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Delivering decision making support to people with cognitive disability — What has been learned from pilot programs in Australia from 2010 to 2015

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Abstract

The UNCRPD has generated debate about supported decision making as a way to better enable people with cognitive disability to participate in decision making. In Australia, between 2010–2015, a series of projects have piloted various models of delivering decision making support. A critical review was conducted on the program documents and evaluations of these pilot projects. The pilots were small scale, conducted by both statutory and non-statutory bodies, and adopted similar designs centred on supporting a decision maker/supporter dyad. Primarily, participants were people with mild intellectual disability. Themes included: positive outcomes; uncertain boundaries of decision support; difficulty securing supporters; positive value of program staff and support to supporters; limited experience and low expectations; and varying value of written resources. The lack of depth and rigour of evaluations mean firm conclusions cannot be reached about program logics, costs or outcomes of the pilots. The pilots demonstrate feasibility of providing support for decision making rather than resolving issues involved in delivering support. They suggest that some form of authority may facilitate the role of decision supporters, help to engage others in a person's life, and integrate decision making support across all life domains.

KEYWORDS
acquired brain injury, cognitive disability, decision making, intellectual disability, supported decision making

1 | INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) generated significant debate both in Australia and internationally about the rights of people with cognitive disabilities to make decisions about their own lives. Some interpretations of article 12 of the Convention suggest that the concept of supported decision making should replace substitute decision making and guardianship, to ensure that people with disabilities have the necessary support to exercise their legal capacity on an equal basis with other citizens (Salzman 2010; Kohn et al. 2013). Supported decision making originated in Canada in the 1990s to deal with legal barriers to receipt of individualised funding by people with intellectual disabilities created by issues of competency (Bach 1998). Since that time, it has been understood in three ways: "a process of supporting a person with decision making; a system that affords legal status; and a means of bringing a person's will and preferences to the centre of any substituted decision-making process" (Browning et al. 2014:34).

In Australia, the introduction of the National Disability Insurance Scheme [NDIS] and its focus on choice has heightened interest in supported decision making, as an estimated 60 per cent of participants will have a cognitive disability and many will require support to make decisions (Bigby 2016). There is, however, very little knowledge about the delivery or practice of supported decision making however it is understood, as most articles and reviews about this topic adopt "standard, normative, doctrinal or policy analysis methodologies" rather than being empirically oriented (South Australian Office of the Public Advocate 2012–2013:58). Despite the adoption of schemes in Canada and Sweden that afford legal status to supported decision making, there is no published research on the way these operate or their impact on the quality of decision making support that indicates their effectiveness (Kohn et al. 2013). In Australia, as the wheels of legal reform to give legal status to supported decision making turn slowly, attention has turned to the types of programs and practices necessary to deliver supported decision making, understood either as a process of supporting a person with decision making or a means of bringing their will and preference to the centre of any substituted decision making (Browning et al. 2014). Ways of delivering supported decision making are the focus of this paper. In the absence of legal reform, we refer to *support for decision making* to avoid confusion with supported decision making as a system that affords legal status (Bigby & Douglas 2016).

In some parts of Canada, supported decision making has legal status through, for example, Representation Agreements (Gordon 2000). The broad flexible definition of capacity in the provisions for Representation Agreements enables people who are more commonly considered by the law to be incapable of entering into contracts to appoint a representative to assist them to make decisions and, if necessary, make decisions on the person's behalf. Representation Agreements give legal standing to supporters and recognise that decision making can be a shared process (Gordon 2000). The Swedish Godman system is another example of supported decision making having legal status (Gooding 2012). This system provides for a court appointed volunteer to act as "the benevolent bridge that a person with intellectual disability needs to claim his or her rights" by facilitating their self-determination and, if necessary, representing the person. Similar to the Canadian provisions, appointment of a Godman has no consequences for the legal capacity of the person with cognitive disability (Tideman 2016).

The Australian Law Reform Commission and Commissions in Queensland and Victoria have favourably considered the arguments for the introduction of supported decision making as a system that affords legal status, and the need to reform guardianship (Queensland Law Reform Commission 2010; Victorian Law Commission 2012; ALRC 2014). Four decision making principles to be followed by Commonwealth, state and territory laws were recommended by the ALRC in 2014: the equal right to make decisions; the provision of support in decision making to the level necessary to enable people to participate in decisions that affect their lives; decisions be directed by individual's will, preferences and rights; and legal frameworks to protect against abuse and undue influence. To date, however, in Australia there has been no legal reform that affords supported decision making a legal status, as has occurred in Canada or Sweden. Notably, in Victoria use of a standard threshold of legal capacity effectively excluded people with existing cognitive disabilities from new legal provisions that enabled the appointment of a supportive attorney to support a person to make decisions (The Victorian Government 2014).

