Responding to Complexity in the Context of the National Disability Insurance Scheme

Kirsty McKenzie and Jennifer Smith-Merry

The University of Sydney, Centre for Disability Research and Policy, Sydney School of Health Sciences, Faculty of Medicine and Health, Sydney, New South Wales, Australia

* Email: jennifer.smith-merry@sydney.edu.au

Background: Personalisation in disability support funding is premised on the notion that services come together through the individual. Where people have very complex needs, many individuals and their supporters find it difficult to facilitate services themselves. This article examines the Integrated Service Response (ISR), an Australian response to complexity implemented during the National Disability Insurance Scheme (NDIS) roll-out. We explore its facilitation of collaboration in the context of the NDIS. Results: Results from interviews and observation of collaboration suggest there are multiple challenges with effective inter-organisational collaboration under the NDIS, including communication between services, and the loss of previous ways of addressing complexity and crisis. Participants valued ISR as a response to complexity, including its ability to facilitate collaboration by ‘getting the right people at the table’. Conclusions: While programmes such as ISR may improve inter-organisational collaboration around specific clients, broader ongoing systemic approaches are required to address system-wide issues.

Keywords: Disability, personalisation, integrated care, complex needs.

Introduction

Since the 1990s, there has been an increased emphasis internationally on personalisation in disability support provision. Replacing funding systems where organisations apply for funding to provide services, disability support schemes have emerged which provide individuals with budgets to purchase their own care. This shift is in part a response to the independent living movement (ILM) which argued against models of care which were seen as paternalistic (Dodd, 2013; Edwards, 2019). One such scheme is the Australian Federal Government’s National Disability Insurance Scheme (NDIS) which began in 2013 and reached full country-wide scheme rollout in 2020. The NDIS is in part a response to Australia’s obligations under the United Nations Convention on the Rights of Peoples with Disabilities (2006), which reframed disability support within a human rights approach (Wilson et al., 2022) and emphasised ‘respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons’. As such, the NDIS emphasises personalisation through choice and control as key to its design. However, within schemes such as the NDIS, personalisation sits at the intersection of discourses of autonomy and choice and market-based approaches to service provision. The NDIS market-based model provides people assessed as eligible for the scheme with individual budgets matched to their support needs (based on the NDIS funding criteria,
e.g. no health-related supports). Participants may use this budget to purchase relevant services from providers. ‘Choice’ under the NDIS model is therefore the right to choose from available services within a market, with some arguing that the original emancipatory goals of the ILM have been co-opted by a neoliberal agenda which sees ‘disabled people as consumers of services and competitive markets as providing the answer to their problems’ (Edwards, 2019: 53). Furthermore, while a neoliberal agenda of consumer participation in competitive markets has characterised disability service provision in many countries (Dodd, 2013; Carey et al., 2018), in Australia market-oriented personalisation is the only avenue through which people with disabilities can access many services. This differs from other countries (e.g. the United Kingdom) in which individuals may opt-in to personalised approaches to service provision (Carey et al., 2018). The market-based approach to service provision has been heavily critiqued, as markets may not provide needed services, and individuals may not have the requisite skills and resources to exercise choice (e.g. David and West, 2017; Cukalevski, 2019; Spivakovsky, 2021; Wilson et al., 2022). In addition, personalisation and choice-making may be less effective for those with complex support needs (Wilson et al., 2022).

Dowse and Dew (2016: 129) define complexity as the ‘intersection between an individual with a high level of need in one or more areas and across multiple domains, and his or her environment including services and the systems underpinning them’. Systems may be more or less capable of coordinated responses, where care coordination refers to shared communication and actions between providers, people with disability and their families and supporters (Green et al., 2018: 5). However, collaboration is a process which must be deliberately engaged in, and this may be more difficult where individuals have needs in multiple domains. Those people may be especially at risk of not having their needs met in contexts where there is poor coordination between different service providers or service fragmentation due to lack of effective collaboration or integration within the service system (Harvey et al., 2017; Altman et al., 2018; Breen et al., 2018; Mundy and Hewson, 2019). Collaboration and integration, although not synonymous, both involve a focus on shared understandings and goals between individuals and/or organisations, and deliberate organisational and systemic work practices such as information sharing (Andreassen, 2019). In an integrated system, these arrangements may be more formal, and include clear protocols for coordinated service provision between organisations, and formalized statements of goals and joint service agreements between organisations (Breckenridge et al., 2015). Andreassen (2019) has argued that information sharing and joint action between organisations can be particularly hindered where there are multiple systems and differing approaches and agendas.

