, what services are funded and how providers are selected.

The combined impact of the planning process and plan implementation in the emergent markets for services was most keenly felt when plans were complex and multiple agencies were engaged in the delivery of different aspects of these. Providers commented on perceived gaps for people with intellectual disability, brain injury and complex behaviours. In such circumstances it can be difficult to identify providers with the right mix of services and specialist staff, resulting in the involvement of multiple providers which increases the risk of inconsistent support for highly vulnerable people. Providers did not consider that there were sufficient market incentives to address such issues. Moreover, some were also concerned that recent market entrants did not have the right mix of policies, practices, and specialist staff to provide sufficient quality, creating further risks.

What this all means, and which is of specific importance to the topic of this inquiry, is that the way that the emergent markets in disability services function is only partially explained by costs encountered in the provision of disability services and the ways that these have been priced by the NDIA. The pricing guide has a significant impact. Nonetheless, other features of the scheme are also responsible for the transformation of the service sector and the way that emergent markets function. At this stage in the research it is not clear that the market mechanisms which have been designed into the NDIS comprise the best and most effective strategy to address these issues, including: service quality, service gaps, addressing complex needs, promoting greater collaboration among providers to advance client outcomes.

Conclusions

At this early stage of the research it is possible to conclude that:

- The implementation of the NDIS has increased not reduced service system complexity
- The implementation of the NDIS has not facilitated greater collaboration between providers
- The planning process requires greater specialist input and consultation with service providers, likewise, plan implementation requires specialised support
- The pricing guide largely functions as ceiling on cost recovery, exposing providers to financial risks in many cases
- There are evident gaps in the service provision market, particularly for individuals with complex and multi-faceted needs.

Together these factors suggest risks for scheme sustainability and effectiveness. The implications of this for participants and providers are different. For participants navigating the complexities of the NDIS planning process and the market in disability services is overwhelming not empowering. This was largely experienced as a significant stressor and source of confusion, frustration, and anxiety for both the individual and their family. Providers are proving highly adaptive. Cautious optimism about the prospect for growth, sits alongside ongoing frustration with aspects of scheme complexity—legal and regulatory issues—and the limitations of the pricing guide.

To date, the research suggests a nuanced analysis of the efficiency and effectiveness of the ways in which market mechanisms have been entrenched in NDIS operations. While there are reports of creativity and innovation, market gaps pose real limits on the adequacy of the service response for people with complex needs, which can mean that budgets are underspent and the opportunity to improve the lives of people with a disability is not realised.

Recommendations

The research suggests that addressing the following factors would assist with improving the efficiency and effectiveness of the emergent markets. Consistent with the argument above, these recommendations are not limited to features of the emergent markets, but aspects of the broader scheme which have implications for the operation for the emergent markets in disability services:

- More effective monitoring of service quality, with relevant information about organisational performance to be made accessible to NDIS participants and providers.
- Adaptations to the pricing guide that will support the increased employment of qualified staff in service delivery and reflect the true costs of service provision, which includes more than client contact and direct delivery.
- Investment to build the skill levels and capability of key NDIS workforces, particularly planners and support co-ordinators. One of the key issues here is to support people with multi-faceted needs and co-morbidities, who are likely to experience continued social marginalisation, all of which have behavioural and psychosocial implications, requiring thoughtful and person-centred responses.
- Investment to promote greater collaboration between service providers, within regions, and when multiple agencies are involved in the implementation of complex plans. The potentiality of support coordination to achieve this outcome is yet to be realised.
- Investment in research and development of technologies and services that can be more effectively deployed in emergent markets to promote social access, wellbeing and independent living.
- Direct commissioning of highly specialised supports and public provision of services in thin and regional markets. There are clearly multiple markets operating in the provision of NDIS supports and strategies to address gaps in the markets for the provision of housing support, transport access and assistive technology are required in particular.

Preliminary findings from the organisational interviews

Table 2: Organisation Managers Recruited (n = 28)

Organisational Focus	Not-for-profit	Government	Private for Profit	Social Enterprise	
Disability Provider Coordination and Support Services	6	1	4	2	**13**
Community and Mainstream Services	5	3	2		**10**
Information and Linkage Services	4			1	**5**
					28

For reference, participants have been assigned a number 1 to 28, M (denoting Manager) and identified as NGO, Private or Government. NGO provider (M02, M03, M04, M07, M08, M09, M10, M11, M13, M14, M16, M17, M18, M19, M22, M24, M29); private provider (M01, M05, M12, M20, M21, M25, M27); and government provider (M06, M23, M26, M28).

