

ORIGINAL ARTICLE

# A case study approach to understanding the pathway to individualised funded supports under the National Disability Insurance Scheme for community-dwelling individuals with acquired brain injury

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## Abstract

**Background:** The National Disability Insurance Scheme (NDIS) offers opportunity against a historical background of underfunded and fragmented services for people with disability. For people with acquired brain injury (ABI), concerns have been raised about how they access NDIS individualised funded supports. The aim of this research was to explore how community-dwelling individuals with ABI in Queensland navigate the NDIS participant pathway to individualised funded supports.

**Methods:** This study used a multiple case study design within a policy implementation framework. Twelve people with ABI, nine family members and eight NDIS funded and mainstream service providers participated. Data was collected from relevant NDIS documentation, health records and semi-structured interviews with individuals with ABI, family members, and service providers.

**Results:** The current study highlighted the complexity of navigating the NDIS participant pathway of access, planning, implementation and review for people with ABI, their family and service providers. The NDIS pathway was impacted by the insurance and market based NDIS model itself, time, communication, and the requirement for external supports. Equally, the process was affected by environmental factors, individual person and injury factors as well as service providers, with a range of outcomes evident at the individual, family and system level.

**Conclusions:** Findings suggest that the NDIS has struggled to make specific allowance for people with ABI and the complexity of their disabilities. Providing people with ABI access to the NDIS Complex Support Needs Pathway may redress many of the difficulties people with ABI experience accessing and using NDIS funded supports.

**Keywords:** Disability services; acquired brain injury; policy implementation; case study

## Introduction

In 2011 the Productivity Commission described Australia's support for people with disability as inequitable, underfunded, fragmented, inefficient and lacking choice (Productivity Commission, 2011). The response to this scathing review, the National Disability Insurance Scheme (NDIS), has been described as being among the most important social policy innovations implemented in Australian history (Mavromaras, Moskos & Mahuteau, 2016). The NDIS is a national tiered insurance scheme providing insurance (guaranteed support) to all Australians in the event of disability (Tier 1), information, linkages and capacity building (ILC-Tier 2) and long-term individualised

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funded care and support to people with a significant disability that is likely to be permanent (Tier 3) (NDIS Act, 2013).

For people with significant disabilities, it is the provision of these individualised Tier 3 funding supports that have become the predominant focus. Potential participants follow the NDIS participant pathway that includes submitting an access request, receiving the access outcome, completing a planning meeting, receiving the approved plan, implementing the plan, and reviewing outcomes. The NDIS, under the governance of its administrative body the National Disability Insurance Agency (NDIA), uses an individualised funding approach (in contrast to traditional service block funding). This shifts funding from service agencies to individuals, thereby aiming to move the design and control of individual supports from the service to the user (Kendrick, Ward & Chenoweth, 2017). As such, the user becomes a key actor in policy implementation rather than a passive recipient of services, assuming responsibility for progressing through the pathway to secure funded supports. The intention of this focus was to promote greater independence; increased social and economic participation; support provision; choice and control; inclusion, participation, certainty, rights, respect and dignity (NDIS Act, 2013).

The NDIS is still a relatively new policy yet recent evaluation suggests that many people with disabilities and their families have received life-changing supports (Mavromaras *et al.*, 2018). Equally, a raft of inefficiencies and difficulties have been uncovered that may compromise the NDIS achieving its stated objectives (Tune, 2019). Challenges predominantly emerge in three main areas, namely eligibility and access caveats necessitated by the NDIS insurance model (Carey, Malbon & Blackwell, 2021; Wilson, Campain, Pollock, Brophy & Stratford, 2021), the shift to individual funding (Blaxland *et al.*, 2020; Foster, Henman, Fleming, Tilse & Harrington, 2016), and system readiness (Foster *et al.*, 2021). Specific difficulties have been identified such as skill and knowledge deficiencies in NDIA staff (Hurley & Hutchinson, 2021); inequity in access (Cations, Day, Laver, Withall & Draper, 2021; Tune, 2019; White, Spry, Griffiths & Carlin, 2021), compromised choice and control due to administrative complexity (Carey *et al.*, 2021; Earle & Boucher, 2021; Lloyd, Moni, Cuskelly & Jobling, 2021; Mavromaras *et al.*, 2016), significant time delays in access, planning and implementation (Houston, Foster, Borg, Nolan & Seymour-Jones, 2020; Loadsman & Donelly, 2021), thin service supply (Loadsman & Donelly, 2021; Quilliam & Bourke, 2020) and poor service quality (Cortese, Truscott, Nikidehaghani & Chapple, 2021; Hough, 2021).

Importantly, the NDIS is tasked with supporting people with a broad range of disabilities and their individualised needs in order to provide appropriate lifelong supports and achieve the intended outcomes of the scheme. Acquired brain injury (ABI) is one complex disability that can impact a mix of physical function, communication, cognition and the ability to control and manage behaviour (Australian Institute of Health & Welfare, 2014). Further, ABI is recognised as the ‘invisible’ disability resulting in family, friends, services and supports often ignoring or misunderstanding its impacts (McClure, 2011). People with an ABI also experience a high incidence of co-morbidity (Xiong *et al.*, 2019), are over-represented in the criminal system (Farrer & Hedges, 2011), have very high rates of homelessness (Stubbs *et al.*, 2020) and low workforce participation (Van Velzen, van Bennekom, Edelaar, Sluiter & Frings-Dresen, 2009). Approximately 2.5% of Queenslanders under 65 years of age (those eligible for the NDIS) have been estimated to have an ABI (Australian Institute of Health and Welfare, 2007). As at 30th September, 2021 people with an ABI made up 3.5% of NDIS participants in Queensland (NDIA, 2021–2022).