The least restrictive foundation of Australia's guardianship system means that most people with cognitive disability do not have a guardian, but are supported to make decisions on an informal basis by family, friends or paid staff who also make informal substitute decisions on their behalf. Advocates and researchers are beginning to ask questions about the way informal support is provided, if practice reflects rights principles, the dilemmas supporters experience, their accountability, and whether the NDIS should fund support for decision making as a reasonable and necessary disability-related need (Bigby 2014; Headlund 2016). Support for decision making was, for example, one of the first issues tackled by the NDIS advisory group of people with intellectual disability (Galbaly 2016).

The small body of research about the practice of support for decision making illustrates its complexity, and the importance of both a positive support relationship whereby the supporter/s hold the individual as central to the decision making and of context and ongoing commitment to the preferences and changing needs of the individual (Knox et al. 2015a,b, 2016a,b; Watson 2016). Research has also identified the challenges of unduly influencing decisions, managing risk, and dealing with conflict among those involved in a person's life (Bigby, Whiteside & Douglas, 2017). Douglas et al. (2015) identified four empirically based propositions that characterise effective decision making support: orchestration by the primary supporter; commitment to person; support principles; and a repertoire of strategies that can be used flexibly depending on the type and context of particular decisions.

In Australia, initiatives have also begun to explore and organise more formal ways of delivering support for decision making, in the space between systems that afford legal status such as those in Canada and Sweden and the invisibility, in Australia, of support that is provided informally by family and staff. Rationales for these pilot decision making programs were to ensure support reflected a rights-based approach, assure greater accountability of supporters, provide training and back up to supporters and expand the availability of decision making support to people without strong or resourceful informal networks.

Between 2010 and 2015, six pilot programs were run: two in South Australia (SA1 & SA2), and one in each of Victoria (VIC), New South Wales (NSW), Australian Capital Territory (ACT), and Western Australia (WA) (Wallace 2012; ADACAS Advocacy 2013; Western Australia's Individualised Services 2014; Community Matters 2015; Westwood Spice 2015; Calnin 2016). At the time of writing, four other pilots were in operation and not yet completed or evaluated: two in New South Wales; one in Victoria; and a randomised controlled trial of training for supporters was commencing across three states (Bigby et al. 2015).

Pilot programs offer potential insights into the feasibility and benefits of taking a more formal approach to delivery of support for decision making, and ways of organising delivery of support to different subgroups of people with cognitive disability. Understanding more about these programs may not only inform the development and evaluation of new programs but also the design of legal reform and ways of implementing any future schemes of supported decision making in Australia. Therefore, the aim of this study was to review the contribution of completed pilot programs by scoping the relevant grey and research literature to answer the following questions: what support for decision making programs have been developed in Australia for adults with cognitive disability, and how has their effectiveness been evaluated?

2 | METHOD

Scoping reviews can be used to identify and describe work on a given topic in order to inform research, practice and policy development (Daudt et al. 2013; Arksey & O'Malley 2015; Miake-Lye et al. 2016) They are a particularly useful method when it is difficult to define a narrow research question, no prior synthesis on the topic is available, few studies have been completed and typically use variable data collection and analysis procedures (Crooks et al. 2010; Arksey & O'Malley 2015). In the case of this review, we followed the five-step process described by Arksey and O'Malley (2015) that covers formulation of the research question, identification and selection of relevant studies/projects, charting of the data and reporting the results.

The guiding research question for the review focused on identifying the extent, nature and range of literature about programs designed to deliver support for decision making to adults with cognitive disability. Specifically, we sought to examine these programs with respect to their rationale, program design, methods and characteristics, organisational arrangements and participants. We also set out to consider the effectiveness of these programs through summarising the methods and results of program evaluations where these data were available.