1. Transition to a new funding model

Pressure of 'back of house' preparations

The general view from participants interviewed is that the transition to the NDIS has been challenging, although for some, the initial pressures and uncertainties had started to dissipate with more familiarity and adaptation to the new model. Most described a period of 'back of house preparations' to transition their organisational processes and operation to the new funding model (M02, NGO; M06, Gov; M08, NGO; M09, NGO; M18, NGO; M28, Gov).

The common view was that organisational principles and models of working had not changed, but due to the new NDIS environment, adjustments and changes have been necessary to become more financially viable, including: the type and number of services provided; the type of disability or 'customer' they work with; the type of work they do and/or roles catering to the NDIS (for example, establishing support coordination or more educative roles) (M01, Private; M22, NGO; M28, Gov; M03, NGO; M11, NGO; M13, NGO; M19, NGO; M23, Gov; M24, NGO; M26, Gov; M27, Private; M28, Gov).

Restructuring to expand the commercial expertise of the business (M10, NGO) and maintaining the business or making adaptations were largely seen as organisational strategies to acknowledge the inability to "be everything to everyone" but rather to determine what the organisation was good at, and could be/marketed as a specialist in (M05, Private; M07, NGO M11, NGO; M20, Private; M22, NGO; M29, NGO).

The transition work increased internal pressures (M02, NGO; M03, NGO; M04, NGO) and administrative loads (M01, Private; M18, NGO; M19, NGO; M21, Private), and involved costly and time-consuming processes and administrative changes (M07, NGO; M03, NGO; M08, NGO; M09, NGO; M21, Private). This displaced investment in other critical activities such as staff training and network building (M01, Private; M09, NGO; M19, NGO), which has also proven to be an ongoing challenge under the new funding model and price guides.

- Increased administrative staff "just to deal with NDIS" (M01, Private; M19, NGO; M21, Private), including administrative training (M21, Private)
- Changes to billing systems (M03, NGO; M08, NGO)
- One Private organisation had made deliberate efforts to improve their financial system that would align with the NDIS portal and built cash reserves to "allowed us to transition comfortably" (M07, Private)
- Needing to invest in IT and operational systems "to become operational, efficient and effective" (M08, NGO; M21, Private)
- Constantly changing service agreements and associated continuous budget tracking (M21, Private)
- Reduced profit margins for private organisations (M01, Private; M19, NGO)

Financial vulnerability versus opportunity

There were a range of views about the shift from block funding to an individualised funding model based around a billing process, with reports of financial vulnerability e.g. needing to "scale up to survive (M24, NGO), or "panicking" about resources (M14, NGO), and for some, impacting the scope for innovation, versus the new approach representing business opportunity.

Notably, early reservations about the competition between organisations were largely seen as reducing as the market matured (M05, Private; M08, NGO; M18, NGO; M28, Gov), organisations differentiated themselves (M05, Private; M07, NGO; M11, NGO; M20, Private; M22, NGO; M29, NGO), and organisations realised the significant demand for services (M05, Private; M07, NGO; M21, Private; M28, Gov).

However, experiences varied from "people are now scrambling for business" (M19, NGO) to a sense that the "threat doesn't exist in business anymore, where it previously did", because of the increased demand for services under the new funding model and the complexity of needs (M01, Private). Where there was a sense of competition, the perception was "new start-up organisations are seen as a competitor [rather] than…long-standing traditional organisations" (M04, NGO).

Complexity and restrictions of price guides

There was a mix of opinions about the price guides and in some cases, a level of confusion and concern, about ongoing changes to price guides and the extent to which there is adequate flexibility for organisations.

- Limitations of price guides:
    - Specific challenges in providing quotes for partial services (M11, NGO)
    - Price guide not reflecting variation from 'particular' pathways (e.g. expected cost of equipment), not accommodating 'case conferences' when there are complexities, and lack of provision for travel impacts for those in regional areas (M28, Gov)

- The sector is still trying to work out what are adequate and appropriate prices for direct outputs (M10, NGO)
- Price guide not taking account of the complexity of some clients, where the workload is "amplified where you have a client who has high medical needs, as a result of their disability" (M06, Gov)
- Deskilling the workforce to operate with reduced funding for similar level of service (M08, NGO).