Concerns regarding how people with ABI will interact with the NDIS have been identified yet there is little in the way of published research to justify or expand on these concerns. It has been suggested that people with ABI and associated cognitive impairments may not have the knowledge or capacity to understand the NDIS and its pathways (Lakhani, McDonald & Zeeman, 2018); may not manage the inherently complex administrative NDIS processes and documentation associated with accessing individualised supports (Mavromaras *et al.*, 2018); may struggle to understand and optimise choice and control in planning and implementation of plans (Fawcett & Plath, 2014;

Warr et al., 2017); may experience difficulties in communicating their needs to planners and assessors (Kendrick et al., 2017); and may lack capacity to self-manage funds and to advocate for self (Soldatic, van Toorn, Dowse & Muir, 2014). Indeed, Blaxland et al. (2020) found that only 4% and 7% of people with ABI and stroke respectively self managed their NDIS plans while only 8% and 13% respectively were partially managing their plans. These issues may be more challenging for those with recent ABI (Foster et al., 2012; Zasler, Ameis & Riddick-Grisham, 2013), those from Aboriginal or Torres Strait Islander backgrounds (Stephens, Cullen, Massey & Bohanna, 2014; Townsend et al., 2018) and those with socio-economic disadvantage (Cortese et al., 2021). They may further be complicated where individuals with ABI have little family support (Cortese et al., 2021) or where transitions are required between existing insurance or disability services (Esterman et al., 2018; Lakhani et al., 2018).

In short, concerns have been raised about the capacity of people with ABI to become the key actor and driving force in implementing such a complex policy. Stephens and colleagues (2014) argue that there is a need for additional and specialised measures to ensure equity for and across people with ABI, especially those who are already marginalised. Given the existing paucity of research, further research is urgently needed to understand how individuals with ABI access and navigate the NDIS participant pathway to individualised funded supports.

### ***Policy implementation as a conceptual framework***

*Policy implementation* as a conceptual framework considers the successes and failures of a stated policy once it is underway. While implementation is usually considered *policy in action*, another approach is to think about policy implementation as *policy becoming action*, based on the assumption that it is a messy, ambiguous and complex process that evolves through the actions of implementers (Schofield, 2004). Taking this approach, these *action actors* and the *processes* by which policy is implemented and solutions solved (Schofield, 2004) are the major concerns for research since there is an assumption that action actors know what to do (Barrett & Fudge, 1981). One of the problematic features of NDIS individualised supports for persons with ABI is that the policy now co-opts people with ABI and their families into being interpreters of policy and decision-makers whose actions (and inactions) directly impact implementation. Furthermore, it situates them in new forms of relationships with providers and planners where they are directors and treasurers of their funded supports. The involvement of a multitude of actors (people with ABI, planners, providers) makes this more complex because how they implement policy will be a function of how they interpret their responsibility, accountability and roles. Therefore, focusing on how these policy action actors understand and negotiate their tasks, responsibilities and capabilities is important in the negotiation of individualised funded supports and a key empirical problem guiding the current study.

### ***Aims of the project***

The aim of this research was to explore the pathways and processes navigated during implementation of individualised supports under the NDIS in Queensland for community-dwelling individuals with ABI using policy implementation as a conceptual framework. Specifically, the research asked:

1. How have individualised supports been negotiated along the NDIS participant pathway by the ‘action actors’ involved (people with ABI, families and providers)?
2. How successful has the NDIS been in achieving choice and control for community-dwelling adults with ABI as perceived by the ‘action actors’ (consumers, families and providers)?

## Methodology

### ***Study design and ethical approval***

Using policy implementation as a conceptual framework for the research, the current project adopted case study methods that are widely accepted in social science research (Miles & Huberman, 1994; Yin, 2003). Case studies are useful for analysing contemporary events over which the investigator has little or no control (Yin, 1994). A multiple case or cross-case study assists to explain the causal links in real-life situations that are too complex for a single data source or experiment. The study adopted a multiple case design using within-case and cross-case analysis across the various action actors (people with ABI, family members and service providers) involved in navigating NDIS processes and pathways to securing and using individualised funded supports over the period of NDIS rollout from 2016 to 2019. The study was approved by the Metro South Human Research Ethics Committee (HREC/16/QPAH/588) and conducted according to the National Health and Medical Research Ethical Guidelines (National Statement on Ethical Conduct in Human Research, 2018).

## ***Participants***

The case design focussed on the individual with ABI as each case. A convenience sample of twelve participants was recruited from clients of the Acquired Brain Injury Outreach Service (ABIOS), a state-wide community rehabilitation service in Queensland, Australia. A research team member personally invited the individual with ABI to participate after identifying that they were eligible for or accepted as a NDIS participant. Exclusion criteria were lack of capacity to consent to the research and those that were ineligible to access the NDIS because of their age. Recruitment occurred once potential participants were clients of the service and therefore clients with new (recently discharged from hospital) and pre-existing (longer-term) injuries were included. In terms of the NDIS, this also meant that some participants had already commenced the NDIS process when becoming an BIOS client while others were preparing to submit an access request. The period of recruitment was from December 2016 to February 2019.

In order to capture the complexity of ‘action actors’ involved in navigating and implementing NDIS policy for each case, a range of stakeholders were included. For each case (individual with ABI), up to two family members or significant others were included and one or more nominated community service providers (either NDIS funded or mainstream services). As part of providing consent, the individual nominated stakeholders relevant to their funding application. As NDIS funded service providers were not always identified at recruitment, participants were invited to nominate service providers at any time during the data collection process. These other stakeholders were invited to participate by telephone (or in-person if possible) and provided written consent by mail. Participants were also asked for consent to access their health record to identify significant milestones and challenges relevant to their NDIS funding application.

## ***Data collection***

For each case, data was collected from a range of sources including relevant NDIS documentation held by the individual with ABI (including individual approved plans), health service records and semi-structured interviews with individuals with ABI, family members, and NDIS funded and mainstream community providers. A combination of data sources provided opportunity to examine the evolution of policy through procedural processes and as dynamics of decision-making, negotiation and problem solving. Semi-structured interviews involved participants being asked a series of questions by telephone (necessitated by distance and consistent with the BIOS model for nonmetropolitan-based clients) related to their NDIS funding. An outline of these questions is provided in Fig. 1.