Personalisation is based on the premise of system coordination through the individual and ideally by the individual. However, fragmented systems may be ‘too complex’ for individuals to navigate (OECD, in Breen et al., 2018). While the number of people with complex support needs may be relatively low as a proportion of the entire population, service sector time and costs for supporting these needs are high (Goldhar et al., 2014; Nurjono et al., 2019). Systemic complexity and fragmentation may also mean providers working with such clients are unable to effectively address client needs that span several services. Without effective service system responses, clients may be at risk of homelessness, incarceration, or other negative outcomes (Joubert and Power, 2005). Addressing complexity should therefore be a priority in the implementation of the NDIS. Examining specific local responses to complexity within the context of personalisation may offer valuable insight into how best to address such issues.
This article examines the Integrated Service Response (ISR), a local response to complexity implemented in New South Wales (NSW) Australia during the roll out of the NDIS. The programme aimed to improve outcomes for individuals with complex support needs and increase inter-organisational collaboration during NDIS rollout where existing support systems were transitioning to the new ways of working. The ISR was independently evaluated by a research team from The University of Sydney and Deloitte Access Economics. This article draws on one part of the ISR evaluation – findings from semi-structured interviews with ISR staff and stakeholders, and observations of ISR collaboration workshops – to gain insight into how the introduction of personalisation under the NDIS impacted effective collaborative practice, and how ISR operated as a response to complexity by building collaborative practice around a client. The following specific research questions were addressed:

- What difficulties do service providers face with inter-organisational collaboration since the inception of the NDIS?
- How did the ISR model facilitate collaborative practice?
- What are the barriers to service provision for individuals with complex needs?

Complexity in the context of the NDIS: the need for ISR

Systemic problems associated with addressing complexity are not new. However, the system changes involved in the shift to the market-based service model of the NDIS in Australia created additional service system complexity. For example, Green et al. (2018) have argued that the marketisation of services under the personalisation model of the NDIS has reduced collaboration and increased competition between organisations, which is accompanied by reduced trust and information sharing and a concomitant reduction in effective coordination of care. This has also been seen in recent surveys of the disability sector (e.g. National Disability Services, 2021). In addition, in some areas there has been a loss of previous ways of managing complexity at a systems level. For example, in NSW the Department of Ageing Disability and Home Care (ADHC) had responsibility for case management of clients with disability and complex support needs, and operated as a provider of last resort. With the introduction of the NDIS, the department was disbanded. There is now no organisation with final responsibility for supporting people with complex needs in crisis situations and capacity to coordinate care across multiple service providers. In addition, programmes such as Partners in Recovery (PIR), previously funded nationally by the Federal Government to facilitate inter-organisational collaboration and support for people with complex psychosocial needs, were disbanded.

In place of these previous ways of managing complexity, and in line with a shift to personalised budgets, are approaches based on coordination through the individual. However, individuals may lack capacity or effective family support to manage the coordination of their disability support. Under the NDIS, individuals may receive assistance from a support coordinator to coordinate and access services. Support coordinators are funded through an individual’s NDIS plan as an allowable expense where they are deemed necessary to meeting an individual’s needs. One of the roles of the support coordinator is to ‘plan in advance for potential crisis situations’ (NDIS, 2021), but as individuals working outside of government, they often lack capacity to mobilise other organisations for crisis intervention. Support coordinators do not have the power to compel providers to collaborate or to take on clients. In addition, not all services required
by an individual will be funded as part of an NDIS plan, which necessitates integration across service providers and systems, making effective collaboration essential. However, collaboration itself is not funded under NDIS funding rules, meaning that support coordinators cannot use funds from a client’s plan to bring relevant services together or to attend inter-organisational meetings. Green et al. (2018) have noted that the lack of funding for collaboration is likely to further limit the capacity for effective care coordination. This means that people with complex needs can sometimes become stuck in risky or costly situations which neither they nor their existing service providers can easily address.