- The laborious nature of the billing process:
  - Laboriousness of line items and "processing millions of transactions of line item code" is challenging for organisations (M12, Private; M19, NGO)
  - Need to be extra diligent "because if one of those codes is wrong then you're billed wrong" (M21, Private)
  - Several organisations expressed frustration at delays in payment, especially if the NDIS participant is self-managed (M04, NGO; M24 NGO) with significant "time and…effort chasing unpaid bills" (M24, NGO), to the point where two organisations are considering legal action, ceasing services to NDIS participants, and use debt collectors.
  - Some concern was expressed about self-managed packages and lack of surety of payment for services and "bad debtors" (M04, NGO; M24, NGO)

- Lack of margin in the NDIS funding model to accommodate activities that were historically part of organisational life and maintaining quality in service provision
  - Lack of resources for staff training (M19, NGO; M11, NGO; M09, NGO; M03, NGO; M26, Gov): "who pays to train them…we only get funded per customer per service hour" (M11, NGO)
  - Asking staff to accept unpaid hours for training: "we're asking people to do things in their free time, which I think is incredibly challenging and very unfair" (M19, NGO)
  - Reduction in routine networking that has been historical to collaborative service provision (M28, Gov)
  - Organisations identified struggling to continue performing services that are not billable but considered "expected" (e.g. advocacy) (M19, NGO; M24, NGO), or support coordination where funding isn't provided (M04, NGO)
  - Lack of funding flexibility to address "issues" that arise (M03, NGO)
  - Additional pressures were in some cases described as a risk – to the quality of the services (M19, NGO), to the "longevity of employees" (M19, NGO), to the financial viability of the organisation (M24, NGO), and ultimately to the well-being of NDIS participants. An example from one not-for-profit NGO of the compounding challenges emanating from the price guide:

At least one private provider identified potential benefits or opportunities of the NDIS price guide for both organisations, referring to volunteer organisations and being able to now "actually bill an NDIS participant and charge against the plan" (M12, Private) and reinvest it into the organisation

Lack of resourcing to enable organisations to transition

Organisations identified a lack of resources to the whole sector to assist with the necessary system change: assisting agencies to adapt to the NDIS model (M01, Private; M07, NGO; M11, NGO); including changed workloads with more complex governance structures (M11, NGO), and some organisations "still catching up" with the legislative change, and "what that *means from a governance and risk point of view* (M11, NGO)

Sufficient staff to deliver services based on level of demand (M18, NGO); with limited resources and training for a system under pressure with increased workloads (e.g. higher supervision ratios resulting in workloads increasing 40%) (M03, NGO); and competitiveness for staff recruitment and retention, when coming from the "same pool" (M04, NGO)

Additional work associated with new reporting arrangements relating to quality and safeguards creating challenges because "now the margins are so slim, and we have three times the workload" and organisations cannot claim for that whereas pre-NDIS there might have been better access to funding for such activity (M18, NGO).

Caution optimism and measured growth

Most organisations were challenged by decisions about the level and area of expansion and/or expanding too fast. It was clear that financial vulnerability and ongoing changes associated with implementation of the NDIS were part of organisations decision-making. Strategy and adaptation involved decisions about what the service focus would be going forward, for example, for example, "not [to] do every service type" or "restrict the types of service provision" (M08, NGO).

While all organisations were "finding their niches a bit more" (M05, Private; M11, NGO; M20, Private; M22, NGO; M29, NGO), some had an expectation of demand would drive future growth but preferred a measured approach and not to expand too rapidly (e.g. M11, NGO; M12, Private; M21, Private; M22, NGO; M27, Private; M29, NGO) and others saw opportunity but were uncertain of success in the new environment (M14, NGO; M19, NGO; M27, Private).

Deciding the 'customer base'

Organisations were also making deliberate decisions about their 'customer' base and focus going forward. Both NGOs and private providers recognised that 'business decisions' were being made where the customer focus and/or types of services provided needed to be reconsidered for both commercial viability and risk, regularly talking about the 'ideal customer' (M05, Private; M08, NGO; M11, NGO; M14, NGO; M19, NGO; M21, Private).