A customised search strategy using three key concepts was developed. These concepts included support for decision making OR supported decision making; disability, cognitive OR intellectual, and project OR program OR training. Limitations were defined for language (English), location (Australia) and search period (1 January 2010 to 30 December 2016). Records prior to January 2010 were excluded given the recent nature of work in support for decision making in Australia. Through our connection with the Australian Supported Decision Making Network and our extensive participation in Supported Decision Making forums, the authors were aware that little work had been completed in this area, particularly work that would be available in academic databases. Thus, the search strategy was applied to databases with broad coverage for the academic literature (Google Scholar) and the grey literature (Google). In addition, a manual search of the reference lists of selected records/studies was undertaken.

A total of 495 citations were initially identified (four via database [Google scholar] searching and 491 via grey literature [Google] and hand searching). All titles and abstracts or descriptions were reviewed and nine records were retained (two database [Google scholar] and seven grey literature [Google]). The two records identified in database searching were Burgen (2016) and Wallace (2012) and the seven records identified through broad web searching were ADACAS Advocacy (2013), Mills et al. (2013), Western Australia's Individualised Services (2013, 2014), Community Matters (2015), Westwood Spice (2015) and Calnin (2016). These records were then reviewed in full and found to relate to six individual programs/projects and included the evaluation reports for five of the six programs. We then conducted a targeted web search around these programs to identify

additional sources of program specific information to augment the descriptive data concerning specific components of these programs.[1] Data extraction for each project was completed across four descriptive categories: (1) organisational arrangements (e.g., time period, auspice, funding source), (2) project features (e.g., aims, design, methods, resources), (3) nature of decisions (e.g., scope of decisions, use of decision making agreement), and (4) the participants (e.g., criteria for participation, disability type, number, recruitment process). Data about the five evaluations were also extracted and categorised according to method and limitations, outcomes, facilitating factors and barriers.

3 | RESULTS

Descriptive overviews of the programs and the evaluations are in Tables 1 and 2 respectively. The programs were small with between six and 36 people with cognitive disability participating as decision makers and similar numbers of supporters. They were time limited and funded by government or short-term grants from philanthropic or industry bodies. All were non-statutory, meaning that supporters had no formal legal standing and decision making rested with the person with disability rather than being shared with a supporter.

3.1 | Program aims

Programs shared common aims of exploring ways of supporting greater involvement of people with cognitive disabilities in decision making about their own lives, and trialing models of providing support for specific subgroups of this population. SA1 initially focused particularly on people at risk or already subject of guardianship, but subsequently discontinued inclusion of the second group. ACT sought to involve people with more complex needs than those in the SA1 program, and VIC targeted socially isolated people without any existing support for decision making. In contrast WA targeted people with already existing networks of support who, with knowledge and resources about support for decision making, were likely to influence the practice of service providers.

3.2 | Program design

As Table 1 shows, at the core of each program was a dyad of a decision maker with cognitive disability and a decision supporter. With the exception of WA which worked with preexisting dyads, program staff helped to form dyads, from the decision makers' own informal support network or by actively recruiting paid supporters or volunteers to the role. Once formed, program staff trained dyad members about decision making and provided ongoing support either individually or jointly to dyad members. The design of each program differed slightly. For example, ACT focused more on the skills of decision makers than other programs and adopted a two-step process that included an initial *decision readiness* phase. This phase, which aimed to develop skills in decision making of the person with cognitive disability, preceded recruitment of supporters, formation of and support to the dyad.

Characteristics of supporters and recruitment methods differed between programs. In ACT, SA1, SA2 and NSW, program staff assisted decision makers to identify supporters they already knew, whereas in VIC supporters without any prior connections to decision makers were recruited through the existing volunteer programs run by the Office of the Public Advocate. Payment status of supporters also varied. In WA and SA1, supporters were unpaid, primarily family or friends of the decision makers, in VIC they were unpaid volunteers and in ACT they were a mixture of paid staff (direct support staff, advocates or program staff) and unpaid family or friends.