The Integrated Service Response

ISR was a time-limited (2017–2019) government initiative that aimed to coordinate wraparound support for people with disability and complex support needs, whose wellbeing was threatened by risk of a crisis. ISR aimed to facilitate collaboration between relevant NSW Government agencies, the National Disability Insurance Agency (NDIA – administers the NDIS), and service providers involved in the care of people with disability to address these complex support needs. A memorandum of understanding (MOU) was signed by the Secretaries of NSW Government agencies which may be involved in supporting people with disability and complex needs, and the NDIA provided written support for the operation of ISR. The ISR team comprised the programme director, ISR facilitators, and a data analyst, and was governed by an Implementation Steering Committee made up of senior NSW Government agency staff and NDIA representatives.

Clients could be referred to ISR if they were a NDIS recipient or likely to be eligible for the NDIS and at risk of crisis, required assistance from more than one service provider, and local options to resolve the client’s issues had been exhausted. For referred clients who did not meet this threshold, information was provided to referring organisations to assist with their own resolution of client needs. For those clients accepted into the programme issues included, for example, placement breakdown, transition from custody or inpatient care, families struggling with escalating behaviours of concern in children or adults, and transition from youth to adult services. To illustrate the nature of ‘complexity’ under the NDIS, a typical ISR client is described in Figure 1. This is entirely fictional and is not based on any real case, but shows the level of complexity and risk experienced by ISR clients.

For accepted clients, ISR was a three-month intensive facilitated process, including background information gathering about the client, and a four-hour face-to-face ‘pop-up’ workshop involving relevant stakeholders from across relevant sectors. Workshop processes included discussion of the client information to gain a comprehensive and consolidated perspective on client needs, and development of an immediately implementable action plan (with confirmed responsibilities and timeframes). Planning for future potential crises was also in scope. Clients consented to the ISR process – however, they were not present at workshops and had no other direct involvement in the process. ISR had no funding to assist clients to access services and was not a crisis referral service. Instead, it operated by finding capacity for action within existing service systems, with the MOU providing authority to facilitate active collaboration between organisations. While providing a service to improve outcomes for clients with complex needs ISR was also explicitly tasked with improving service system capability for this client cohort; and had the capacity to inform government about systemic issues via the programme Steering Committee, thereby contributing to broader policy change.
In the ISR workshop stakeholders were supported to identify and work towards meeting the needs of an individual client. Workshops typically began with team-building exercises, discussion of collaboration, and identification of roles and responsibilities. The team then focussed on identifying the ‘predictable future without change’ for the client (i.e. risks to the client and community if nothing changed). It then moved on to building a ‘new vision’ for the client and allocating who could do what to attain this vision (including identifying gaps). The aim of these activities was to develop a collective (inter-organisational) view of client needs, and a coordinated action plan. At the end of the workshop, one workshop attendee would take on the role of team leader going forward, and would take oversight of ongoing collaborative practice and organise ongoing meetings. These meetings continued to implement agreed coordinated actions and put in place collaborative strategies for future potential crises beyond the engagement of the ISR team. The ISR intervention concluded with a closure meeting, usually three months after initiation, where members discussed progress and ongoing issues. Teams could continue to meet after this point, without facilitation from ISR.

The ISR was implemented to address complexity stemming from both system and client needs. In this article we examine this complexity, including how the context of personalisation under the NDIS influences system complexity, and provide insight into how the ISR programme model was designed to address this complexity.

**Methods**

The data this article draws on are from semi-structured interviews with ISR staff and stakeholders, and observations of ISR workshops. This data set was collected as part of an evaluation of the outcomes of the ISR programme focussing on how successful ISR was in: meeting its objectives to improve outcomes for referred clients; facilitating integrated working within the broader system; and helping to address systemic issues. As outlined above, this current article focuses on how ISR operated to facilitate collaboration for clients with disability and complex needs, and does not address these broader programme evaluation results which will be reported elsewhere.
Participants and recruitment

ISR staff and stakeholder interactions were observed at six workshops and three closure meetings. Workshop participants were given a brief presentation about the evaluation at the beginning of workshops or closure meetings and given a consent form. In the event that an attendee did not consent, no notes were taken about them. Consent was obtained from thirty-one participants who attended a workshop or closure meetings.

Thirty-one interview participants were recruited via an email from ISR with interested participants contacting the researchers directly. Participants were fourteen senior representatives from NSW Government agencies and steering committee members; fourteen stakeholders (including the NDIA and government and non-government service providers) from pop-up teams and workshops; and three ISR facilitators.