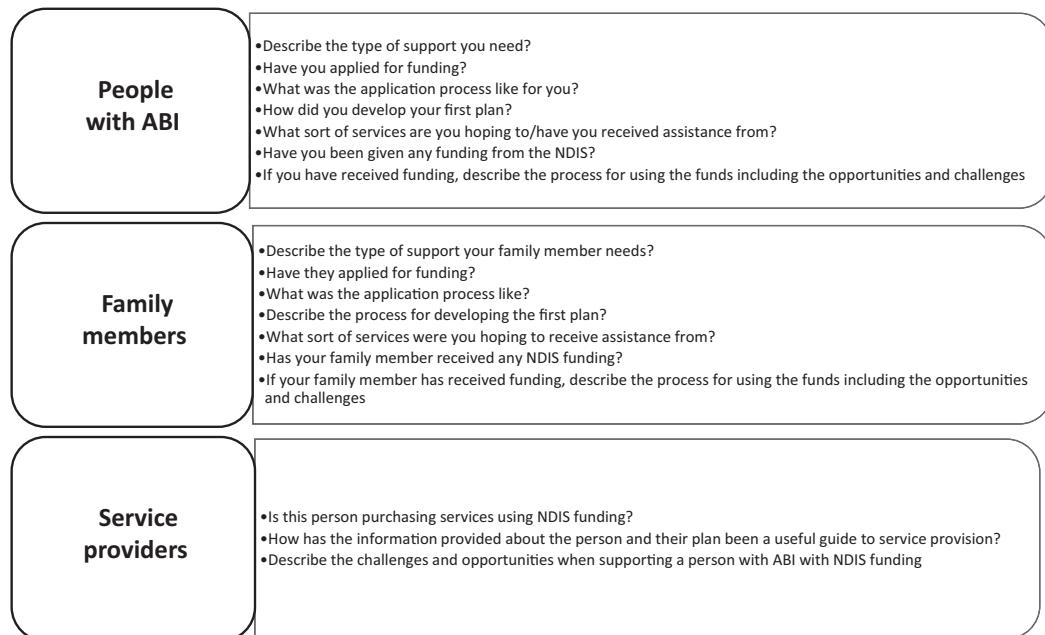


Figure 1. Interview protocols for ‘action actors’ – people with acquired brain injury, family members and service providers.

Data collection commenced in January 2017 and was completed in February 2019. Interviews lasted between 15 and 60 min as determined by the participant’s desire to express their current situation. Interviews were conducted with individual participants only and separate interviews were conducted with family members and service providers. A research team member who did not have a service role with the individual participant (no pre-existing relationship) conducted interviews. As such, all research team members (male and female) conducted interviews and all were qualified health professionals with experience in brain injury rehabilitation. All participants were aware that the interviewers were healthcare professionals employed at the ABIOS and were conducting this study to improve NDIS outcomes for people with ABI. Regular research team member meetings were conducted to ensure that consistency was being maintained across interviewers.

Interviews were initially intended to be conducted every fortnight for up to six months for individuals with ABI and every month for up to six months for family members/significant others and community service providers. The rationale for the planned data being collected in this way related to (a) an anticipated 12-week NDIS funding application process and (b) the need for individuals to have opportunity to involve services once funding was approved or declined. However, timeframes of the NDIS access and implementation process were highly variable. For some people, this process occurred much more quickly than 6 months and therefore data was collected over a shorter period. For others, this process was extremely protracted and data collection occurred over periods of greater than 12 months, albeit not on a fortnightly basis. The course of NDIS funding implementation rather than data saturation was used to determine the number of interviews conducted.

Given the sheer volume of qualitative data being collected by telephone, the internally funded nature of the project and the need for participants to feel comfortable to comment on difficulties experienced throughout the NDIS pathway, the decision was made not to audiotape interviews. Qualitative interview data was collected through field notes taken within the interview template. Regular reviews of field notes were conducted iteratively by the research team to ensure

consistency of interviewing and reporting. Demographic, injury and NDIS process information was collected in a template with data sourced from approved documentation, health records and information provided within the context of semi-structured interviews.

### **Data analysis**

Data analysis was undertaken at multiple levels both within and across cases. The first approach involved conducting within-case analysis. For each case (participant, family member and service provider), documentation and semi-structured interview data were used to create a visual timeline across the different phases of the participant pathway. Significant events, activities and influential factors identified from documentation or from interviews were then placed on the timeline.

Process tracing was used to evaluate causal links between specific events and processes (e.g., NDIS funding and implementation of a planned service). Process tracing is perhaps the most important tool of causal inferences in qualitative and case study research (Collier, Brady & Seawright, 2010; Mahoney, 2012). Using data collected across all data sources, standard tests utilised within process tracing (e.g., straw in the wind, hoop and smoking gun tests) were used to establish that a specific event or process took place, a different event or process occurred after the initial event or process and the former was a cause of the latter (Mahoney, 2012). A focus was placed on identifying how processes took place or how factors influenced the process (Beach & Pedersen, 2019). For illustrative purposes, if it was established that the planning meeting did not result in an appropriate approved plan, evidence was sought to explain how that happened (e.g., planner didn't ask the right questions, didn't record information correctly or didn't clarify their notes with the participant).

Once a clear picture of each case had been established, cross-case analysis was undertaken to make comparisons between cases. This involved comparing across timelines, examining where processes were working smoothly in one case and how that differed to another. Attention was paid to identifying individual (e.g., nature of cognitive impairments) or situational factors (e.g., rural location) that were explanatory of differences. Comparisons were also made at the action actor group level where similarities and differences were noted between people with ABI, family members and service providers to highlight discrepancies in perspective. Within and cross-case analysis was undertaken by two researchers (MK and MS).

