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Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences

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ABSTRACT
Background: Supporting participation in decision making is complex, dynamic and multifactorial. The aim of this study was to understand more about the difficulties parents of adults with intellectual disabilities experienced in providing decision support and their strategies for resolving them.

Method: Participants were 23 parents who regularly provided decision support for their adult with intellectual disabilities. Most of the adults (19) lived at home. Parents participated in semi-structured interviews at least three times during the study. We applied a social-constructionist theoretical perspective and a template approach for analysis.

Results: Findings fell into three core categories, making the right decision, factors that made decision support difficult, and strategies to manage uncertainty, which included controlling, influencing, expanding the adult’s horizons and enabling risk.

Conclusions: The knowledge gained will help in building the capacity of parents to provide decision support that better understands and respects the will and preferences of the person they support.

KEYWORDS
Supported decision making; parental support; rights; support practice

The United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006) marked a paradigm shift in thinking about decision making by people with intellectual disabilities. By asserting the right of all people with disabilities to participate in decision making, the CRPD shifted the focus from issues of individual capacity and substitute decision making to ones of access to support and the adequacy of decision support practice (Carney, 2017). Article 12 of the CRPD requires member states to “provide access by persons with disabilities to the support they may require in exercising their legal capacity.” Article 12 and the subsequent Comment by the Committee on the Rights of Persons with Disabilities (2014) generated considerable debate about the concept of supported decision making (Arstein-Kerslake, 2017; Bach & Kerzner, 2010; Glen, 2020). This concept has been regarded as a legal framework to replace or complement guardianship provisions and as a practice of support for decision making regardless of legal context (Browning et al., 2014).

Growing interest in supported decision making has spawned scholarship about legal structures for promoting decision-making rights, mechanisms for safeguarding (Then et al., 2018) and philosophical consideration of the relational nature of autonomy and decision making (Mackenzie & Stoljar, 2000). At an applied level, research has explored the processes of decision support (Browning, 2018) and components of practice that enable people with intellectual disabilities to participate in decision making (Bigby & Douglas, 2020; Douglas & Bigby, 2020; Shogren et al., 2019; Watson, 2016).

The strand of research about supported decision-making practice is the most underdeveloped but is fundamentally important to the successful implementation of legal reform. For example, although supported decision-making schemes were established in some provinces in Canada and Sweden prior to the CRPD, there is little evidence about the support practices and extent to which schemes deliver on promises of increased participation and respect for a person’s preferences (Kohn et al., 2013). Notably, one of the very few published studies of decision support in the context of Representation Agreements in British Columbia, Canada, suggested that while legal recognition helped supporters...
navigate the practicalities of providing support with external parties, their practice did not always reflect the ideals embedded in the scheme (Browning, 2018). Notably also, reviews of recent pilot supported decision-making programs in Australia and internationally provide few insights into decision support practices (Arstein-Kerslake et al., 2017; Bigby et al., 2017).

Research about processes of supporting people with intellectual disabilities to participate in decision making suggests a complex, dynamic and multifactorial process involving the interaction between the expressed will and preferences of the supported person and supporter’s interpretations and responses (Browning, 2018; Watson, 2016). Browning’s model demonstrates how support varies with each decision, influenced by the experiences and attributes of the supporter and person being supported, their support relationship, the context, the nature of the decision and its potential consequences (Browning et al., 2020). Accordingly, reflecting the combination of unique characteristics embedded in each of these factors, every instance of decision support is likely to reflect to differing degrees the rights-based expectations embedded in the CRPD. This type of generic model of the process of support, however, does not explore the specific support strategies or other factors associated with effective or rights-based support.

The factors most consistently identified as contributing to a rights-based approach to decision support are a trusting relationship between a supporter and a person with intellectual disabilities, knowledge about the person, familiarity with their modes of communication, commitment to their right to participate in decision making and positive attitudes toward risk (Burgen, 2010; Douglas et al., 2015; Watson, 2016). Some evidence suggests that the nature of informal support for decision making from either parents or paid staff has changed little over time and lags behind expectations of the rights-based paradigm shift as decision supporters struggle to resolve conflicting imperatives of rights, risks and practicalities (Bigby et al., 2019; Devi et al., 2020; Mc Kearney, 2020a, 2020b; Pilnick et al., 2011).