Data collection and analysis

Ethics approval was gained from the University of Sydney Human Research Ethics Committee. Interviews were semi-structured, recorded and transcribed. They focused on the interviewee’s involvement within the ISR process and opinions of ISR effectiveness and need. Observational data were derived from notes made at pop-up workshops and closure meetings on the following topics: identified client and system problems and suggested solutions; body language, emotional expression, and engagement of participants; side-conversations and interruptions; and how the facilitators responded to issues raised by participants and managed conversation.

Qualitative data (observation notes and transcripts) were analysed using NVivo 12 by the researcher who conducted the interviews and observations (KM), using an iterative thematic analysis approach described by Braun and Clarke (2006). Following this method, data were read and reread to gain a sense of overall emerging issues and with the aims of the research in mind. Each transcript was then coded line by line to identify similar concepts, ideas and patterns in the data. Attention was also given to whether there were any deviant cases (uncommonly expressed ideas) that might be important for the study. Once an initial set of codes was derived, these were grouped into themes. To ensure that the data reflected the views of participants and were not overly simplified, emerging themes were then checked against the transcripts as a whole. After the themes were finalised, they were developed into a narrative, which both explained the themes and provided evidence from the data in the form of quotations that exemplified the themes. Throughout the process, KM discussed emerging themes with another research (JSM) and kept notes of her own emotional reactions and used these to reflect on and explore emerging themes. The themes presented in the results reflect those themes relevant to the aims of the article to discuss how ISR operated as a response to complexity in the context of the rollout of the NDIS.

Results

Collaboration in the new world of the NDIS: who you get on the day

The idea that people were trying to navigate the ‘new world’ of personalisation and a market-based disability support sector came up repeatedly in workshops and interviews. Participants characterised this new world as one of confusion, fragmentation, and the loss
of previous ways of working with clients with complex needs [P02, P04, P06, P07, P09, P10, P11, P12, P13, P14, P18, P19, P20, P21, P24, P26, P27, P28, P29, P31]. Some participants described this in terms of increased workloads and the need to ‘go above and beyond’ or work outside the scope of their role to get outcomes for clients [P01, P04, P10, P15, P17, P18, P20, P28, P31].

We gave all of that [funding] away to the Commonwealth... and then at some point in time someone said hang on, there’s a whole lot of functions that we used to do that we’re not doing any more ... So, we then had to reinvent ways of doing things that were done for us before by ADHC because no-one stopped to think about what things wouldn’t be provided back to us by NDIS (P21).

Participants also expressed considerable difficulties in working effectively with other government agencies and service providers [P03, P04, P05, P07, P08, P09, P16, P17, P19, P24, P26, P28]. Service system fragmentation meant that even identifying who to talk to could be time-consuming and frustrating.

I have a bunch of different contacts in [the organisation] but then they all go oh, that’s not me, that’s not me, that’s not me... It’s really difficult to know who to speak to. There’s no list (P19).

Participants described systems for inter-organisation communication that sometimes operated effectively, but were often ad hoc and dependent on whether people already had a contact in another organisation [P03, P04, P05, P06, P07, P09, P27]. A pop-up workshop participant observed that getting the required information could come down to whether that person ‘was there on the day’. Difficulties with effective inter-organisational working were perceived to be exacerbated under the NDIS, which had led to service providers working in silos, or feeling that their organisation was working alone to support clients with complex needs because other organisations did not want to be left with full responsibility for the client [P01, P02, P04, P07, P08, P11, P13, P14, P16, P18, P19, P20, P21, P28, P31]. These issues were seen to cause increased risk for clients.

Enabling collaboration

Given the issues with inter-organisational collaboration identified in the preceding theme, the majority of participants indicated that there was a need for a programme such as ISR to facilitate effective collaboration and communication. Many specifically argued that ISR should continue beyond its funding period because of the ongoing and unchanging need for such a programme in the context of the NDIS [P01, P02, P03, P04, P07, P08, P09, P14, P15, P19, P21, P24, P26, P29]. Participants valued ISR because they could facilitate communication with other organisations in a context in which they could not do so themselves [P01, P04, P07, P09, P10, P12, P13, P14, P15, P17, P19, P21, P24, P26, P27, P28, P31], and many suggested that client outcomes would have been impossible without ISR involvement [P01, P03, P07, P13, P14, P17, P19, P20, P21, P24, P26].

