

Moving from Support for Decision-making to Substitute Decision-making: Legal Frameworks and Perspectives of Supporters of Adults with Intellectual Disabilities

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ABSTRACT

The United Nations Convention on Rights of Persons with Disabilities (UNCRPD) has significantly changed the way our society views models of decision-making for adults with cognitive impairment. The formerly-accepted substitute decision-making models – where a person can legally make decisions for an individual, often guided by the ‘best interests’ principle – are considered less desirable than supported decision-making which prioritises an individual’s ‘will, preferences and rights’. However, disciplinary differences in understandings about what these concepts entail and how they should look in policy, legal and practice frameworks persist.

For many, supported decision-making is experienced through informal support for decision-making through close family, and in the absence of a legal appointment. What this support looks like and whether it can help achieve the aim of greater participation by people with intellectual disability is still being empirically examined. In addition, the circumstances when that support moves into informal substitute decision-making is largely unexplored. It is also unclear whether the reasons for such a shift mirror the legal requirements for the appointment of a formal substitute decision-maker under Australian law.

This paper uses a subset of qualitative data from interviews with parents who act as supporters to adults who have an intellectual disability. The overall aim of the study was to explore the impact of training in applying a practice framework (the La Trobe Support for Decision Making Practice Framework) about effective support for decision-making. We show that promising development is reported from the impact of capacity-building training for supporters, with evidence that the decision-making capabilities of adults with intellectual disabilities can be seen to shift over a period of time and training informal supporters can be effective in moving the dial as to when a supporter finds it necessary to step in and make a substitute decision. However, we also demonstrate that considerations of

'risk' and future opportunities for the supported adult are nuanced factors taken into account by supporters who shifted into a substitute decision-maker role and this is not well accounted for in our legal frameworks.

Keywords – substitute decision-making, supported decision-making, intellectual disability, UNCRPD, Law

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1. INTRODUCTION

The United Nations Convention on Rights of Persons with Disabilities (UNCRPD) marked a significant shift in the way society considers adults with disabilities, including cognitive disabilities (Kohn, Blumenthal, and Campbell 2013: 1120; Quinn 2020). It continues to shape government disability policies globally, many of which emphasise that people with disability are entitled to fully participate in community life, live independently and access services equally (Australian Government

2021; European Commission 2021). Article 12 of the UNCRPD has acted as a catalyst in re-shaping policy about, and sometimes legislative approaches to, models of decision-making for adults with a cognitive impairment. Significantly the historical norm of paternalistic substitute decision-making on behalf of people with disabilities (i.e. where a person can legally make decisions for an individual, guided by the 'best interests' principle) is now less acceptable, and instead, supported decision-making which prioritises an individual's 'will, preferences and rights' and decision-making autonomy is

considered a better approach. Article 12 recognises the right of people with disabilities to ‘enjoy legal capacity on an equal basis with others’ and requires State parties to ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’ (UNCRC art 12, (2)-(3)). This formed the basis of the concept and practice of support in decision-making or supported decision-making.

While no fixed definition exists, the term supported decision-making has been applied in relation to the practical process of providing support in decision-making and the legal recognition of the concept (Browning, Bigby, and Douglas 2014: 693). Both aspects of supported decision-making aim to maintain or extend a person’s involvement in making decisions affecting them for as long as possible, as an alternative to more restrictive substitute decision-making which necessarily removes rights from individuals. However, as discussed below, a lack of a fixed definition and disciplinary differences in understanding around terminology can lead to difficulties.

While still relatively uncommon, there is increasing legal reform globally leading to formal recognition of supported decision-making (e.g. *Assisted Decision Making (Capacity) Act 2015* (Ireland); *Powers of Attorney Act 2014* (Vic), Pt 7; Largent and Peterson 2021). This has occurred in different ways that range from formally recognising the supporter role – including articulating a method of appointment, expressly granting supporters specific rights (e.g. access to information) (see Then 2013: 148-154) – to merely recognising in general principles the preference for support in decision-making to occur before any substitute decision-making occurs for an individual.

Australia ratified the UNCRC in 2008 but made an interpretive declaration relevant to article 12: ‘Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards.’ (Australian Government 2008)

The UNCRC Committee has recommended Australia review this interpretive declaration (Committee on the Rights of Persons with Disabilities 2013) and has expressed the view that substitute decision-making legal frameworks are largely inconsistent with the UNCRC and called for their abolition (Committee on the Rights of Persons with Disabilities 2018: [7]). While the UNCRC Committee’s views are not binding on Australian governments, their comments are considered highly persuasive and may be looked to in interpretation of the UNCRC (McCallum 2020). Despite this, many countries – including Australia – maintain substitute decision-making laws and, where relevant, view formal recognition of supported decision-making as an adjunct to substitute decision-making frameworks (Then et al. 2018: 73).