Whereas some providers saw an increase in their 'customer base', there was also an emphasis on being more selective because of the new funding model, and needing to stay financially viable, particularly given the possibility of providing only partial plans: "who is our ideal customer that meets the commercial side and the risk side of the same time" (M11, NGO).

- Targeting specific customers, and "choosing which part of the market they're going to provide services to" (M08, NGO)
- Maintaining discretion about customers, including working to determine the 'right' customer or maintaining tighter controls on customers e.g. developing a screening process to match the customer with the new business strategy (M11, NGO); and avoiding being the 'provider of last resort' (M11, NGO)

2. Quality and responsiveness of the provider market

Influx of providers and change of organisational forms

The influx of providers and also the instability of providers were issues raised by organisations. The general sense was that there had been an influx of new provider organisations, but also some closures since the NDIS. Again there were mixed views about changes in the provider market since introduction of the NDIS, including that the NDIS had "not fundamentally changed" (M29, NGO)

the market yet, and a contrasting view about the influx of new organisations who were not necessarily skilled.

- The variable quality, experience and knowledge of new providers was raised as a concern, as was the lack of incentive for organisational forms other than a sole trader model outside of the metropolitan areas.

- The influx of sole traders was" offering really good value for money for community access" (M08, NGO), but equally this was a "challenging space" (M12, Private; M19, NGO) in regard to staff training, compliance and safety given 'lean overheads'.

Perceived gaps in specialised areas

There were generalised comments about specific areas of market failure but a notable issue were the perceived gaps in certain service segments such as demand for housing or lifestyle supports, and specialist areas of provision such as intellectual disability, brain injury and behaviour supports. There was also a view that such gaps were an opportunity to bring "creativity into the market" and housing providers especially in the SDA market was a specific example (M08, NGO).

The complexity of need was raised by several participants, specifically relating to gaps in specialist areas of service provision such as intellectual disability and brain injury, and in behaviour support planning, alongside restrictive practices, as examples. A general view was that timely services could mean a compromise on quality (M01, Private; M11, NGO; M17, NGO; M19, NGO; M23, Gov)

Meeting complex needs in a more marketized environment was challenging. People with an intellectual disability and/or people on the social margins, complex behaviour supports, including restrictive practices, and people with long-term neurological conditions, were specific examples were lack of skills, knowledge and capacity were highlighted (M01, Private; M17, NGO; M23, Gov).

These concerns were compounded by what organisations saw as the less than satisfactory provider list and general lack of accessible information about what providers offered in the NDIS. This led to 'cold calling' and scoping out providers that were trusted.

Gaps in assistive technology, home modifications, respite care (M06, Gov), supported independent living and group homes, and community transport (M14, NGO) were raised. Repercussions of the lack of available supports, or the significant time delays were also identified, including the need to justify underutilised funds at plan review.

Home modifications also experience significant delays, largely due to complicated approvals processes and plan reviews with significant implication if the individual is waiting for the home modifications to be discharged from hospital (M01, Private).

Added repercussions with these delays then come about when the plan is reviewed but has been underspent. Underspending the budget due to the inability to find specialist providers was a concern expressed by a number of providers.

2.3 Quality and responsiveness of workforce

Local Area Coordination
The role of Local Area Coordinators (LACs) was poorly perceived, with organisations considering the role ineffective and LAC quality varying on an individual basis because of:

- Poor clarity and understanding of the role (M24, NGO), associated with the perceived "rapid implementation of a half thought-out scheme" (M07, NGO) and poorly trained and qualified people, occupying the Local Area Coordinator role, including being inexperienced in the disability area, (M10, NGO; M24, NGO) and lack of due diligence (M20, Private). Consequently, training and coaching of LACs were deemed "crucial" aspects of the Scheme (M12, Private).
- Local Area Coordinators were not active in helping to guide and connect participants (M12, Private)
- Lack of infrastructure and resourcing across the sector was a contributing factor to ineffectiveness of Local Area Coordination, which consequently was perceived as systemic failure (M10, NGO; M29, NGO)

NDIS Planners
Consensus that NDIA Planners were inconsistent in knowledge of disability (M19, NGO); inconsistent in their understanding of the NDIS rules, legislation and entitlements, yet the quality of a plan rested heavily on this role; and that administration can overshadow quality of communication, relationships and knowledge, e.g. of whole family network ((M17, NGO; M19, NGO; M20, Private). More direct and routine contact with Planners was required.