TABLE 1 Descriptive summaries of support for decision making pilot programs

	SA1	ACT	NSW	Vic	SA2	WA
Organisational arrangements	2010–2012. SA Office of Public Advocate (OPA). Funded by MS McLeod Benevolent Fund & OPA	2012–2013. ADACAS an advocacy organisation. Funded by Disability ACT.	2013–2014. NSW Office of Ageing, Disability and Home Care; NSW Public Guardian; NSW Trustee & Guardian. Funded by NSW Dept. Family and Community Services.	2013–2015. Vic OPA. Funded by Vic OPA and Vic Law Foundation.	2013–2015. Office of the Health and Community Services Complaints Commissioner (SA HCSCC). Funded by SAHCSCC.	2013. WA Individualised Services (WAID). Funded by NDS and WA Disability Services Commission Quality Improvement Grant.
Project features Aims	Aimed to provide early intervention for people at risk of guardianship through an alternative to guardianship, and alternative decision support for people already under guardianship by using supported decision making principles.	Aimed to demonstrate the importance of support for decision making being available to people with complex decision support needs who are socially isolated and for whom there are few expectations about decision making.	Aimed to develop a support for decision making model and practice in the NSW context and promote new ideas about support for decision making.	Aimed to explore a model of support for decision making for socially isolated people without informal supporters and trial the use of volunteer supporters.	Aimed to build capacity in the service system for support for decision making, give greater voice to people with disability and avoid complaints about disability support services.	Aimed to develop support for decision making skills and knowledge among service providers and embed support for decision making as part of quality services in order to give greater choice and control to people with disability.

(Continues)

TABLE 1 (Continued)

	SA1	ACT	NSW	Vic	SA2	WA
Design	Formation of and support to dyads of decision makers and supporters. Dyad relationships either preexisting or newly matched by the program. Most supporters unpaid with some form of preexisting relationship.	Two-stage process. First, increasing decision readiness of participants and then formation of and support to dyads of decision maker and supporter. Dyad relationships either preexisting or newly matched by the program. Most supporters unpaid with some form of preexisting relationship.	Formation of and support to dyads of decision maker and supporter. Range of supporters including paid service providers, 10/19, family 7/19, friends 1/19, paid advocate, 1/19 and coordinator 6/19.	Formation of and support to dyad of decision maker and volunteer supporter with no prior connection to participant. No paid supporters, all volunteers.	Formation of dispersed dyads of decision makers and supporters, hosted by different disability service providers. Enablement of facilitators in each service to support dyads in their service. Range of supporters including family members (2/8) and volunteer (1/8).	Skill development of participants, and their existing networks of supporters.
Methods	Formation of dyad from among existing supporters or recruitment of new supporters. Training and regular support to dyad members and regular monitoring of progress.	Coaching in decision readiness for participants. Formation of a dyad from among existing supporters or recruitment of new supporters. Support to members of the dyad and regular monitoring of progress.	Formation of dyad from among existing supporters or recruitment of new supporters. Training and regular support to members of the dyad.	Recruitment and training of volunteers not previously connected to the decision maker. Formation of dyad from volunteers and support to dyad members, primarily supporters. Advocacy and referral for decision makers about implementing decisions.	Training and mentoring of facilitators, organising a facilitators community of practice. Formation of dyad from among existing supporters or recruitment of new supporters, training and regular support to members.	Training workshops, reflective exercises, short-term mentoring and development of multimedia guidance materials.

(Continues)

TABLE 1 (Continued)

	SA1	ACT	NSW	Vic	SA2	WA
Resources	Three staff; coordinator, peer worker and monitor with interchangeable roles	Two staff; coordinator, 15 hours a week, and monitor 18 hours a week.	Two staff roles; full-time coordinator and several part time facilitators.	One staff; full-time coordinator with back up support from OPA staff.	Two staff roles; a coordinator and several facilitators each located in a different service.	Two staff roles; workshop facilitator and mentor.
Nature of decisions	Use of formal decision making agreement and wide range of decisions included excluding financial.	Use of formal decision making agreement and wide range of decisions included excluding financial but including spending of money managed by others.	Use of informal decision making agreement and wide range of decisions including financial	Use of formal decision making agreement and wide range of decisions included excluding financial but including spending of money managed by others.	Use of formal decision making agreement and wide range of decisions including financial.	No information on decision making agreements. Wide range of decisions.
Participants	32 participants reduced to 26 by the end of the project, included equal proportions of people with intellectual disability and acquired brain injury or neurological disease. Multiple ways into the program.	6 participants. Included people with a wider range of needs than in SA1, and people with complex communication needs. Multiple ways into the program.	26 participants reduced to 20 by end of the project. Majority were people with intellectual disability (22) but small number with acquired brain injury or undisclosed impairment. 85 per cent communicated with speech. Multiple ways into the program.	18 participants reduced to 12 by the end of the project. All people with borderline or mild intellectual disability who were socially isolated without existing informal supporter for decision making. Several had guardians. Most participants referred by OPA.	11 participants reduced to 7 by the end of the project. All people with cognitive disability but no further details available. Self-selection into the project by clients of services where facilitators worked.	36 participants no breakdown but likely to have all been people with intellectual disabilities. Self-selected with their existing supporters.