The challenge for decision supporters is often portrayed as a binary between paternalism, acting in the best interest of the person, and empowerment, respecting rights to exercise choice and participate in decision making (van Hoothen et al., 2002). The reality is more complex, particularly for family supporters as Browning’s model of the factors influencing processes of decision support suggests. For example, Curryer et al. (2015, p. 394) propose that “family support is provided on a continuum from proactive empowerment to fear-based protection.” A later paper from the same Australian study suggests that the role of mothers in supporting decision making varies from that of a facilitator of implementation, a guide, an influencer and in some cases a final decision maker (Curryer et al., 2020). The mothers in that study were concerned not only about the consequences of decisions for their adult son or daughter but also consequences for themselves. That study showed that decisions were often negotiated between mothers and their adult children who appeared happy to accept restrictions on rights, regarding it as a sign of love. Similarly, a Canadian study found that family supporters tried to balance the needs and preference of their young adult with intellectual disabilities with those of the whole family system, and at times, used moral justification to override their preferences (Taylor et al., 2019). These studies demonstrate the influence on decision making that family supporters wield because of their strong, close and long-term relationships with their adult child with intellectual disability.

Weighing differences between a person’s underlying will and immediate preferences pose a challenge for supporters (Carney et al., 2019). A recurring theme in studies of family support suggests that parents formulate long-term visions for their adult child’s life, such as being independent, having a job or leaving home. These aspirations act as proxies for their will, influencing the long-term direction of parental guidance and decision support (Bigby et al., 2019; Curryer et al., 2015, 2020).

Internationally, supported decision-making schemes have not been widely adopted despite the deliberations of Law Reform Agencies in many jurisdictions (Then et al., 2018). In Australia, there is growing likelihood of a support for decision-making scheme for participants of the National Disability Insurance Scheme (NDIS) (Then et al., 2018). This likelihood has been driven by flaws in the design of the NDIS (2013), which included among its aims the increased choice and control of people with disabilities over services (Cu kalevski, 2019). Since its introduction, a reversal of the downward trend in guardianship for adults with intellectual disabilities has occurred, and growing evidence suggests that this group is not participating in planning processes (Bigby, 2020). Building the capacity of decision supporters will be fundamental to any supported decision-making scheme, and furthering the rights of people with intellectual disabilities to participate in decision making regardless of whether decision support is formalised or remains informal (Carney, 2017). Deeper understanding of the issues that supporters find difficult and their strategies for resolving these will help to inform capacity building for supporters.
This study is part of a program of research about the experiences of receiving decision support by adults with cognitive disabilities and of supporters in giving support. The research is informed by an evidence-based support for decision-making practice framework (Framework) (Douglas & Bigby, 2020) developed as a guide to assist supporters to focus on understanding and acting on the will and preferences of the person they support. The Framework conceptualises support for decision making as requiring seven iterative steps, delivered through individually tailored strategies and informed by three principles (see Figure 1).

The focus of this study is steps 3 and 4 of the Framework. In step 3, understanding the person’s will and preferences for the decision, supporters assist the exploration of all possible options and preferences by taking a “blue sky” approach unencumbered by constraints. In step 4, supporters consider refining the decision to take account of constraints. These steps were selected as the ones our data suggested posed most challenges for parents. Accordingly, the study aim was to gain a greater understanding about issues parents found difficult in providing support during these steps of decision support and the strategies they use to resolve these. The research questions were (1) what do parents of adults with intellectual disabilities grapple with in providing support for exploring preferences, decision constraints and consequences of decisions and (2) what strategies do they use to respond to these issues. The data reported in this paper are a sub-set from the larger study and do not include experiences of the adults supported.

**Methods**

We used a social-constructionist theoretical perspective, reflecting the focus on the subjective realities of decision supporters of people with intellectual disabilities (Bryant & Charmaz, 2007). In keeping with this perspective, an exploratory qualitative design was used to generate data using semi-structured interviews and template analysis (King, 1998). Approval was given by the University Human Research Ethics Committee and all participants gave informed consent to participate.

**Sample and recruitment**

Following a purposive sampling approach, participants were recruited by distributing information about the study through the industry organisations that were research partners and the researcher’s networks of advocacy, parent and disability support organisations. Participants were 23 parents who regularly provided decision support for their adult child with intellectual disabilities, and who were willing to participate in multiple interviews over time about their decision support. Parent’s ages ranged from 47 to 74 years with a mean of 58 years, and three-quarters (18) were mothers. They lived in the three Eastern Australian states, Victoria, Queensland and New South Wales. The adults they supported ranged in age from 18 to 39 years with a mean of 27 years. Most of the adults (19) lived at home with one or both of their parents. The severity of their intellectual disability was reported by parents and ranged from profound to mild.