Support Coordination
There were both positive and negative views about the quality of Support Coordinators (SCs), with some indicating less than optimal coordination due to lack of professional knowledge and skills. Some of the ongoing issues identified by participants (M01 Private, M23, Gov, M28 Gov, M29, NGO) were:

- A lack of understanding of the role
- A lack of systemic knowledge and skills that were required
- Lack of knowledge specific to specialist contexts
- Limited educational background and a perception of deskilling of this workforce
- The administrative approach of SC

Many of these issues were linked to the perceived lack of quality in coordination between the health and NDIS interface (M01 Private; M23, Government; M28 Government). In response, to perceived poor quality of Support Coordination, organisations were endeavouring to get involved in planning processes to 'protect' or 'advocate' (M23, Gov; M28 Gov); building and maintaining good relationships with quality coordinators; and offering training in support coordination.

3. Challenges of multi-agency provision under the NDIS

As anticipated under choice and control, there is an awareness that NDIS participants are broadening out their combination of service providers and that this is generating a more complex multi-agency approach to supports. Consequently, many providers talked about the need for providers to rethink their multi-agency approaches and partnerships to deal with both the

opportunities and risks. Specific to the risks of multi-agency provision in funded supports is what providers see as the 'segmentation of plans', and accompanying that, incomplete or less than optimal information sharing and communication among multiple providers; inconsistencies in practices and variations in quality.

Incomplete knowledge of support plans

Providing only part of a support plan and not seeing the complete plan was a risk to quality and safety, due to lack of communication and information sharing, lack of clarity about roles and responsibility, and subsequently, accountability for crises. These were particularly concerning with the more complex support plans and/or involving behavioural support components.

Both the funding model and partial involvement in a plan could negatively impact the quality and energy for inter-agency collaboration, although this was seen to be important (M03, NGO; M12, Private) (M02, NGO; M03, NGO; M08, NGO; M10, NGO; M12, Private; M18, NGO; M24, NGO).

There was a view if an agency is providing a very small amount of care, there is less interest in having staff attend stakeholder meetings and team meetings to resolve problems, but this may be variable depending on if there's a commitment to the NDIS participant. Furthermore, the cost of sending staff to participate in such processes could out-weigh other priorities.

Effort and risks of complex support plans

The issue of complexity was raised again this time in relation to multi-agency provision (M06, NGO; M08, NGO; M10, NGO; M11, NGO; M19, NGO; M21, Private; M24, NGO), namely, timely communication across providers, effective handling for emergency situations, siloed working, as well as managing inconsistencies in practices such as with complex behaviours.

- A need for efficient and consistent communication and good work relationships - for organisations who are delivering parts of services are exacerbated for clients with complex and multiple needs, especially in instances of high turnover of Support Coordinators and where emergency decisions need to be made.
- A need to clarify roles and responsibilities and a need for designated responsibilities and a point of control for complex support plans (M19, NGO; M21, Private; M24, NGO)
- Organisations had mixed opinions about receiving information about additional services being received by NDIS participants, with some considering it essential, while others only considered it necessary if issues arose.
- Clarity of roles and responsibilities was essential with complex behaviours.
- Multiple organisations identified the inconsistencies in state- and federal-based restrictive practices as a major challenge, with organisations having to navigate "very complex legal and compliance issues" (M08, NGO). Keeping up with new and continually evolving legislation was time consuming and there was very "little wriggle room in your NDIS funding" to enable joint or collaborative approaches to complex or multiple needs (M06, NGO).
- Concerns that the commercial aspects of the NDIS environment could be a disincentive to inter-agency collaboration and sharing information (M02, NGO; M06, Gov; M08, NGO; M10, NGO; M18, NGO; M24, NGO).

Local strategies to manage risks

There were views about how to manage perceived risks of multi-agency provision and improve information sharing and coordination, but without any specific incentives to do this, efforts were

largely situational and local and related to good working relationships, however, this was with the understanding that any coordination with other providers was unfunded work.