Supporters were expected to have attributes such as respect for the rights, values, goals and experiences of each individual, good interpersonal skills and the ability to recognise conflicting interests. They were expected to commit time and provide support for as long as was needed for a decision to be reached, and either have a trusting relationship with the decision maker or the capacity to build one. Little detail was available about the expected practice of providing decision making support, although this was to some extent implicit in the training materials which alluded to things such as: supporting decision makers to take risks, change their minds, make decisions others may not like, and extend their experiences. The job description for the VIC volunteers included compliance with the Office of the Public Advocate's code of practice for volunteers, supporting decision makers to act on decisions, and recognising issues that should be discussed with the program coordinator (Burgen 2016). SA1 described the supporters' role as helping decision makers to access information, discussing available information in understandable ways, and advocating for decisions made to be acted on.

3.3 | Program methods

In most programs, a coordinator directly supported either or both members of dyads but staff roles differed slightly. SA2 used a dispersed model in which the coordinator trained and supported several facilitators, who in turn each supported a small number of dyads in their own agency. WA provided only a short period of support to dyads, which meant the work of the coordinator centred on the development and dissemination of resources to decision making supporters. In NSW, the coordinator also acted as a supporter in at least one dyad, and in SA1 and ACT, a staff member referred to as a *monitor* played a similar role to the coordinator.

All programs developed educational materials for training and reference purposes. These were based on philosophical values, human rights principles and person-centred planning resources rather than significant research evidence. ACT was the only training program to include any references to research or theory about decision making and these were generic papers about the psychological processes of decision making. The materials emphasised the significance of dyad relationships, commitment required and the type of rights-based principles that should inform support practice that had been conceptualised in the 2014 ALRC report. They did not include concepts such as orchestration described by Douglas et al. (2015) and gave little attention to the types of micro support strategies described by Bigby, Whiteside, and Douglas (2017), and the type of support that might work best and for whom.

3.4 | Resources

The logic models of the programs were difficult to piece together as there was little information about resource inputs, outputs or outcomes of programs. For most programs, although information was available about the titles and roles of staff, details were not available about their skills and qualifications or the time fraction they were employed or rate of pay. Similarly, there was little information about outputs such as the number of decisions participants made and whether decisions were implemented.

3.5 | Nature of decisions

Decisions within the programs' scope were varied and wide ranging. Financial decisions were excluded in SA1, ACT and VIC, and SA1 focused particularly on "bigger" decisions, of the type

more likely to necessitate involvement of a guardian. Most programs used a formal decision making agreement to negotiate expectations dyad members had of each other and, in some cases, to identify the decisions participants wanted to make.

3.6 | Participants

As already discussed, programs targeted different subgroups of people with cognitive disability but despite this the majority of participants overall and in most programs were people with mild intellectual disability. SA1 was the exception where people with some form of brain injury made up 50 per cent of participants. No information was provided about how judgements concerning the nature and severity of people's disability were made. Participants had been recruited through contact with auspicing agencies' existing service users or advertisements and outreach. As Table 1 shows, there was some attrition among decision makers, which in VIC was explained by people with complex and chaotic lives having little time or space to form new relationships with supporters (Burgen 2016).

A second strand of SA1, that had sought to recruit people into the program who were already under a guardianship order, was discontinued due to difficulties with recruitment. However, people under guardianship were included in several other programs. In these cases, while guardians remained responsible for formally making decisions, supporters were able to spend more time working with the person to help them express their preferences than might be possible for statutory guardians.

3.7 | Program evaluations

The program evaluations explored process issues and outcomes. Table 2 provides a summary of the methods used and highlights the limitations of these. Evaluations were primarily descriptive, and used interviews and focus groups to elicit the views of key stakeholders, along with case notes or other program records to capture data about participants and processes. The support to dyads was not analysed in any depth, and vignettes were the primary means of illustrating support practice. Some of these studies lacked a clear evaluation model or the reports provided insufficient detail to make sound judgements about methodological rigour and the validity of findings. For example, the proportion of program participants involved was often not clear or small, and several studies did not include all stakeholder groups. It appeared that only one study had received ethical approval and had been conducted by academic researchers rather than internally by program staff or consultants.