**Data collection**

Each parent was interviewed at least three times during the course of the study. A semi-structured interview was used to ask parents to reflect on support they provided for decision making and to describe a recent instance in detail. The number of interviews with each parent varied as some were also involved in a training program and follow up mentoring that further explored their decision support. Four parents participated in 3 interviews, 16 in 4 interviews and 3 in 7 interviews. Nineteen parents participated in one or more mentoring sessions.

The initial interview was conducted face to face and subsequent interviews by phone, in person or using video conferencing. Interviews lasted between 60 and 90 min and were conducted by the third author and an experienced research assistant between December...
2016 and June 2020. Interviews and mentoring sessions were digitally recorded and transcribed.

Data analysis

NVIVO v.12 qualitative analysis software was used to support the analysis and manage the data. A template approach was used (King, 1998), which, similar to Charmaz’s (2003) sensitising concepts, meant some codes were defined prior to the analysis. The template codes were based on steps 3 and 4 of the Framework (understanding the person’s will and preference for the decision and refining the decision and taking account of constraints) and other codes were developed inductively as the analysis progressed. Line by line coding, using grounded theory techniques (Bryant & Charmaz, 2007), was followed by focussed coding to identify themes, which were then refined into broader thematic categories. The analysis was undertaken by the first author in regular discussion with the second author. The emergent themes were then discussed and refined further with the other authors.

The core categories are illustrated with quotes. The source of quotes is indicated by the name of the parent and a number signifying which interview they came from, i.e., Jane, 3 indicates the quote is from the third interview with the parent Jane. All names have been changed to provide anonymity.

Findings

All the parents had provided support for their son or daughter with a broad range of decisions for many years and suggested they knew him or her extremely well, perhaps, more so than anyone else in their life. The findings fell into three core categories, making the right decision, factors that made decision support difficult and strategies to manage uncertainty. These together with sub-categories are represented in Figure 2.

“Making the right decision”

Parents found it difficult to manage the high degree of uncertainty inherent in decision support, wanting to ensure, but never being certain, that their support would eventuate in what they thought would be the “right” or “appropriate” decision. Kate captured this sense of uncertainty when she talked about a health-related decision.

But the point is you don’t have a double-blind trial. There isn’t someone over there who has got the alternative choice to operate with. So, you just don’t know until you get to the end of this if ever, whether that decision was right or not. (Kate, mentoring)

What the right decision might be was subjective, shaped by the values and judgement of supporters. Bernice and Gabby’s comments about supporting their adults with intellectual disability illustrated this subjectively. Bernice (3) said “…I really want to be confident that she [daughter] is making what I would regard as good choices” and Gabby (4) “…as long as they’re not poor decisions because that’s our job too to make sure that he’s not making poor decisions.”

Parental investment in reaching the right decision varied, mediated by the nature of the decision and the perceived consequences of making a “wrong” decision, for both themselves and the person they supported. As Samuel’s comment illustrates, some parents were relatively unconcerned about decisions when they thought the outcome was unimportant and provided little support to explore preferences about such decisions, he said “there’s some decisions without consequence and I’ll let him do it. So, making a decision on a meal, it’s up to him totally.”

Notably, the topic of a decision per se or other features such as scope were not good indicators of parental investment or perceived consequences. For some parents such as Samuel, what his son ate was inconsequential; but for others, such as Bernice, discussed below it was very important.

Factors that made decision support difficult

For those decisions that mattered to them, the doubts that parents harboured about reaching the right decision centred around their perceptions of the adult they supported. Of particular concern to parents was their son or daughter’s limited awareness of possibilities and poor insight about options, constraints or consequences of the decision.