At the coding level, data was integrated within and across cases to build a picture across the NDIS participant pathway. Explanatory and causal factors from each case were placed along the pathway and grouped semantically and linguistically by one researcher (MK). The research team then met to discuss the grouped factors. One researcher (MK) then collated the collective results of this discussion diagrammatically and in tabular form. This final analysis was taken back to the research team with each of the case study pictures and cross-case analysis for discussion, refinement and integration. The focus here was identifying how each of the case study pictures could be represented by the diagrammatic findings (i.e., did the diagram provide an appropriate representation of each case?).

### **Findings**

The staggered rollout of the NDIS in Queensland, combined with the geographical distance of potential participants necessitated a protracted period of data collection in excess of 2 years. The final sample included twelve people with ABI, nine family members and eight service providers. No individuals approached for participation declined involvement in the study and there was no drop out. Table 1 provides details on the sample and demographics. Across the 29 participants, a total of 122 semi-structured interviews were conducted, 72 of these with individuals with ABI, 35 with family members and 15 with service providers. Table 2 provides details of the participants for each case, their relationship and the number of interviews conducted for each. In

**Table 1.** Demographic and Injury Characteristics of Sample

People with ABI		N = 12
Gender	Male	5
	Female	7
Age	Range 29–66 <sup>a</sup>	
Marital status	Single	4
	Married	4
	Separated/divorced	4
Location	Metropolitan	9
	Regional/rural	3
Educational level	Did not complete high school	6
	Year 12	3
	University degree	3
Employment	Unemployed	10
	Paid employment (part time)	2
Nature of injury	Traumatic – vehicle	2
	Traumatic – other	2
	Non-traumatic (including stroke)	8
Time since injury	Less than 1 year	6
	1–3 years	1
	Over 3 years	5
<b>Family members</b>		<b>N = 9</b>
Relationship to person with ABI	Partner	3
	Parent	3
	Other	3
Gender	Male	1
	Female	8
<b>Service providers</b>		<b>N = 8</b>
NDIS funded	Yes	3
	No	5
Type of service provider	State health	5
	Direct service provision	1
	Support coordination	2

<sup>a</sup>The participant aged 66 years completed an access request prior to age 65 but entered the study at 66 years of age.

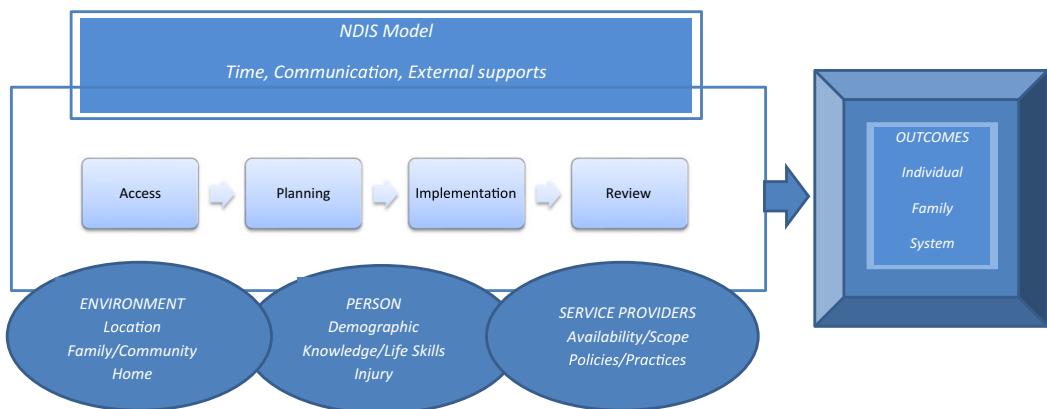
reporting individual quotes, individuals are identified by their participant number (1–12) and their participant group of clients, families and service providers (C, F or SP).

Within- and cross-case analysis highlighted the complexity of navigating the administrative journey to NDIS funded supports for people with ABI, their family and service providers. Across the recognised sequential stages of individualised funded support within the NDIS, namely access, planning, implementation and review, each case took very different pathways with varied

**Table 2.** Relationship Between and Number of Interviews per Participant

Participant ID	Participant	Number of interviews			
		Family 1	Family 2	Service provider 1 <sup>a</sup>	Service provider 2 <sup>a</sup>
1	7	2		1	1
2	5			2	
3	5			1	
4	4	9		1	
5	11			1	
6	7	6			
7	6	2	2	2	1
8	4	2			
9	5	5			
10	9			2	1
11	4	4		1	
12	5	3		1	

<sup>a</sup>Some service providers were interviewed in relation to more than one participant.



**Figure 2.** Internal and external factors along the NDIS participant pathway affecting outcomes for people with acquired brain injury.

timelines. The journey and the relative ease and success of the journey was impacted by the NDIS model itself, time considerations, communications, and the requirement for external supports. Equally, the process was impacted by environmental factors, individual person and injury factors, as well as service providers. A range of outcomes were evident at the individual, family and system level. Figure 2 provides an overview of this process.

### ***The NDIS process***

Throughout each phase of the process there were unique challenges for people with ABI. At the access phase, people with ABI and families alike found the application form itself confusing and complicated. In most instances, the person with ABI could not complete this independently and

its completion and quality depended on who did the application. '*Getting into the system is an issue. NDIS disregard a lot of information because decisions are made by people who are not qualified- the unassuming nature of ABI makes it difficult to articulate need*' (7SP1).

People with ABI identified that there was no way they could access the NDIS independently, thereby seeking support from family members, the health system and existing service providers to enable access submission and negotiate the early planning phase. '*The NDIS is over my head. I'd be stuffed without help. No one in my circle would have the time, skills or capacity to help me*' (8C). This placed enormous pressure on these external supports to do the 'unpaid' work of system navigation. '*My [ABIOS Rehabilitation Coordinator] filled out all the forms because there was lots of paper work and I was confused about it all*' (10C). For service providers, this was a large financial and workload burden. For family members, this was extremely stressful and added a further layer of burden. One family member stated that '*it's been confusing and it's hard to help when it is confusing for me too*' (9F). For some service providers, this meant they were providing services pro bono without any guarantee of future funding. In the absence of family supports, access requests and evidence gathering were solely supported by services that, as yet, had not received NDIS funding (e.g., 10C) or alternatively, individuals attempted the access request themselves, only to be rejected (e.g., 5C). Within-case analysis typically found that timelines were protracted for these individuals.