3.8 | Positive outcomes

Overall, positive judgements were made about the impact of these programs in advancing knowledge about support for decision making, outcomes for both decision makers and supporters and the feasibility of this type of program. The most common outcome for decision makers was increased confidence in making decisions. For example, one participant gave information about ways to support his understanding and decision making to his health professionals. Other outcomes included increased experience of making decisions, greater autonomy, and participation in a wider range of activities.

Supporters were generally positive about their involvement in programs, deriving satisfaction from the benefits they perceived for the person they supported. They also pointed to changes in their own work practice or interactions that meant they were more likely to recognise potential

TABLE 2 Summary of evaluations

	SA1	ACT	VIC	NSW	SA2
Methods and limitations	Interviews with participants, supporters and staff. Small sample, use of percentages only to report findings rather than raw numbers.	Interviews (termed conversations) with six decision makers, survey of supporters and compilation of case studies. Small sample only of decision makers.	Interviews and survey of participants at three time points. Small sample only of decision makers and limited response to follow up interviews and surveys.	Interviews (4) and focus group with 7 supporters (volunteers). Small sample only of supporters.	Interviews and focus groups with decision makers, supporters, trainee facilitators, and supervisors and managers at different levels. Small sample, data from survey of facilitators not used due to low numbers.
Outcomes Decision makers	Increased decision making confidence, skills and self-determination. Greater social capital and community engagement.	Not reported.	Not reported.	Increased understanding of supported decision making. More involvement in decision making about day-to-day, big, medical decisions, and financial (most increased) aspects of their lives.	Increased confidence in decision making, confidence, better able to communicate goals and preferences and greater willingness to try new things. Positive and practical outcomes of decisions made (e.g., employment, education).
Outcomes Supporters	Changed interactions with decision makers and improved interpersonal relationships.	Not reported.	Changed relationship with decision makers to one of friendship and deeper understanding of their experiences.	Increased understanding of supported decision making.	Better knowledge about the decision maker.
Outcomes Broader level	Support for decision making seen as an alternative or to be used as part of guardianship practice	Understanding that support for decision making can work with guardianship	Knowledge about supporting socially isolated decision makers incorporated into other OPA projects.	Not reported.	Impact on decision makers not part of the program, aspects of facilitators work and their organisations, such as learning decision making skills, greater listening for meaning and knowledge about support for decision making.

(Continues)

TABLE 2 (Continued)

	SA1	ACT	VIC	NSW	SA2
Facilitating factors	Formal decision making agreements facilitated communication between decision makers and supporters. Flexibility enabled the coordinator to take on role of advocate for the decision maker. Inclusion of advocacy in supporters' role. Support from coordinator for supporters to better understand their role.	Formal decision making agreements facilitated an individualised approach to support. Using advocates enabled decision makers to participate in the project and/or implement decisions made. Strongly motivated supporters. Participants who have experience of making decisions and are "decision ready".	Effective communication to participants about their rights to make decision. Commitment by supports of at least 12 months to the program. Familiarity of supporters with the disability sector. Induction, training, and ongoing support to supporters.	Individual support from facilitators to supporters increased their confidence and capacity to provide support. Support from facilitators with implementation of decisions. Supporters able to commit adequate time, who were respectful to people with disabilities, had common sense, good communication and advocacy skills and high ethical standards about maintaining privacy and confidentiality.	Stability of facilitators and replacements available to step in if necessary. Support for facilitators through Community of Practice meetings. Supporters with larger social networks enabled participants to identify increased choices. Participants with sufficient cognitive capacity, adequate mental health, a decision to make changes in their lives and with time to commit to decision making.
Barriers	Tensions between families and decision makers when supporters were not family members.	Time and difficulty of identifying and securing supporters. Problems in understanding family dynamics and negotiating their real or perceived authority. Tensions experienced by guardians between their statutory role and supported decision making principles. Difficulties for participants in choosing specific decisions and not seeing themselves as decision makers.	Tensions with roles and expectations of others involved in a decision maker's life, such as family members or paid support workers.	Supporters did not find written resources useful and these did not reduce their need for individual support from facilitators. Social isolation of participants and lack of decision making experience. Conflict between supporters and with others involved in decision maker's life, particularly family members.	Social isolation of decision makers and lack of available supporters placed high demand on facilitators to recruit supporters.

for autonomy or offer choices about everyday things to the people they supported. The revocation of one couple's guardianship orders was seen as in part due to a change in the way their capacity was perceived by others. In particular, the evaluation of SA2 alluded to the positive impact on broader organisational practices that resulted from staff being involved in the program.