Limited awareness of possibilities, “it’s more of an abstract kind of idea”

In step 3 of the Framework, supporters are encouraged to take a “blue sky” approach in exploring possible options for the decision and the person’s preferences about these. Parents often thought that the preferences their adult expressed were too narrow and not sufficiently well informed or forward looking. They saw this as stemming from the adult’s limited life experiences and their intellectual impairment, which hindered thinking on a conceptual level or imaging possibilities beyond their own direct experiences. Concerns about having a too narrow view spanned many types of
Making the right decision

Factors that made decision support difficult
- Limited awareness of possibilities
- Limited understanding of constraints and consequences
- Immediate impact on wellbeing
- Longer term impact on goals
- Time factors

Strategies to manage uncertainty
- Controlling
- Influencing
- Expanding horizons and enabling risk

Figure 2. Diagram showing core categories.

decisions, from scheduling regular activities to setting life goals. Parents said for example:

So, the scheduling ... it’s more of an abstract kind of idea ... he wouldn’t be able to say, “Look, you know, let’s move this class to Wednesday nights and I can pick something else up on Monday.” (Joanne, 1)

I just am really conscious of the big picture that I’m trying to work towards for Sally when she might not have the capacity to think in those same big terms. (Bernice, 2)

Parents were also concerned about the adults’ limited experiences of decision making, of being asked to express their preferences, having their preferences respected and trying out new options. They thought these factors limited the adult’s willingness to try out or explore new options, and often led to deference to the suggestions of others rather than expressing their own preferences or saying no to what was offered. Parents said for example:

... he often will say no to things and you know that if you can just get him over that little speed hump he’ll really get a lot out of it. (Alannah, 3)

Limited understanding of constraints and consequences, “those things that she might like are not the best things”

Parents found it difficult to respect preferences when they felt the potential consequences of a decision were not understood. This was most challenging in situations when parents thought the person’s wellbeing might be jeopardised if an ill-conceived preference shaped a decision.

Parent’s perceived potential jeopardy to wellbeing embedded in preferences in many different situations. First were those where respecting a preference might lead to tangible harm to health or wellbeing. Such decisions concerned things such as eating habits, accepting necessary support, going out alone or being placed in a context that might provoke a heightened sense of anxiety. Brett talked, for example, about the situation he had faced where respecting the observed preferences of his daughter might cause her physical discomfort. He said:

Well, there’s her preference, to eat everything that’s in front of her, or everything she can see, or everything that’s in her lunch box straight away at morning tea-time. That seems to have communicated a clear preference for her. The thing that that needs to be weighed up against is whether – if she eats everything, and then she has the water that she really should have, at that point in time, it could actually overfill her. And it can lead to gagging, possibly vomiting. (Brett mentoring, 3)

Similarly, Kate talked about the possible negative consequences of respecting her son’s preferences to be left alone without a carer overnight. Relaying an earlier conversation, she said:

[and he said] ... “I’m 21 now, I’m a grown up, I can do this myself.” I said, “Oh, so you can get yourself out of
bed, into your wheelchair, onto the toilet, wipe your bottom, get back into bed?” “No,” he said. (Kate mentoring)

The second type of situation concerned decisions that might result in less tangible compromises to wellbeing by obstructing longer-term goals. As these quotes illustrate, preferences might undermine realisation of goals around things such as skill development, independence or moving out of the parental home. Parents said for example:

… her idea of a plan would be that she’d like to work there [supported employment service] five days a week. I don’t see that as the best plan for her because I think there are now possibilities that weren’t there before that she should explore. (Jodie, 1)

So, everything we do is to work towards independence. Yeah, independence. … well, I did know I didn’t want him living with me when I was 80 … . (Margot)

The extent to which preferences were realistic was also difficult for parents. Many felt the adult they supported did not fully grasp practical constraints on their preferences, such as availability of resources or the skills required. As Kate said:

… He might have a really grand idea about what he’s capable of doing… he has unrealistic expectations about what could happen or what he can achieve. So, it’s about managing his expectations about what he can expect from life. (Kate, mentoring)

Related to issues of realism, some parents felt that a limited understanding of constraints and consequence led to overconfidence that had to be managed. This situation was captured by Kate’s (1) comments about her son, “the difference between ability and confidence is risk. That’s what it is. And you’ve got to close that gap.”

A third type of difficult situation related to time factors, when parents thought either delaying or prematurely exploring options and preferences might compromise longer-term wellbeing. For example, some parents felt they should begin supporting exploration of preferences about moving away from the family home, in order to ensure adequate time to fully consider options before circumstances arose that might dictate the decision had to be made quickly. As Susan (1) expressed, there was an “answer that needs to happen.”