For people with ABI, providing the appropriate documentation and evidence to affix to their application was sometimes difficult, especially for those who had sustained their injury many years previously and for those whose impairments were primarily cognitive (or invisible). This often required them to revisit their specialist which resulted in time delays while waiting for an appointment or to acquire expensive neuropsychological reports. '*I had to have a medical review with the brain injury unit for my application because I had my injury a long time ago*' (10C). Several participants reported that general practitioners (GPs) often lacked an understanding of the NDIS process and the nature of evidence required for access, thereby resulting in them providing minimal or insufficient evidence to support the access request. '*It is very easy for important information to be missed in the access request that would be detrimental to the client's chances . . . it is very easy for GPs to underreport the extent of the client's disability*' (7SP1). When an initial access request was unsuccessful, participants described a back and forth process of gathering further evidence. '*I have applied three times and been rejected twice . . . I got accepted on my third application and it was a long process*' (9C).

When reaching the planning phase, participants identified that the ease with which this process proceeded depended to a large degree on the skills, knowledge and experience of the planner. '*There is no such thing as consistency in the NDIS. The only consistency is inconsistency. Every planner takes a different approach. It's just luck of the draw*' (11SP).

For those who perceived their planners listened, had some understanding of the nature of ABI and who actively involved the person with ABI and their family in the planning process, this occurred quite smoothly. For others however, there were difficulties faced when the planner lacked an understanding of ABI. '*I was in planning meeting- planner was nice but didn't quite understand stroke- was not asking the right questions*' (7F1) For example, planners might perceive that the person could physically manage the task of dressing themselves or making meals but failed to understand that supervision and support was required for them to cognitively manage this task.

Within interviews, most of the participants with ABI and their families described how the individual was not actively included in planning meetings. Even where they were present, the person with ABI often felt lost and silenced in the process and therefore had little understanding of their resultant plan. '*He lost the thread multiple times during his planning meeting and I had to prompt, provide answers and clarify. At the end of the planning session he had very little recollection of what had happened*' (3SP). Many people with ABI struggled to articulate their needs sufficiently within a planning meeting without family or service provider support.

I don't know what is available. Like an ice cream shop and don't know what new flavours there are. I have trouble identifying what my needs might be... NDIS don't care or don't have the expertise to help (1C).

In other instances, discussions that occurred within planning meetings were not perceived to translate to the resultant plan. '*The plan is too generic and things he asked for have been knocked back*' (1F).

Participants reported that planners often made assumptions about the presence, capacity and willingness of informal supports. For example, if family were present, there were assumptions that they would play a major caring role, or be coordinating supports and services.

The NDIS did try to get a family member to coordinate care, myself, my sister or mum's brother but there is too much to do- wouldn't have known where to start and there is too much in our own lives- no capacity (7F1).

Within cases where the person with ABI had sustained their injury several years ago, individuals with ABI, families and service providers identified the planning phase as painful and confronting for the person with ABI who had to either self-identify their deficits or be confronted by discussions about deficits of which they lacked awareness. Service providers clearly linked this to the deficits-based nature of access and planning necessitated for NDIS individualised funded supports. '*Because her injury was more than 5 years ago, she has grieved her losses- the need to revisit these is challenging... it was confronting*' (7SP1).

In several cases, service providers perceived the opinions and expert advice they provided to support planning for the person with ABI was not heeded or respected, diminishing the professional status of their role and requiring them to do additional advocacy work in reiterating and explaining the needs of the individual. '*Doctors and therapists who know the person and have professional responsibilities to the scheme are reporting needs that are being overruled by administrative staff who are inexperienced within the NDIA... do they think we are lying?*' (5SP).

The NDIS process became simpler for many during the implementation phase, particularly if the individual with ABI had support coordination included in their plan to take on the role of implementing and managing service providers. In some cases, however, support coordinators or service providers worked pro bono because they had not been funded yet. For those who had no support coordination, difficulties continued. '*I am not sure what I need to do... do I need to ring around services to get support... haven't been provided much direction about this. Just confused*' (4F). For others, particularly those in rural areas or those who required specialist ABI services, there were difficulties in identifying appropriate providers or accessing these services in a timely manner, especially where providers were not registered NDIS providers and had limited knowledge of how to achieve this. Some participants reported that service provider quality was lacking as was flexibility. This frequently required changing providers from those who were used prior to NDIS funding, a difficult process for the person with ABI to recognise and oversee. In general, implementation was better with plan managers, support coordinators and services that worked together to build capacity.

Having good therapeutic support is a positive- all services are needed and getting the right people has been the key so that everyone is working together... The combined effort of [service] and supports coordination is what assists clients to get through this process (7SP1).

The review phase occurred at different points for different cases. For many, a review was required to respond to NDIS plans that were not "fit for purpose" due to issues during earlier phases (e.g., no support coordination funded, insufficient care hours funded, deteriorated function during lengthy process). This meant that for some cases the review process was undertaken before

they had even used any funds to implement services. People with ABI, families and service providers all identified that a review was required more often for people with "invisible" disability compared to those with more obvious (physical) disabilities with which planners had familiarity. '*ABI is a hidden disability and there are no mechanisms to assist people. Generating good evidence is difficult particularly for cognitive and behavioural issues*' (1ISP).

### **NDIS model impacts**

The insurance and quasi-market-based focus and implementation associated with the individualised funded support process offered challenges for many cases. Service providers highlighted that the deficits-based nature of the model is problematic for people with ABI, as they often lacked insight into their disability and struggled to acknowledge, recognise and/or articulate their impairments and support needs as required throughout access and planning phases. '*The system is tokenistic, not transparent and inflexible because of the client's inability to understand*' (10SP1).