They’re invaluable. On a case by case, individual by individual basis, they are incredibly important... Because they are the only way at the moment that we can have any inter-agency interaction... It’s just I cannot describe to you how difficult it is to try and navigate to disability and other social services systems across the state (P07).
For some [P01, P07, P09, P13, P14, P15, P18, P19, P26] this was expressed in terms of ‘clout’. There was a perception that ISR ‘were able to use a level of clout that individual agencies like ours aren’t able to exert’ (P14), and could ‘nudge organisations to come to the table’ (P09); and ‘keep people accountable and . . . involved’ (P13). Participants felt that ISR was appropriate ‘if you have a service that totally refuses to engage’ (P18). While participants described the operation of the ISR in terms of ‘clout’, ISR staff themselves talked about the MoU as providing capacity to bring organisations together and be ‘direct and directive’ in asking for someone to represent the organisation at the workshop. However, some participants questioned whether ISR actually did have this capacity, and expressed disappointment that they could not make particular organisations attend meetings or participate in the process [P02, P05, P06, P16, P21]. It is worth noting here that the MoU did not extend to private service providers – however, the primary concerns expressed by these participants was non-engagement from certain government agencies.

**Integrating collaboration: (not) supporting people to work with each other**

There was considerable evidence that participation in ISR workshops and pop-up team meetings was not easily integrated into existing workplace practices for some service providers. For example, interview participants described the four-hour workshops as ‘arduous’ (P06), ‘a barrier for our staff’ (P07), ‘expensive’ (P16) and ‘onerous’ [P20]. Furthermore, during the workshop observations some stakeholders were unable to attend workshops due to staffing issues in their organisation, arrived late, or had to leave early. During the workshops, one service provider refused the role of team leader because she indicated that her manager would not allow it. Another workshop participant had been directed by a manager not to attend the workshop. For this participant, collaborating to generate solutions to client problems in effect meant ‘breaking the rules’ by acting outside of their usual role (Pop-up workshop observation). This shows that in some organisations there were barriers to, or sometimes little or no support for, staff participating in collaborative practices.

During interviews, some participants reflected on the organisational barriers to collaboration within workplaces, where workshop participants might take from the workshop new ideas or ways of working that would be difficult to implement in their workplace because of existing workplace structures [P07, P10, P12, P13, P14].

I just think the reasons why these teams don’t [collaborate] aren’t because people don’t want to, or people don’t know how to – a lot of the time it’s because their work conditions, or their workloads, prevent them . . . the way in which the workplaces have been established make it really difficult (P07).

The idea that collaboration is not part of normal work practices was raised by ISR facilitators and other interviewees in the context of the need for a top-down response to give ‘people permission to work with each other’ (P13).

**Collaboration in an already ‘stretched’ system: doing differently or going above and beyond**

As noted above, interview participants described the new world of the NDIS as one where they had to operate outside their normal roles and ‘go above and beyond on a daily basis’
because collaboration did not fit within the new way of working or funding under the NDIS. ISR’s relationship to this discourse of going above and beyond is complex. ISR did not have access to dedicated funds to broker solutions for clients (e.g. accommodation solutions). One interview participant described how, in this context, all ISR could do was ask other organisations to ‘maximise whatever they’ve got’ – for example, by ‘talking accommodation providers into taking a difficult client’ but also engaging with government agencies to provide additional training to staff to support clients more effectively (P09). Pop-up workshop facilitators suggested that funding provided under the NDIS created opportunities for a client that they had never had before, and the workshops explored ways to use, maximise, or renegotiate a client’s individual funding under the NDIS to achieve better outcomes. In addition, the pop-up workshop processes aimed to facilitate inter-organisational collaboration around a client, with a focus on finding capacity within the existing service system, rather than asking staff to do more, or go beyond the scope of their roles. However, there was some evidence that service providers experienced their involvement with clients with complex needs as requiring them to either work outside the scope of their normal role or do work for which they would not be remunerated. This was mentioned in interviews [P04, P09, P11, P15, P18] and was evident in pop-up workshops, where participants described ‘doing it for the love’; ‘not billing all the hours’, ‘doing more than [I] normally would’; and doing things that ‘we aren’t supposed to [do]’ to achieve outcomes for ISR clients. A significant issue raised repeatedly at pop-up workshops was that some provider staff were not remunerated for attending. This was because some organisations are wholly dependent on NDIS funding, as the NDIS model will only pay for those items of care or support that are able to be claimed in a client’s budget and, as discussed above, does not fund collaboration activities. In several instances ISR facilitators thanked those attending the workshops for their willingness to ‘go above and beyond’ – however, they also recognised the issues associated with asking people to do work that was ‘not factored in’.