**Controlling**

When parents felt a high level of certainty that the person’s immediate wellbeing would be jeopardised if their preferences were respected, they inserted their own preferred option at step 4 when they were supporting refinement of the decision to take account of constraints. This response meant parents either did not consult the person at all or ignored and overrode their preferences. The decisions where this occurred ranged from being about medical care to taking holidays, and commonly concerned jeopardy to health or mental health. Parents said for example:

I won’t let him do anything injurious to his health like take drugs that aren’t prescribed or do something that might break his legs, but apart from that he can just do anything he wants with sufficient support if he chooses to. (Kate, 1)

… I plan his whole universe without telling him … I’ve planned another week off in October to take him away for a couple of days. But I won’t tell him until a couple of days beforehand. Or otherwise, he just gets so hyped that by the time you come to get out the door, there can be tears and all sorts of difficult behaviours. (Alannah, 3)

Notably however, although parents foreshadowed this type of strategy, they gave few examples of where it had occurred.

**Influencing**

More often parents used a range of subtle strategies to manage preferences they thought might compromise longer-term wellbeing. These strategies could be characterised as purposefully trying to influence the options considered or the adult’s preferences so they fell within the parameters of what parents thought would be the right decision. As Iris (1) said about supporting her daughter, “what I do is try and influence her to make the decision that I think she should make.”

One way parents exerted influence was creating artificial boundaries around the options they supported the adult to explore. In many ways, this amounted to imposing constraints on the decision before fully exploring options. Bernice’s comments about having instigated a family culture for decisions about food, which effectively restricted options to those she thought were healthy, illustrated this strategy:

… our family culture is the way we do things around here. Where health and food are concerned, we’re going to have fruit for breakfast and we’re going to have salad with our main meal. … in a way, I’m not allowing too much independent decision-making where those high-level goals are so important. But then I’ve also [left some decisions more open] – do

**Strategies to manage uncertainty**

Parents used three broad strategies to manage their concerns about reaching the right decision while also trying to respect the preferences of the person they supported: controlling, influencing and expanding horizons.
you want to have a salad or do you want to have hot vegetables? (Bernice, mentoring)

Another strategy for influencing was illustrated by Kate who strategically limited options she supported her son to consider to those she thought likely to lead to the right decision. Pursuing this strategy sometimes meant that parents did much preparatory work around some options, which were thus much more well developed than others. As Kate said:

I’m going to have a look at lots of other things and then I’ll come to you with the ones that I think are the best and you’re going to choose. (Kate, 1)

A related strategy was to avoid exploring associated decisions that might flow from the persons preference or simply delay exploring some options. For example, Nikki talked about not raising with her daughter decisions that might follow from staying over at her boyfriend’s house:

… she doesn’t seem to give me the impression she really understands what the next step is. And I’m not sure I want to tell her … Well we’re just going to string it along and have the sleep overs for a bit. (Nikki, 2)

Parents referred to themselves as being “a great salesperson” (Bernice, 2) or having to “do some manipulation” (Margot, 3). Some persuasive strategies involved presenting options in particular ways, such as being selective about the pros and cons, emphasising some options over others and phrasing information so as to obscure some options. For example, Nikki said:

Once I’ve said, “Do you want to come for a walk” and she’s answered no well then that’s it … I should have worded it a bit differently, maybe if we go for a walk around there we might stop at that coffee shop. That would get her to go for the walk. (Nikki, mentoring)

Rather than withholding information about options or framing them in a certain way, another strategy was to proactively put a decision on the agenda and begin discussing options. Samuel reflected how he had done this.

We’re starting to work on a decision about his accommodation but that’s longer term so I’m bringing it up slowly to help him come up with a decision. (Samuel, 2)

Expanding horizons and enabling risk

In contrast to controlling or influencing, many parental strategies for managing uncertainty could be interpreted as coming from a developmental perspective. They involved supporting the person to explore their preferences further or expanding the options being considered before acting on expressed preferences. For example, both Nara and Kate talked in very similar ways about the support they had provided to their daughter and son, respectively, about deciding to go to a respite service. Kate said:

… he needs to experience what it’s like to be out there with people who he knows and gets on with and seeing what that’s like. Because without experiencing it he actually isn’t going to be able to make a decision. So, it’s about getting him to understand what that means. (Kate, 1)