This paper describes the legal substitute and supported decision-making frameworks (excluding mental health legislation) that operate in Australian jurisdictions and goes on to offer some insights into the lived experience of those providing informal support to adults with an intellectual disability. We use the term ‘informal’ here to indicate where a person in a supporter or substitute decision-maker role acts in that role without a specific legal appointment (e.g. has not been appointed as a supportive attorney, a guardian or enduring power of attorney). In this paper, whether the person acting in those roles is paid or unpaid is not relevant to them being an informal or formal supporter or substitute decision-maker. The importance of informal supporters is recognised in the Australian Government’s Disability Strategy 2021-2031 where it states that ‘supporting individuals and organisations who provide informal care and support can increase the participation of people with disability in community life’ (Australian Government 2021).

Our paper demonstrates that, while promising development is witnessed from the impact of capacity-building training for supporters, individuals providing support often move from a supporter role to an informal substitute decision-maker and back again depending on the decision and circumstances relevant to that decision. While this move is perhaps not surprising, we elucidate the tensions that exist between trying to offer

good support for decision-making, and balancing immediate choices with long term aims within a support dyad. It also demonstrates that the issue of ‘risky’ decision-making by an adult – a factor that is legally relevant in some jurisdictions – remains a vexed practical issue, with supporter subjectivity in assessment of risk for different decisions sometimes resulting in a slide into substitute decision-making by some supporters.

2. UNDERSTANDINGS OF SUBSTITUTION AND SUPPORT

The extent of practices that constitute support for decision-making and substitute decision-making can blur at the edges – particularly in the context of ‘informal’ supporters and substitute decision-makers. We have found that understandings of these theoretical concepts and practices are often dependent on disciplinary perspectives and nuanced understanding of CRPD Committee interpretations. The distinctions between these two concepts and practices, and intertwined terms such as ‘will, preferences and rights’, are arguably emerging with academic discussions of their meanings still ongoing (Carney et al. 2019). This is perhaps most clear when we consider legal understandings of what constitutes substituted decision-making as interpreted by the UNCRPD Committee.

In seeking their abolishment, the UNCRPD Committee has defined substituted decision-making regimes in the following way:

Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where: (a) legal capacity is removed from a person, even if this is in respect of a single decision; (b) a substitute decision maker can be appointed by someone other than the person concerned, and this can be done against his or her will; or (c) any decision made by a substitute decision maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences. (Committee on the Rights of Persons with Disabilities 2018, [27])

This definition largely accords with legal understandings of formal substitute decision-making: it relates to when legal authority is given to another to make a decision on behalf of an individual (usually due to decision-making incapacity). Indeed, in all Australian jurisdictions, legal substitute decision-making frameworks still provide for (a) and (b) to occur. However, interpretation of (c) leads to additional questions. While substitute decisions can be made by another person under guardianship and related legislation, often this will not necessarily be in accordance with an ‘objective “best interests”’ test. Most Australian substituted decision-making legislation is now informed by human rights developments and substitute decisions are often informed by principles that prioritise what the adult would have wanted (White, Willmott, and Then 2018: 210-213). Only in Victoria has the legislation explicitly adopted the ‘will and preference’ terminology (see e.g. *Guardianship and Administration Act 2019* (Vic), s 9).

However, in recognising that for some individuals, it may be impossible to determine their will or preference, it has been conceded that an alternative, ‘best interpretation of the will and preference’ standard should be applied as a last resort.

This standard implies ascertaining what the person would have wanted instead of deciding on the basis of her/his best interest. The process should include consideration of the previously manifested preferences, values, attitudes, narratives and actions, inclusive of verbal or non-verbal communication, of the person concerned. (Special Rapporteur on the Rights of Persons with Disabilities, 2017: [31])

While debates continue on how to understand and apply the ‘best interpretation of the will and preference’ standard (see Skowron 2019; Carney et al. 2021), many consider this to be a form of supported decision-making rather than substitute decision-making. This can be most relevant in the context of those who support people with severe and profound cognitive disabilities, where those who know those individuals best make decisions for them, but using their knowledge of the individual, rather than a best interests model, to inform their decisions (Mackenzie and Stoljar 2000; Bach 2017;

Watson, Wilson, and Hagiliassis 2017). The central aspect of providing support in decision-making is placing the person being supported at the centre of decisions and to have them participate meaningfully to the extent possible, even if not directly. This much is recognised in the La Trobe Support for Decision Making Practice framework (Douglas and Bigby 2020).

From a legal perspective, this can seem to be stretching the meaning of support – both as a colloquial term, but also in relation to how it has been translated into legislation – as some would consider this type of approach to already be included as an example of ‘good’ substituted decision-making under the existing Australian decision-making frameworks (see e.g. Victorian Office of the Public Advocate 2020: 7-11). Legal frameworks necessarily have to draw a line between support and substitution, whereas many would see the practices of support and substitution as a continuum.

What this reveals is the extent of potential overlap between the practice of support in decision-making and substitute decision-making. These differences go beyond an issue of semantics as clarity regarding what we mean when we use different terms is important to advance discussions around formal decision-making schemes but also how informal decision support and informal substitute decision-making occurs. In the end, it is the way those with cognitive impairments are included and able to participate in decision-making in some way that is most important.

Ultimately, we should aim to share a common language to talk across disciplines, providing greater clarity and increasing our ability to communicate clearly to families, support workers and people with cognitive disabilities.