- Establishing clear expectations with other providers about what multi-agency provision is going to look like
- Long-term providers, in specialist areas such as mental health and neurological conditions, opted for more caution about who they were prepared to work with and scoped out providers or preferred to work only with trusted agencies, or were prepared to intervene if necessary
- Maintaining intimate knowledge of participants to understand the situation
- Trying to establish good relations with new providers and/or putting effort into relationships with Support Coordinators as a central point of contact
- Initiating collaborative meetings of providers

Early insights from NDIS Participants interviewed

Interviews have been conducted with seven NDIS Participants and one parent of an NDIS participant with profound disability and complex needs, all living in South-East Queensland. The NDIA participants included two females and six males, aged between 20 and 55. All had different combinations of disabilities, including severity and complexity, with six of the seven having an intellectual disability. Overall, the NDIS Participants expressed gratitude for the positive change that the NDIS has brought to the quality of their lives, and for some their families lives as well, including opportunities to participate more in the community, learn new skills, "live a normal life"(P02) and have greater "security" for the future. The greatest challenge, however, experienced by all NDIS participants was the difficulty navigating and understanding the NDIS process, system and rules, often felt to be an impediment in being able to ascertain and attain what they are entitled to under the NDIS. This was largely experienced as a significant stressor and source of confusion, frustration, and anxiety for both the individual and their family.

The complexity of the NDIS make it hard to navigate

Difficulties experienced navigating the NDIS included a lack of understanding the rules and entitlements; processes around access and plan reviews; and transparency of NDIA Planner decision-making.

- *Understanding rules and entitlements*

Interviewees all expressed a lack of understanding about the NDIS rules, especially supports they are entitled to, what evidence or supporting paperwork they need to put forward a case, and when or how they can argue more strongly for what they want. In general, there was a sense of needing to know the NDIS system, but the NDIS system itself not providing adequate information, so individuals needed to seek their own information from providers, informal personal networks, advocacy organisations and build up their own knowledge base and self-educate on appropriate supports to request. However, this wasn't always easy, with sometimes conflicting understandings/information, as well as regular changes to NDIS rules.

For one individual, the stress experienced in anticipation of a meeting with a NDIA Planner was debilitating and had significant consequences for receiving requested supports because he couldn't advocate for himself:

I was really stressed about it, which that day I had to medicate myself…So, really, at the plan meeting, I really couldn't, what would you say, I couldn't really speak for myself."… "I didn't really get what I was after in my plan, because I couldn't really speak for myself (P02)

For a number of individuals, even once they had received a plan, they found how to use the budget "very confusing", and a barrier to be able to self-manage.

- *Understanding the process*

Most participants struggled to understand the process, especially around planning and plan reviews. One individual, however, due to having a direct contact and a consistent NDIA planner found it easy to liaise with the NDIA and get assistance understanding the process. Others found the processes "confusing" and the system a "black box". For the majority, information about the NDIS processes and support for plan reviews came from their providers. One participant with an intellectual disability argued that change is needed at the NDIS information level regarding greater clarity of the process and in language he can understand. He experienced the language the NDIA planner used in meetings "confusing" and "unclear", as did his parents (P06). Another participant had, after an initial meeting with an NDIA planner, only had subsequent contact with a Local Area Coordinator (LAC) for plan reviews. He felt uncertain about the information conveyed from the LAC to the NDIA Planners. For this same reason of not knowing the information passed between a LAC and an NDIA provider, as well as the LAC having no "authorising power", the parent of one NDIS participant with complex needs strongly advocated to liaise only with an NDIA Planner.

- *Understanding the decisions*

For several NDIA participants the lack of understanding of rules and entitlements was exacerbated by a lack of clear reasons as to why requested supports were not granted (P06, P01) or existing funds reduced (P07). One participant described feeling "vulnerable" to NDIA making decisions without adequately consulting and considering his context, especially demanding greater support from his children. One participant described feeling "vulnerable" to NDIA making decisions without adequately consulting and considering his context, especially demanding greater support from his children. Not understanding the decisions was for some NDIS participants accompanied by a questioning of whether the NDIA planner adequately understood the individual's disability.