Service providers also identified that aspects of the model were not responsive to need and this resulted in change and adaption being crisis driven. One service provider reported that their client had a serious fall and had to be hospitalised because physiotherapy support services designed to prevent this were rejected in the initial plan. '*It took a disaster [for appropriate supports to be approved]*' (5SP).

Service providers were also concerned that the model adopted a 'one size fits all' approach that failed to adequately recognise the unique needs of people with ABI, and lacked the flexibility required to respond to changing and episodic needs. '*They don't account for the episodic and roller coaster ride of ABI- crises arise periodically if specialist supports are not there- the system is reactionary only*' (7SP1). What was considered reasonable and necessary for people with ABI and their families did not necessarily concur with the NDIA, and people with ABI felt that they had to fit into someone else's schedule. '*They put in roster and ring fortnightly. I don't need a roster. I only got to go to Bunnings when I need it. Now I have to plan it*' (1C).

Participants commented that the quasi-market-based model for NDIS providers created an environment where opportunistic and predatory providers, operating in competition, scrambled to lock people with ABI into service contracts, thereby securing market share. '*Since my plan has been submitted [existing service provider] have been acting like vultures- they just see money and keep trying to get me to sign agreements that were never in place before*' (7C).

Participants identified challenges communicating with planners, the NDIA itself as an organisation and with direct service providers. As one family member stated, '*the process has so much potential for breakdowns in communication- it is like Chinese whispers*' (12F). People with ABI in those cases often co-opted their service providers to manage communication. Service providers sometimes identified unresponsive or inappropriate communication from the NDIA as an organisation and with specific NDIA staff including planners. '*When he received his plan, the planner gave him a long explanation over the telephone about how to implement the plan. When asked whether he had any questions, he told the planner he didn't understand anything you said*' (3SP). Much of the written correspondence from the NDIA was perceived as too complex for people with ABI to understand. Equally, people with ABI, families and service providers felt that the NDIS web portal and internet resources were not easy to navigate.

I asked to see the plan but was told no we can't print it out but you can get it online. Get on MyGov, could not see plan. I rang them and finally got it. The plan is so subjective, it is ridiculous (IC).

Reports and decisions were regarded as difficult to interpret and personal communications that would have been more effective for people with ABI were infrequently adopted as the standard for

communication. *'I have been given a package. So much reading in it. It doesn't stick in my head. It's just words and it doesn't sink in'* (3C).

Communication underscored a broader timeframe challenge across the NDIS pathway. Cross-case analysis identified that timeframes for communication and for stepping through the process from access to implementation and review were highly variable across participants and were a key indicator of the perceived ease with which individuals received NDIS funding. *'There were significant time delays in the process. There was four months between the planning meeting and the plan being provided, despite repeated phone calls'* (3SP). Many delays were experienced in the access phase and this could have a negative influence on perceptions right from the beginning, particularly for people with ABI who often had their own challenges in time management.

I have found this very stressful . . . I feel I have virtually no control over the process . . . I am pissed off that the NDIS couldn't provide help when I needed it. They weren't there when I needed them (11C).

### ***Environmental impacts – enablers and barriers***

Both within and across cases, a range of personal, environmental and service provider factors were identified as enablers or barriers to the experience of accessing funded supports. The invisible or hidden nature of ABI was a key factor identified by people with ABI, families and service providers. This impacted the access process because the exact nature of the injury was not immediately obvious to GPs and NDIA assessors, and the planning process when planners did not fully understand the ways in which that hidden disability impacted on the daily lives of individuals. *'The planner might have had some understanding of ABI particularly the physical challenges but not sure they had a good understanding of the cognitive issues'* (4F). Cognitive impairments associated with the person's ABI also negatively impacted the NDIS process. People with ABI often expressed the fact that by the time their plan was ready to be implemented they didn't have any recollection of the planning process by which the plan was created. Equally, those with difficulties in planning and organisation related to their injury could not negotiate the complex process of access, planning or implementation. *'The NDIA has a poor understanding of brain injury, not realising the issues that people with ABI have in organisational and planning skills that are needed to develop and coordinate plans . . . the need for supports coordination is being unheard'* (5SP).

The personal environment of the individual with ABI could complicate the NDIS process on a number of levels. Where the individual with ABI lived in a regional or remote area or where they were geographically distant from their nearest NDIS office, planning was particularly impacted as it was frequently conducted by telephone instead of in-person. People with ABI described this as impersonal and hard to follow. Families described the degree to which people with ABI fatigued in the planning process and could not adequately articulate their needs through this communication channel. *'The plan was done over the telephone and took two and a half hours. If we had not been present, things would not have gone well. She couldn't answer 50% of the questions'* (6F). People with supportive family and community as well as conducive home environments were more likely to feel supported in the NDIS process. Cross-case analysis identified that those who were married, those who were younger and more computer literate, and those who were more educated, generally encountered an easier process. Individuals with financial literacy and enhanced social and communication skills were perceived by service providers as more successfully able to negotiate the complex bureaucratic and social process involved in securing NDIS funding. These skills enabled people to better articulate their needs, comprehend written and personal communication, advocate for their rights and interact with service providers. One participant with a professional background could more easily rationalise the process and therefore accepted the bureaucracy and associated delays.

I know from watching the media that this is a very big project to implement and may experience long rollout periods. I can work around the services that are in place at the moment because I can see light at the end of the tunnel (7C).

The service provider environment was either an enabler or barrier, particularly during the implementation of supports. The availability and scope of existing and new service providers was particularly influential. *'There is a huge increase in demand for ABI services but there are few services for people with ABI including supports coordination. True specialist services are overwhelmed'* (11SP). For those in regional or rural environments, generalist services were limited in number and flexibility and specialist services with understanding of the unique needs of people with ABI were absent. This often meant that while services may have been funded under a NDIS plan, these services did not exist or were underdeveloped and therefore not provided as per the plan, resulting in underuse of funds.