Similarly, another strategy was to enable the person to experience and learn from the consequences of their preferences, despite the potentially risk averse effect on their wellbeing of doing this. Talking about his son and decisions about social or leisure activities, Samuel explained how he used this strategy with his son:

… he can’t see it’s going to affect him, so I just wait until it happens, and it’s usually not a high consequence problem. It’s almost like fall and then realise I can pick him up … (Samuel, 3)

Nara talked about the learning that had resulted for her daughter from giving her the experience of buying clothes alone, which resulted in significant overspending of her own money, and Joanne about helping her son to realise the consequences of his preferences for certain types of food:

… I think he’s starting to make the connection because sometimes when he’s insisted on having that food we’ve gone “alright” and then that evening he’ll have a sore tummy and he’ll be feeling quite average, quite poor so we’ll say “alright well this is what you wanted to eat and this is how it’s made you feel now.” (Joanne, mentoring)

In adopting this strategy of learning from what might be regarded as poor judgment, parents tried to ensure a safety net was in place to minimise negative experiences, as Margot explained about her son’s preference to travel independently:

I feel the decisions he makes now are far better, but we had to work through that. And I let him get lost. I just let him take photos of where he was, the street signs, and tell me where he is and then go and get him. I decided – he actually learns that he can’t just get on any tram and go around the country … he was pretty scared when he got lost out. (Margot, 1)

Other developmental strategies involved building the adult’s confidence and trust in their own preferences or judgments. This approach meant parents actively tried to listen more carefully to what the person said about their preferences, as these comments from Catherine and Joanne illustrate:

… I listen to him more. I’m more aware of his body language … And I make a point of talking with him. Sit down and having a yarn. And trying more and
more to affirm his decisions. “good choice, mate.” “good thinking.” (Catherine, 2)

...we’ve sort of taken a step back and just listened to what he’s actually saying. ... it was really good to have him express himself like that, and to be able to listen to what he’s actually saying and do something about. (Joanne, 2)

Confidence building strategies extended to encouraging the person to be more assertive about their preferences, and parental actions to raise expectations that paid workers would more actively support expression of preferences. This type of strategy was illustrated by Kate talking about her interactions with her son, and Joanne talking about her instructions to her son’s support workers:

... what I’ve tried to do is make Jasper speak for himself, and the first place he has to do that is with me. So, I have to allow him to say what he wants, express what he needs, and even show anger ... he also is learning to say, “No, I don’t want to do that, I don’t like that.” ... “I want to go and do this instead.” (Kate, 1)

We expect you to have a conversation with Brendon, don’t make all his choices for him. Encourage him to speak to you, express himself ... express ideas and things that he wouldn’t necessarily talk to us about perhaps. (Joanne, 2)

Some parents were aware of the influence they often exercised as they supported decision making. As Nikki said, “I worry about it sometimes that maybe I’m not giving her the choice” (Nikki, 2). One strategy to curb their influence was to consciously try to reduce their investment in reaching the right decision and be more confident in the person’s own judgement. For example, Mary talked about leaving her daughter to make decisions for herself even though she was not sure they would always be the right ones, and Bernice about widening the parameters around options she offered:

...the important thing is to provide Sally with practice decision-making. ... what I’ve done always is just get the list and you’ve got to select and rank order ... this time I thought I’ll print this out and show it to Sally, discuss it with Sally and give her an opportunity to actually select stuff. (Bernice mentoring)

Discussion

The findings suggest that the parents in this study were deeply committed to the wellbeing of their adult son or daughter, which at times meant they compromised their rights to participate in decision making or overrode their preferences. Parents were challenged by the uncertainty inherent in supporting decision making, wanting to ensure the “right” decision was made, while also recognising the subjectivity of this. It was clear, however, that parents understood the “right” decision in terms of outcomes rather than a participatory decision-making process.

Our findings point to the multi-layered nature of decision support and that making judgements about the extent to which decision support strategies are rights-based and empowering relies on interpreting supporter intent and actions as well as outcomes for the person being supported. For example, we identified some parental strategies that at first glance appeared paternalistic, but when explored further, could be interpreted as fostering greater participation in decision making by the adult, by expanding their repertoire of experiences and better equipping them to express preferences in the future. Examples included parents disrespecting a person’s initial preferences and exploring others or foisting experience of additional options on the adult before settling on a preference. Such strategies can be interpreted as widening the decisional frame, in order to both manage risks to wellbeing arising from preferences that result from having only experienced narrow options and an intention to develop the adult’s skills and experiences in order to increase their participation in future decision making. From another perspective, it could be argued however that such strategies are unjustified, and may be coercive or detrimental to short term wellbeing. For example, McKearney’s (2020a) ethnographic study describes the immediate anguish strategies of this type caused to one man in an accommodation service.