Collaboration across the service system: (not) starting from scratch every time

Beyond the resolution of issues for referred clients, one of the other goals of ISR was to improve service system capability including inter-organisational collaboration across the sector, and specifically to develop new capacity and capability within local service systems to deliver wrap-around, multi-agency, person-centred supports. Interviewees also endorsed this role for ISR [P03, P13, P19, P20, P30]. Collaboration was built through developing relationships with specific people in other organisations, but also knowledge of what organisations could offer clients. However, some participants also questioned whether ISR would lead to system-wide improvements in collaboration [P01, P07, P21, P26, P31].

So, they get involved for a limited period of time on a particular case with a particular group of people. Now, they may establish really good collaborative practice around that case with those people, but it’s very, very specific. The idea that that piece of work is then going to come somehow to [change] the broader public service and everyone is going to start working together more effectively as a result of this process is perhaps a little bit optimistic (P21).

Another participant commented that ‘we’re starting from scratch on each and every occasion. We don’t seem to be starting from any higher level of agreement or
understanding.’ (P31). For these participants, there was little experience of increased collaborative practice beyond the programme, although this was seen as centrally important across the sector. It may be that these individual participants in the ISR process were not in a position to be able to see broader change because their interactions with ISR were isolated to one client. ISR did in fact have broader influence on systemic issues through government discussions around the gaps revealed (P01), as discussed below.

Beyond client-centred collaboration: revealing the gaps

For some participants the real value of ISR was not just that it facilitated client outcomes through collaborative practice, but that the ISR process revealed the gaps for clients with complex needs that could not be addressed even through appropriate collaboration [P09, P12, P13]. For P09, a main issue lay with personalisation as a guiding framework. Under the NDIS, clients:

...can’t opt out of self-governance... [T]hese people have an extra layer of risk because the NDIS fundamentally doesn’t acknowledge these people exist in the system... [ISR] shone a light on the complexity of the system when someone can’t self-govern (P09).

With respect to systemic issues, ISR had the capacity to inform higher levels of government about such issues via the Steering Committee. This was outlined at workshops whenever an issue was raised and was a process valued by participants. For example:

ISR should be informing NSW government about areas of best practice. They should be forcing [government departments] to be looking at their practice and how they work with [this client group]. So I’m hoping it also has an influence on how the New South Wales Government works, and the day to day service of working with difficult and complex [clients]. (P01)

However there was some evidence that participants were not aware of this, did not perceive that it had any long-term impact or, more generally, that they wanted ISR to do more to address systemic-level issues as well as individual client needs (e.g. P04).

Discussion

This research aimed to understand the problems with inter-organisational care faced by service providers working with clients with complex needs since the inception of the NDIS, and how ISR operated to facilitate collaboration in this context. The findings presented here indicate considerable problems with effective inter-organisational collaboration to support individuals with complex needs in the new world of personalisation. These results accord with other research and programme evaluations (e.g. Malbon et al., 2019a; Marathon Health, 2020). These problems are not new to personalisation, pre-dating ISR with the same concerns giving rise to programmes such as Partners in Recovery (see below), but personalisation via the NDIS compounds these existing issues because of the introduction of a funding model which results in competitive quasi-markets and the loss of coordinating government agencies such as ADHC in NSW.
Personalisation is based on the assumption that collaboration occurs through the individual and that the individual is essential in the process. The existence of programmes for addressing complexity such as ISR implicitly problematises this assumption because they do not engage with the person with complex needs directly; however, they are arguably critical to the effective operation of the NDIS as a personalised scheme that recognises complexity by solving problems of coordination not able to be addressed by the scheme architecture itself. ISR thus served an important role by setting up the external framework for problem solving and collaboration necessary for personalisation to take place. Ideally, an individual with complex needs would enter a system where there are already effective processes in place for inter-organisational collaboration, but this has not been the case under the NDIS (Malbon et al., 2019b) and programmes such as ISR have been needed to fill this gap.