Another participant with a progressive and degenerative condition found the lack of understanding of his condition and therefore his needs often lead to "arbitrary arguments" (P07). Others expressed this more generally as a lack of consideration of tailoring supports to their disability, situation, and goals.

Accessing the market and services, and the appropriate fit of services

Although individuals were generally satisfied with their individual support providers, there were several concerns related to a lack of appropriate individual provider skill and understanding of either their role (for example, plan manager and support coordinator) or the disability (for example support worker understanding and training in a specific disability). NDIS Participants generally felt that they could raise issues (including support staff professionalism) and have them promptly addressed and remediated, while one interviewee escalated an issue to the NDIS Quality and Safeguards Commission.

The ability to choose (or remove) a provider was “one of the strengths” of the NDIS, a challenge was selecting providers with appropriate skill and knowledge, often seen as “trial and error”:

For a number (P01, P02, P04, P08) of interviewees, staff turnover was an issue, predominately due to the need for new staff to be trained to become familiar with their individual support needs and building rapport. For some, this training around specific individual needs was provided by family members rather than the provider, adding significant time and concern when staff turnover was experienced (P01, P07). One individual had chosen to change his providers of support workers due to both price (so he could achieve more hours to cover his needs), and to reduce the number of individual support workers entering his home daily. Another interviewee had chosen to directly employ support workers to ensure consistency of workers, have “quality, trained and experienced staff” and pay them an appropriate amount reflective of those skills to support an individual with “medically complex” needs (P07).

Several individuals were finding it difficult to locate appropriate specialist services in South-East Queensland. One male with a speech impairment was finding it challenging to find a speech therapist in Brisbane who treats adults. After having unused funding in his plan for 2 years due to an inability to find a therapist (having sought assistance from family, NDIA and provider) he was at the time of interview on 5 waitlists of 1-2 months delay each. Another individual was finding a significant delay in finding an appropriate psychologist but was unsure the reasons behind the delay. For another NDIS participant, delays were experienced to find both support workers with appropriate expertise in complex needs and a specialist speech therapist and exercise physiologist. This same individual also experienced significant delays for assistive technology, with waits compounded along the course of provider prescription, NDIA approval process, and technology availability and delivery (P07).

Consistent with the views of organisational participants, the role of the Support Coordinator was also raised as critical for some NDIA participants to be able to adequately manage their funds. Two participants had Support Coordinators in their plans, while one was applying for a coordinator to help manage the complexity of multiple services. One individual “enjoy[s] the mental challenge” of self-managing his plan, while the remaining NDIS Participants had their support primarily coordinated by a family member. One individual acknowledged the benefit of a Support Coordinator was being *enrolled straight away, just to get them going and just teach them the basics* (P02).

APPENDIX

Background to the research

Questions addressed by the Making complex interfaces work for the NDIS - Australian Research Council (ARC) Discovery Project (ARCDP190102711) include:

1. How is the work of NDIS funded supports being instituted and coordinated within local organisations and through online and offline relationships and where are the challenges and opportunities?
2. How are front-line service delivery personnel and participants adapting to the NDIS and coordinating and managing funded supports and where are the challenges and opportunities?
3. What are the features of effective disability governance for the coordination and management of funded supports across service and system interfaces that contribute to quality and sustainability of the NDIS?

Table 1 provides an overview of the mixed methods and digital research tools used to collect data across three tiers and perspectives, commencing with an organisational view.

Table 1: Study design and methods

Level of analysis	Aim	Method	Participants
Tier 1: Organisational	To map the structure of organisational relationships in the NDIS market To explore how organisations are adapting to the NDIS and coordinating funded supports	Analysis of online hyperlink relationships (completed) Semi-structured interviews (completed)	n= 216 websites n=28 managers
Tier 2: Frontline (support coordinators/personal support workers)	To explore how supports are being implemented and coordinated for participants	Semi-structured interviews (currently underway)	n=25 (18 recruited to date)
Tier 3: Participants with a funded package	To understand the experiences of participants who have funded supports	Online survey (progressive roll-out current) Semi-structured interviews (currently underway)	n=150 (estimated) n=20 (8 recruited to date)

In recognition of some of the more the complex service delivery interfaces, the project has a particular interest in coordination between mainstream health and other specialist disability services, and specifically, for those participants whose needs cross health and disability, and who live with cognitive and psychosocial disabilities.