Assessing the quality of decision support and judging its alignment with principles embedded in supported decision-making schemes should be an important safeguarding feature of any future schemes. Finding ways of doing this warrants further exploration. Elsewhere we have argued that focussing on the deliberative and reflective nature of practice to judge its quality may be preferable to focussing on outcomes (Carney et al., 2021), and that the Decision Support Questionnaire we have developed shows promise as a reliable tool to measure shifts by supporters towards greater use of rights-based strategies (Douglas et al., 2020).

The parents in this study reflected that it was not just the limited intellectual capacity of the adult they supported that meant they needed support or struggled to make the right decision but also their limited experience of options and of decision making itself. These parental
perspectives reflect the shift away from assuming problems lie in the static concept of capacity to a more fluid and dynamic approach that recognises decision making capability can be built through experience and good support. Parents managed their son’s or daughter’s limitations with decision making through a blend of restrictive (controlling and influencing) strategies and developmental or empowering (expanding horizons and enabling risk) strategies. These findings clearly illustrate the broad spectrum of strategies a parent might draw on depending on the decision and its context that has been identified in other studies (Browning et al., 2020; Curryer et al., 2020; Taylor et al., 2019) and the dangers of simply labelling a parent as paternalistic.

Some parental strategies, particularly those involving controlling or influencing, were undoubtedly intended to shape preferences. This shaping occurred through curtailing options for consideration, in effect narrowing the decision field. The pattern and frequency of parents’ use of this type of strategy suggests a tendency to skip step 3 in the La Trobe support for decision-making practice framework and think about constraints (step 4) before fully exploring options and preferences (step 3). That parents seemed to do this unconsciously rather than deliberately, points to the importance of training in decision support, and using the La Trobe support for decision-making practice framework to act as a reference point to guide parents’ consideration of each step of the process.

These findings also demonstrate the extent that parents exercise power in the decision support process but that parental support strategies are mediated by the context and nature of each and every decision, reflecting the utility of Browning’s model (2018). Illustrated particularly were the differing degrees of investment parents had in the outcomes of different decisions and the influence anticipated risks to short- or longer-term wellbeing had on their support strategies. This influence of perceived risk highlights the importance of the principle of reflection and review in the La Trobe support for decision-making practice framework and the need to build the capacity of supporters to be consciously aware not only of the strategies they use but also the factors influencing them and the drivers behind them. The principle of orchestration is an important adjunct in the Framework to that of self-reflection, and entails bringing into the decision support process supporters outside close parental relationships who may bring different perspectives that help to illuminate unconsciously held positions by complementing or challenging them.

These findings suggest the limited value of typologies that attempt to sort and label decisions into types such as big or little, significant or minor, based on topic or magnitude. Such labels ignore the significance of context and the individuals’ characteristics to every decision; as shown in our data, where the same topic, what to eat or how much to eat, can be very significant for one adult and inconsequential for another. This situation points to the dangers of restricting supported decision-making schemes or mechanisms for accountability to particular “types of decisions” and the importance of referencing each decision back to the individual and their context.

The findings can be interpreted using the lens of risk and show for the first time how parental support strategies may align with good practice for enabling risk, which to date has predominantly been explored in the context of paid supporters (Bigby, Douglas, & Hamilton, 2018; Bigby, Douglas, & Vassallo, 2018a). Parents used strategies for managing uncertainty and risk to wellbeing in ways that did not curtail participation in decision making. Indeed, some parental strategies reflected the contextually situated and person-centred responses to risk, that Kemshall (2014) argues, are necessary to good practice. Such strategies compare favourably to the predominantly risk adverse practices reported by staff in intellectual disability services that tend to restrict rather than empower rights (Bigby, Douglas, & Hamilton, 2018; Bigby, Douglas, & Vassallo, 2018a, 2018b; Lafferty et al., 2012; McKeeney, 2020a, 2020b). The nuanced examples of parents enabling risk illustrated in the study will be useful additions to existing training materials. The community care risk literature tends to characterise the tension between supporting service users’ choice and control and ensuring their safety and wellbeing as a binary choice versus protection, either-or option to be weighed against each other (van Hooren et al., 2002). In our findings, some parental strategies were developmental and supported risk taking to enable the person to learn from potentially negative experiences, such as getting lost on public transport. In a service context, Sawyer and Green (2013) refer to this as risk benefit assessment – identifying the benefit to wellbeing of risky preferences and the risk of loss of wellbeing if preferences are not respected. This approach resembled that commonly found in dementia care services, which aim to respect individual’s preferences and find ways of realising preferences that minimally interfere with the chosen option, but which also reduced the risk of harm or minimise harmful impact should a negative outcome eventuate (Department of Health, 2010).