3.9 | Facilitating factors and barriers

All evaluations affirmed the core design features of the programs by highlighting the value of support from program staff to decision making dyads. Several evaluations noted the gap between making and acting on decisions, which pointed to the importance of advocacy either by the coordinator or supporters around implementation of decisions. Other factors identified as facilitating outcomes included use of formal decision making agreements to clarify expectations, and characteristics of supporters, such as commitment, familiarity with the disability sector, good communication or advocacy skills, common sense, and ethical behaviour.

Several factors were identified as creating barriers to program outcomes. The most common was tensions associated with the role of decision supporter and consequent conflict with others involved in the decision makers' life that had to be negotiated. Supporters had to find a balance between respecting a person's autonomy, supporting their dignity of risk and ensuring their safety. The challenges of doing this were sometimes compounded by value clashes with others involved in the person's life, who might oppose a decision or assume it should simply be made for the person in their best interests.

Two evaluations, ACT and VIC highlighted the difficulties and time-consuming nature of recruiting people as decision making supporters, despite a majority of supporters being already known to the person with disability. VIC was the only program that relied on supporters without some prior connection to the person with disability. The difficulties of recruiting volunteers were illustrated by a high dropout rate after the first information session about the program (see Burgen 2016).

Two evaluations, ACT and NSW pointed to the low expectations about their involvement in decision making that surrounded program participants and their limited experiences. A lack of decision making experience made it difficult for some prospective participants to identify decisions they wanted to focus on and become involved in a program.

All the programs developed educational materials for training dyad members but the evaluations were silent about the quality and content of the educational materials. Judgements about their benefit varied between programs. Several evaluations noted the usefulness of written materials for supporters, while the NSW one found that written material was not helpful.

4 | DISCUSSION

The study analysed a large body of program documents, training materials and unpublished evaluative reports about support for decision making programs. Although substantial detail was available about individual programs, there was little consistency in this data across the programs. Key missing data, such as details of participant and staff characteristics and resource inputs, made it hard to fully understand and document program logic models and costs. A lack of detail about the design of the five available evaluations meant it was difficult to judge their rigour. The available information suggested, however, that these evaluations were primarily descriptive, did not use representative samples or validated tools and did not compare pre- and post-outcomes. These

limitations mean that only tentative conclusions can be drawn about the effectiveness of the programs and the design features that influenced their outcomes.

This study is the first to draw together key data about Australian support for decision making programs. By comparing and contrasting programs, design similarities and variations have been identified. A core part of all the programs was the position of a paid coordinator who supported and in most cases also helped to form dyads comprising a person with cognitive disability and a supporter by recruiting supporters to this role. Despite the limitations of the evaluations, the findings of this study demonstrate the positive outcomes for people with cognitive disability from this type of program and have identified some key issues to be considered in developing future support for decision making programs.

Support for decision making relied on corresponding support from others involved in the person's life to endorse and implement decisions. Challenges to some decisions and failure to act on them sometimes led to conflict between supporters and others in the person's life. Resistance from others helped to generate the need for supporters to take on advocacy roles and created uncertain boundaries between support for decision making and other forms of support. Research on practice of decision support has identified similar issues (Douglas et al. 2015; Bigby, Whiteside & Douglas, 2017; Knox et al. 2016a) and the practice framework developed by Bigby and Douglas (2016) incorporates some ways of tackling them. For example, they used the concept of orchestration to describe supporters working together with the network of paid and unpaid people involved in a person's life to ensure they benefited from multiple perspectives about options and that whatever decision was made had the backing of those who had to give it effect. The seven steps involved in decision support identified in their framework also provide a way of thinking about boundaries between decision making support, advocacy and care coordination or case management.

The influence of the broader socio-cultural context was evident in the issues encountered within the programs. Difficulties in relationships between supporters and others in a person's life were likely compounded by their lack of knowledge or understanding about rights and the principles embedded in the ALRC report (2014). The need to change attitudes and improve community understanding about rights of people with cognitive disability to participate in decision making was reflected in participants' limited experiences of decision making as well as the low expectations of participation in decision making held by others. These are key challenges confronting the National Disability Strategy 2010–2020 (Council of Australian Governments 2011) and the National Disability Insurance Scheme (2013) that will require long-term and creative strategies to address.