The ISR is only one of a number of responses to complexity that have operated in Australia. Others include Partners in Recovery (PIR), which was a federally-funded programme designed to improve coordination of care for people with severe mental illness. It was implemented in 2013 and gradually defunded with the roll-out of the NDIS. A more recent programme was the Exceptionally Complex Support Needs Program (ECSN), which targeted a very similar client cohort to ISR, and was funded by the NDIA for two years from 2020. ISR had similarities and differences with these programmes that shed light on ways of managing the key tensions between personalisation and collaboration. Within the PIR and ECSN programme models, there was a focus on assisting individual clients with their needs, but also building collaborative practice and stakeholder relationships independently of any specific client. For example, PIR funded support facilitators, who worked directly with clients to identify their needs and broker required services, but also formed relationships within the broader service sector including through participation in existing inter-organisational forums and developing local ad hoc networks (Smith-Merry et al., 2015). Furthermore, PIR also had provision for a dedicated coordination ‘boundary spanner’ (Brophy et al., 2014) or network manager (Henderson et al., 2019) role separate from the support facilitator. This role was aligned with the need to generate system level change and was a key feature of the success of PIR. Similarly, ESCN focussed on enhancing systems-wide collaboration independently of specific clients through activities such as stakeholder workshops (NDIS, 2019; Marathon Health, 2020). Like ISR, these roles and activities sought to provide the collaborative practice framework, or systems architecture, for personalisation. However, in the ISR model, the key mechanism through which collaboration was facilitated was through facilitated workshops focusing on solving client issues related to risk of crisis. Our results suggest that while approaches such as ISR enhance collaborative practice and stakeholder relationships may be useful, they are not sufficient to overcome the widespread issues with collaboration in the sector. These problems need to be taken up at the systems level.

A related issue is that of the involvement of the client in responses to complexity under personalisation. The PIR support facilitator was a dedicated role which worked directly with clients to broker services to meet their needs. However, under both ISR and ESCN, there was no direct contact with the client (although ISR staff did provide mentoring and other support for service providers and support coordinators working directly with clients). In the ISR model, collaboration happens around a specific client who is referred to the programme, and is centred on their needs, but ISR itself lacks the key properties of
personalisation under person-centred care frameworks – of direct involvement with the individual to gain their views on decisions made about their care (Clarke in Riste et al., 2018; Green et al., 2018). ‘Nothing about us without us’ is absent from the ISR operation matrix apart from initial client consent for involvement. As discussed above, ISR processes incorporated information gathering about the client, which was shared with workshop participants to ensure that all relevant organisations had an accurate and comprehensive picture of the client; and identification of who had responsibility for specific aspects of the client’s care, as well as identifying gaps in care. The aim of this approach was to facilitate more effective engagement of pop-up team members with the client. Facilitating discussions between service providers and resolving any differences in opinion about service provision responsibilities without the client present prevented client exposure to these potentially difficult conversations between service providers and government agencies. It could therefore be argued that the ISR approach worked in alignment with the fundamental premise of personalisation as an essential antidote to system complexity when it had failed to deliver the conditions for effective personalisation. Or it could be argued that the core elements of person-centred care were irrelevant to a programme which rightly views operational barriers as residing in the system rather than resulting from the individual. The absence of the client in the ISR process may therefore reflect the instability of personalisation as the prevailing response to disability support for people with complex needs.

In our research, many service providers found addressing the needs of clients with complexity almost insurmountable without processes to facilitate collaboration. While PIR enhanced system collaboration through utilising dedicated staff and flexible funding, ISR utilised a memorandum of understanding to remind government organisations of the agreement that they would ‘come to the table’. Implicit in the rationale for the MOU is that agencies might need this higher-level endorsement of collaborative practice. Our findings suggest that participants really valued the ability of ISR to do this. This was not available under either PIR or ECSN. However, we also found that there were still tensions around whether this approach was useful in terms of achieving engagement of representative from some government agencies.