The client lives in a remote location and only one organisation in town was able to provide support coordination at the time... Ended up not using the vast majority of his funds as what was being offered didn't address his goals (1SP).

While the NDIS model offers a potential environment for service development and expansion, this remained limited during the period of this study.

Where services did exist, one of the major challenges for people with ABI and families were the policies and procedures of those organisations. The NDIS model was perceived to create an environment whereby service providers developed rigid contractual arrangements so as to secure long-term individual NDIS funding. Rigidity in policies and procedures was considered by participants to be counterproductive to flexible, person centred and individualised service provision.

### **Outcomes**

Generally, people with ABI in the current study who had previously been unsupported or under-supported by disability services identified the NDIS as a positive and potentially life-changing policy. Real changes within each case had occurred at an individual level for many participants that were directly attributable to their acceptance into the NDIS and approval of funded individualised supports. Despite the perceived challenges and inefficiencies identified across the NDIS participant pathway for people with ABI that, at times, compromised the stated promise of choice and control, the NDIS contributed to positive outcomes at an individual, family and system level. *'Previously my life has been humdrum. Now I have a weird feeling of support because we are getting progressive stuff done. I am getting control back'* (2C).

Each person with ABI did eventually receive an NDIS plan, regardless of the length of time until realisation or the suitability of the plan. As such, people had services and resources to support them that would not previously have been available. *'People can actually work towards goals. They are able to think about a future. It enables people to have a life. Life is so much better, people can choose where and how to live. It is a profound difference'* (11SP). These services and supports were identified by people with ABI, families and service providers alike as leading to improved functional, psychosocial and financial outcomes.

Many participants felt that they had been given hope for the future, and choice and control. *'I feel like I am finally being listened to and having a choice about what happens in my life'* (7C). For others, despite these services and resources, a number of unmet needs remained and participants were hopeful these needs could be addressed through future NDIS plan reviews. Some service providers questioned whether true choice and control was really achieved. *'The risk for people like this client is that the whole premise of choice and control is really artificial given the level of direction and guidance that is required for them to navigate the process'* (10SP2). Families, despite the

perceived stress associated with the NDIS process, experienced improved family relationships, reduced financial stress, and less carer burden as a result of the increased services and resources available to support the person with ABI. *'The wheels are in motion now and it gives us peace of mind'* (7F1).

At a system level, the outcomes were perhaps a little more equivocal. Individual level funding under the NDIS model has scope to expand the service system in ways that are more commensurate with the needs of individuals. Within urban environments, while slow to respond, there was an expanding service system and service providers identified many new providers emerging to carry the load. Reservations were identified in relation to the quality systems keeping rogue operators in check, and at the time of data collection, no clear findings emerged as to the reliability of these processes. Service providers did welcome the federal support offered by the NDIS, but reported the cost shifting between state and federal systems was problematic. *'One of the problems is the cost to state health departments in providing clinic reviews for clients to acquire evidence to support access'* (5SP).

Further to this, the boundaries between health and disability systems remained murky at times, particularly in relation to ABI where these two systems need to establish clearer interfaces. *'The delays on approval of funding equipment was frustrating because extra evidence was required by speech therapist to state equipment [CPAP machine] was not needed for a health but a speech [disability] issue'* (4F).

## Discussion

The current study represents one of the first in-depth explorations of navigating individualised funded supports under the NDIS for people with ABI specifically. Using a multiple case study methodology inclusive of people with ABI, their families and service providers and a policy implementation framework, the current study traced how this range of action actors experienced and managed a complex NDIS participant pathway through four major stages of access, planning, implementation and review.

People with ABI and families alike found the NDIS pathway process complex and confusing, requiring support to both access and implement it. Often lacking insight into their disability, people with ABI struggled to acknowledge, recognise and/or articulate their functional impairments and support needs. This challenge for people with ABI is evident in the existing literature, predicted prior to (Fawcett & Plath, 2014, Soldatic *et al.*, 2014) and experienced following NDIS roll-out (Lakhani *et al.*, 2018, Mavromaras *et al.*, 2018). Bailey, Plath and Sharma (2021) echoed the findings of the current study, highlighting the work required by healthcare professionals in providing this support.

Coupled with protracted and unpredictable timeframes (Houston *et al.*, 2020) across the process as well as variable and inconsistent communication frequency and methods, these challenges pose a real risk that people with ABI will not optimise the opportunities available through the NDIS, because it is 'all too hard'. Not only does this hinder equitable access but it also feeds frustration and confusion throughout the process. As a result, individuals in the current study required external support for access, planning, implementation and review, placing additional strain on family systems and state funded health services.

The current findings suggest that the NDIS model does not fit people with ABI, and people with ABI do not fit the NDIS model. Many participants identified poorly implemented holistic care and a 'one size fits all' approach that failed to adequately recognise the unique needs of people with ABI and lacked the flexibility required to respond to changing and episodic needs. Foster *et al.* (2016) highlighted that the implementation of 'reasonable and necessary' supports would be problematic based on allocation principles creating further ambiguities in what is already a complex policy framework. Indeed, decisional ambiguities in the determination of reasonable

and necessary supports have been realised (Venning, Hummell, Foster, Burns & Rimmer, 2021). For people with invisible or episodic disability, such as those with ABI or mental illness, these difficulties are further compounded.