It is also likely that some of the issues encountered in these programs stemmed from the non-statutory nature and poorly defined roles of supporters. Supporters had no formal standing and had to establish credibility based on their relationship with the person they supported and a rights perspective. Having to justify to others the type of support provided to a person with cognitive disability is an important accountability mechanism, but schemes where supporters are without formal authority to prosecute the case for acting upon decisions are in danger of undermining their role.

Operating in the informal sphere may also have resulted in a narrowing of the programs' target group to people with mild levels of cognitive impairment and exclusion of those with more severe impairment. It is this latter group for whom recognition of shared decision making is important, as they have difficulties making decisions alone and participate in many decisions through the interpretation of their preferences by supporters who know them well. The nature of support for decision making programs for this group remains largely unexplored by researchers both in Australia and internationally.

A range of supporters were recruited to the programs. Not all had preexisting connections with the person with disability and relationships varied from family member to friend to paid

staff. The programs demonstrated the viability of delivering support for decision making to different subgroups of people with cognitive disability, including those under guardianship and without preexisting decision making supporters. However, while possibilities were illustrated, the intensity of resources required to include these groups of people in support for decision making programs was not quantified.

The design and approach to delivering support for decision making used in these programs illustrated the value of training for supporters, oversight of their role, and provision of support and advice by program staff to either or both members of the dyad. Research about the actual practice of providing support for decision making points to the importance of trusting relationships and the lengthy and time-consuming nature of good support (Knox et al. 2015a,b, 2016a,b). These characteristics of good practice, together with the nested and ongoing nature of decision making in people's lives suggest the need for longevity of decision maker/supporter relationships and programs that can recruit, train and support supporters. The indications are then, that funding for support for decision making programs needs to be medium to long rather than short term.

Our review of the wide range of educational materials developed by these programs to train supporters identified some significant gaps and the evaluations found their benefit to be equivocal. These findings suggest that further development of training materials based on research evidence and evaluation of such programs is needed. In addition, extension of training to include practical application to specific issues confronted by supporters and/or face-to-face problem solving may increase effectiveness. Research by the authors, trialling resources for supporters, and measuring change in approach and satisfaction with decision making support, may go some way to addressing this gap (Bigby et al. 2015).

5 | CONCLUSIONS

This review of Australian pilot support for decision making programs provides some insights to inform future programs, and suggests much more needs to be understood about effective programs for delivering support for decision making. It is evident there is a need to trial support for decision making with the populations left out of these pilots, particularly people with more severe cognitive disability. Programs expended considerable resources recruiting decision making supporters, both known and unknown to the decision maker. Recruitment, retention and support for decision making supporters is an area that requires much more investigation. Certainly, more attention must be given to use of the emerging evidence base about the actual practice of support for decision making and concepts such as orchestration and micro strategies of support in training materials for supporters.

Uncertainty about responsibilities and authority, and tensions between decision making supporters and others involved in a person's life, suggest that future programs must delineate clearer boundaries between support for decision making and advocacy, case management and case coordination. It may be that workable models of delivering decision making support need to straddle civil society and the law. Trialling legal standing for supporters will illustrate what role, if any, that this will have on addressing these tensions. Formal acknowledgement of shared decision making will enable programs targeted at people with more severe cognitive impairment. Formalising a legal system of support for decision making could be achieved either by legal reform or in the first instance confined to the group of people with cognitive disability who are participants in the NDIS through greater use and regulations associated with existing legislation such as the nominee provisions in the NDIS Act (Australian Government 2013).

Decision making, and the need for good support are diffused throughout the lives of people with cognitive disability, rather than a bounded event. The lack of strong evidence about effective models for delivering support for decision making, coupled with the legislative, organisational, and familial complexity of providing support, highlight the need for long-term projects. Findings around limited *decision readiness* of decision makers and the need for change in the socio-cultural climate in which support for decision making is enabled and restrained crystallise this need for long-term support. One possibility is that future decision making programs could be funded on a user pays basis if the NDIS were to recognise and fund this type of support as part of a person's reasonable and necessary disability-related needs. Alternatively, programs with a broad community education mandate could be funded by the second tier of NDIS, the Information, Linkages and Capacity Building program.

The costs of programs and what constitutes a unit of service remain a significant knowledge gap and a potential obstacle for future support for decision making programs. Any new programs require tighter logic models to enable accurate identification of costs and benefits. Unless this is done, support for decision making programs may be dismissed as too resource intensive and decision making support consigned to a short term or crisis role rather than a continuous need for people with cognitive disability.

ENDNOTE

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