Reflecting other recent research on parental decision support for people with intellectual disabilities (Curryer et al., 2020; Taylor et al., 2019), and also those with
acquired brain injury (Knox et al., 2016), the present study found that parents had long-term visions for their adult son or daughter, which were taken as proxies for the person’s will and which influenced support strategies. For example, such visions were reflected in the types of options parents spent more time researching, tried to influence their son or daughter to prefer or the timing of putting certain decisions on the agenda. While there were some examples of these directions being embraced by their adult sons or daughters, there were none where parents spoke about their involvement in determining these visions. The growing Australian literature about planning in the NDIS indicates that adults with intellectual disabilities are commonly left out of planning meetings that set their overarching goals (Bigby, 2020) and that planning processes align poorly with the principles of person-centred planning (Carney et al., 2019). The centrality of long-term visions to decision support strategies and which act as a proxy for a person’s will, demonstrated in the present study, suggests the importance of adequate resourcing and external support for planning and review processes to ensure each individual’s goals are regularly and fully explored in a way that includes them and their wider network of paid and unpaid supporters. Only through processes such as person-centred planning (Lyle O’Brien & O’Brien, 2002), can it be assured that the perspectives other than those of parents inform goals established for people with intellectual disabilities and consequent decision support strategies.

Limitations
The sub-set of data reported in this paper explored parental decision support practice in depth through multiple interviews with each parent. In this study, we were interested in understanding what parents grappled with in providing decision support and their strategies for managing the difficulties they encountered rather than charting change over time in their support practice. The study relied on parents to recount their approaches and did not capture the experience of the adults with intellectual disabilities who were supported. The study included a small number of parents of adults with more severe and profound intellectual disabilities who themselves would have not been able to participate other than by use of time intensive observations, which was not feasible within our available resources. Our analysis did not attempt to compare parental difficulties or decision support strategies according to the severity of intellectual disability of their adult. The decision support experiences of adults who were able to participate in interviews are reported in a paper currently in preparation and the impact on parents of training and mentoring in the La Trobe support for decision-making practice framework is reported in a paper under review at the time of writing (Bigby et al., in press). It must also be acknowledged that all the parents who participated in the study were volunteers, interested in decision support and cannot be taken to be representative of parents of adults with intellectual disabilities in general.

Conclusions
The findings of this study provide an in depth and nuanced account of what parents grappled with when supporting decision making of their adult sons and daughters with intellectual disabilities and the strategies they used in doing so. This understanding adds further knowledge about the experiences of parents in supporting decision making that can be used to complement existing evidence-based training resources about decision support (Bigby et al., 2019) and enabling risk for people with cognitive disabilities (Bigby, Douglas, & Hamilton, 2018; Bigby, Douglas, & Vassallo, 2018a, 2018b). It will help in building the capacity of parents to provide decision support that better understands and respects the will and preferences of the person they support. The multi-layered nature of decision support evident in this study suggests empowering intent may underlie seemingly paternalistic practices. The insights into strategies parents use to influence preferences highlight the importance of supporting parents to reflect on their own practice as part of building their capacity. These findings also suggest the need for accountability mechanisms as part of any supported decision-making scheme that can interrogate the support process, asking questions such as how goals that inform options were arrived at, what options have been considered and how and why some were rejected. The study also points to the importance of building rigorous and robust mechanisms for person-centred planning into the disability support system to ensure adults with intellectual disabilities and others who know them well, in addition to parents, participate in articulating their will and developing long-term life goals. Finally, and on a more positive note, this study illustrates the breadth of developmental and empowering strategies parents use to enable risk taking and its consequent benefits in terms of learning and expanding the horizons of the supported adult.

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