The quasi-market model of the NDIS held its own challenges at both a policy implementation level and as a market driver in the disability sector. As with most deficits-based models, the model lacked spontaneity and flexibility and was at times crisis driven in its response, despite the stated missions of choice and control. The one size fits all approach to access and the bureaucratic and complex nature of individualised funded supports under the NDIS model itself was found in the current study to present unique issues for people with ABI as they attempt to access, plan and implement funding. People with ABI were particularly vulnerable to the predatory nature of providers within a market-driven model. Indeed, Kendrick et al. (2017) questioned how people without capacity or supportive networks will protect their personhood and aspirations from a market-driven service sector with competing agendas that might not have their best interests at heart. The predicted risk that the market would not deliver the required services (Fawcett & Plath, 2014) is supported by the current findings as was the predicted risk of limited corresponding growth in quality (Bigby, 2013). Furthermore, the previously identified potential for rogue operators (Stephens et al., 2014) appears to have materialised for people with ABI, placing an already vulnerable population at increased risk of exploitation. The NDIS Quality and Safeguards Commission commenced operation in Queensland in July 2019 following the completion of data collection for the current study. As a commonwealth statutory body, its role is to regulate the quality and safety of NDIS supports and services. From July 2019 to June 2020, the Commission received 4469 complaints with 1049 of these originating in Queensland (NDIS Quality & Safeguards Commission, 2020). Future research is required to explore how the Commission can protect people with ABI as a vulnerable population.

When we consider the implementation of NDIS individualised funded supports within a policy implementation framework, the action actors, inclusive of their environmental contexts, become integral to understanding (Schofield, 2004). The current study found that a range of environmental factors, unique to those who interact with the NDIS as influential on the process. Influential personal contexts were inclusive of injury, demographics, locality, family/community and home environments. Service provider systems inclusive of availability, scope and practice were also potential enablers or barriers to the NDIS participant pathway. These factors influence not only who interacts with the NDIS, but within which context and with what backgrounds. These factors also influence how action actors interpret their role in the implementation of policy that is purported to offer choice and control over operational details. As Barrett & Fudge (1981) proposed, there is an assumption that implementation actors know what to do. The current findings suggest that this is far from the reality. People with ABI do not understand their role in the process and families attempt to assist but are equally bemused. Service providers attempt to provide advocacy but are often interacting with a system that fails to recognise their expertise. Planners are reported to have little understanding of ABI and therefore struggle to implement policy in ways that optimise choice and control. Wilson et al. (2021) found that the options for choice and control along the NDIS pathway are adversely impacted by personal, programmatic and market barriers for people with psychosocial disability. Indeed, participants in our study reported that outcomes were dependent to a large degree on the skills, knowledge and experience of the NDIS planner, and that planners often lacked clinical skills, did not interact with them on an individual level, and did not always heed advice from other carers and service providers. Plan flexibility emerged as key to achieving choice and control but a lack of clarity surrounding the timeframes for review was highlighted.

There were definitely challenges inherent in the implementation of such a significant policy on a national scale and a number of specific issues experienced by people with ABI, families and service providers in accessing and utilising individualised funded supports. However, the current study found that when individualised supports were adequately funded, commensurate with the

unmet needs of the ABI population, the NDIS offered opportunity, promise and hope for the future. Furthermore, a strategic network of supports were fostered that could build the capacity of people with ABI and the sector to move forward. This represents a major step forward for people with ABI and should not be lost as we identify, plan and implement strategies and supports to improve the implementation of individualised funded supports under the NDIS.

### ***Implications and recommendations***

The current study provides evidence to suggest that changes could be implemented to improve the NDIS participant pathway for people with ABI. Collectively, our findings suggest that the NDIS has struggled to make specific allowances for people with ABI and the complexity of their disabilities. This is akin to neglecting to have audio descriptions for the blind or accessible facilities for those with reduced mobility. In 2019, the NDIS implemented the Pathways Program in an attempt to improve the experience of accessing funded supports (NDIA, 2019). Within the Pathways Program, there is a strategy that would respond to the issues identified in this study, namely the NDIS Complex Support Needs Pathway (Henderson, 2018). The pathway is intended for people with complex needs who are expected to require a higher level of assistance to navigate the NDIS. Criteria suggested for requiring this additional support include: involvement in other government service systems (e.g. health, mental health and justice); multiple diagnosis/clinical complexity; insufficient support to assist with decision-making; and complex behavioural support needs. These criteria are typical of people with ABI and have been highlighted through the current study. The pathway includes six key features to deliver better outcomes: pre-access support; strengthening engagement with other services and supports; specialised planners; planning with participants and other stakeholders, focused on ensuring deep understanding of participant life circumstances; skilled Support Coordinators; ongoing monitoring and evaluation; and plan reviews that measure participant progress toward outcomes. As such, a key recommendation of the current study is that people with ABI are made eligible for support through this pathway. It is through this pathway that the key policy imperatives of choice and control may finally be realised for people with ABI. Future similar research is needed to explore how these recommendations may apply to other populations who experience similar issues with navigating complex government systems such as people with other psychosocial and cognitive impairments.

The current study, while providing insight into the NDIS pathway for people with ABI, their families and service providers, had several limitations that must be considered in interpretation of the findings. The study utilised a convenience sample. While there was considerable diversity across the sample by chance, a theoretical sampling approach may have been more appropriate. Interviews were not audio-taped due to financial constraints and multiple interviewers were used to conduct interviews so as to ensure that interviewers were not also service providers to individual participants. Consequently, the study relied on the accuracy and consistency of field notes collected across multiple sources. This may have had negative implications for the quality, depth and validity of the data although rigour checks were put in place iteratively throughout the project to monitor and improve interviewer consistency.

### **Conclusion**

The availability of individualised funded supports under the NDIS offers opportunity and hope against a historical background of underfunded and fragmented services. Using a policy implementation framework, the current study highlighted the complexity of navigating the NDIS participant pathway for people with ABI, their family and service providers across access, planning, implementation and review. This process was impacted by the NDIS model itself, time considerations, communications, and the requirement for external supports. Equally, the process was impacted by environmental factors, individual person and injury factors as well as service

providers. A range of outcomes were evident at the individual, family and system level. The findings suggest that inclusion of people with ABI in the NDIS Complex Support Needs Pathway may address some of the challenges encountered by people with ABI, offering real choice and control.

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**Ethical standards.** The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

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