ISR operated on the premise that in the new world of personalisation under the NDIS, there is a requirement to find new ways of working collaboratively, so as to address client needs. In this sense, the programme addresses the failure of the architecture for collaboration under the NDIS. However, our research suggests that an approach that simply brings people together to collaborate around an individual client’s needs is problematic and that essential to the ISR model was the broader capacity to effect systemic change. A failure to address these broader systemic gaps effaces both the very real problems service providers face in a service system that is already ‘stretched’ to capacity, and the significant systemic issues (including lack of available services) that have arisen under the market-based approach to personalisation born of the NDIS (Malbon et al., 2019a; Foster et al., 2022). Participants valued ISR’s capacity to facilitate collaboration around a single client but they also wanted it to be clear that there were barriers to effective care that could not be addressed by this approach, and required ISR’s functions to support systemic change at a policy level. This was indeed a function of the ISR model, and participants considered the higher-level systems advocacy on barriers to addressing client needs included in the ISR model as essential.
Furthermore, the discourse of ‘going above and beyond’ was both emphasised and problematised as the means to achieve client outcomes. The ISR did not have any funding for clients, so if additional client funding was needed they asked organisations to explore if they could ‘stretch’, use existing funds differently or find funding in other parts of the system. In contrast other programmes have had direct funding for client needs, including PIR which had client specific funding that could be used to broker appropriate services (Smith-Merry et al., 2015). Questions about funding for collaboration are also an important consideration in understanding the tensions surrounding personalisation and collaboration in the context of complexity. Under the PIR model, the role of the support facilitator relied on block funding to carry out programme aims, and funding was not reliant on engagement with specific clients, thus facilitating opportunities for networking and system building (Smith-Merry et al., 2015). Under the funding model of PIR, involvement in the consortium enabled access to flexible funding for the support of clients and broader systems capacity building (Hancock et al., 2016). This funding was central to successful collaboration (Henderson et al., 2019). However, within the personalisation framework of the NDIS, there is little specific funding for collaboration: as collaboration is not funded under client NDIS plans. NDIS-funded workers may then have little incentive to participate in collaborative activities, thus limiting collaboration within this model of personalisation. The internal evaluation of the ECSN programme also indicated that a lack of funding for collaboration was an issue across the sector (Marathon Health, 2020).

ISR, PIR, and the ECSN all contributed to creating local systems more able to collaborate to address complex needs – however, significant and ongoing systemic barriers to collaboration also exist/remain/are identified (Foster et al., 2022). However, they are all no longer operational or are in the process of being phased out. PIR was terminated with the implementation of the NDIS and ISR and ECSN were both given funding only for a defined period. The reliance on short-lived programmes which focus efforts around individual client needs reinforces the idea that issues lie with the local service sector and not the broader systemic fractures which have increased with the NDIS approach to personalisation and the marketisation of disability support. Furthermore, it suggests that the system of personalisation will run effectively by itself after small-scale local investment in relationship building and capacity building. Our findings problematise this idea and suggest the ongoing requirement for local initiatives such as PIR, ISR and ECSN as well as broader policy frameworks for addressing complexity.

**Limitations**

The present research has some limitations. It is based on data with ISR staff and stakeholders only and does not bring in the experiences and perceptions of people with disability and informal supporters, who may have a different perception of personalisation and complexity, the issues faced and how they might be resolved.

**Conclusions**

Effective inter-organisation collaboration is crucial for supporting people with disability and complex support needs (Foster et al., 2022). The ISR approach was valued by stakeholders, particularly in its ability to bring people together to address individual
client problems and in facilitating collaboration. However, collaboration-based activities need to be actively supported by organisations, and where necessary there needs to be funding available to support collaboration. Collaboration needs to be understood as a shared responsibility (including for funding) between the NDIS and other government departments. More broadly, while small, agile teams such as ISR may improve inter-organisation collaboration around specific clients and influence change at a systems level based on gaps identified, an ongoing systemic approach may be required to facilitate system-wide collaboration and focus attention on broader issues impacting outcomes for people with complex needs.

Our results and discussion suggest some key considerations that might guide responses to complexity under personalisation. Responses to complexity could benefit from:

- Due to the need to facilitate collaboration: incorporating into personalisation systems funding that is dedicated to collaboration-building activities which can be delivered independently of supporting a specific client, such as time for building relationships and networks that can be drawn on for collaboration (e.g. Smith-Merry et al., 2015).
- Because of the utility of the MOU: the need to develop mechanisms for high level explicit permission and expectations to collaborate (including provision for engaging organisations that have not been participating in collaboration activities).
- Because of the inherent difficulties of collaboration in the quasi-markets which come with personalisation under the NDIS: examining and addressing structural, funding and workplace cultural barriers to collaboration.
- Because there may not be existing capacity in the system to collaborate: consider the availability of flexible client-specific funding to broker emergency services for clients and to support collaboration.
- Because of the value placed on addressing systems-level barriers: determine responsibility for consideration of systemic issues, and incorporating mechanisms for reporting and acting on these at a senior policy level in government.

The systemic factors highlighted here, which give rise to fragmentation, indicate that responses to complexity, at both the individual and system levels, should be a permanent feature of the disability support landscape.

Acknowledgements

This project was funded by the NSW Ministry of Health. We thank the team in the NSW Ministry of Health for their assistance throughout the project and publication.

References