3. LEGAL FRAMEWORKS OF SUBSTITUTION AND SUPPORT

3.1. SUBSTITUTE DECISION-MAKING LAWS

Laws exist in most jurisdictions that provide for legally recognised forms of decision-making by and on behalf of adults. Formal substitute decision-making can occur where a competent adult gives decision-making power to someone else for some decisions either temporarily

(e.g. financial power of attorney to conduct business transactions while a person is overseas) or when specific events occur in a person’s life (e.g. authority to make medical decisions at a time when a person does not have decision-making capacity). There are also legal mechanisms for the appointment of a substitute decision-maker such as a guardian or administrator when a person lacks decision-making capacity for some decisions. In Australia, this is usually done by a Civil and Administrative Tribunal. An appointed guardian or administrator may have authority in relation to a subset of decisions (e.g. health decisions, major financial decisions, etc.) and be able to make decisions on behalf of an adult who is considered not to have decision-making capacity in relation to those types of decisions. Most Australian legislation also contains provision for an ‘automatic’ or ‘default’ medical substitute decision-maker in the absence of a formal appointment (White, Willmott, and Then 2018: 261-265). These types of laws are often collectively referred to as guardianship laws or substitute decision-making laws.

In Australia, legal frameworks for substitute decision-making mostly exist at the State or Territory level through guardianship or related legislation. However, for some programs administered at the national level (e.g. the National Disability Insurance Scheme [‘NDIS’] or Centrelink income support payments) there are some substitute decision-maker roles that are applicable throughout Australia. The complexities of the various legally recognised substitute decision-makers in Australia are recognised elsewhere (see e.g. in relation to health care: White, Willmott, and Then 2018: 223-227); and in relation to NDIS planning: Tune 2019:[2.560]; National Disability Insurance Agency 2021: 6).

In addition, while formal mechanisms for appointment of substitute decision-makers are provided for, there is legislative recognition that informal supported and substitute decision-making occurs. Legislation implicitly (and in some cases explicitly) recognises the legitimacy of informal support and informal substitute decision-making. For example, Queensland provides a way of ratifying informal decisions where necessary (*Guardianship and Administration Act 2000* (Qld), s 154).

For the purposes of this paper it is useful to examine the thresholds identified in relevant legislation that set the bar for the appointment of a substitute decision-maker on behalf of an adult. The following legal analysis demonstrates there are generally two common features, which if present, allow a Tribunal to appoint a substitute decision-maker for an adult. While not universally agreed upon, we might consider the current laws to be a proxy for the circumstances in which most Australians would consider it acceptable that substitute decision-making occur. The two hallmarks of the legal framework centre around the concept of the ‘need’ for a substitute decision-maker and a determination of an adult ‘lacking decision-making capacity’ for the decision in question (Blake et al. 2021: 396-400). A third factor is also present in some jurisdictions that relates to ‘risky’ decision-making by an adult.

3.1.1. ‘LACK OF CAPACITY’

There is a presumption at common law, reflected in some Australian legislation, that adults have decision-making capacity (White, Willmott, and Then 2018: 228). This presumption needs to be displaced if decision-making power is to be removed from an adult in relation to any decisions. Most substitute decision-making legislation in Australia requires a finding of a lack of decision-making capacity in relation to a particular decision or class of decisions, before someone else can be lawfully empowered to make a substitute decision on behalf of that person for that matter. The substitute decision-making legislation is not uniform across Australia in how a lack of decision-making capacity is defined and different capacity tests – ranging from a functional capacity test to reasonableness test – are defined for different purposes (White, Willmott, and Then 2018:228-231). For example, the level of capacity that needs to be demonstrated to execute an advance care directive may be different from the level of capacity that is needed to appoint a legally recognised supporter in Victoria (*Medical Treatment Planning and Decisions Act 2016* (Vic), Pt 2; *Powers of Attorney Act 2014* (Vic) ss 4(1), 86(2); (Victorian Office of the Public Advocate 2021: 23 [decision-making capacity to appoint a supporter])). Perhaps the best known description of capacity accords with the

functional capacity test, that mirrors the common law test, and is adopted by most Australian jurisdictions. It has as its main features that if a person is unable to comprehend and/or retain information needed to make the decision, including the consequences of the decision, or the person is unable to use and weigh the information as part of the process of making the decision, they will be found to lack capacity (*Application of a Local Health District: Re A Patient Fay* [2016] NSWSC 624, [37]).

These legal definitional differences and jurisdictional inconsistencies add complexity to what is already a difficult assessment in practice (Shibu, Rowley, and Bartlett 2020). Determining when capacity is ‘lost’ for a particular decision, is no easy task, with limited guidance available for those who are charged with this (see e.g. (Queensland Government 2020); (NSW Department of Communities and Justice 2020)). Time and decision specific assessments of capacity may be made by clinicians, lawyers, or Tribunals in formal settings. Often these determinations of capacity will be formally documented and supported by medical evidence. In contrast, and perhaps more commonly, capacity determinations are made by those who provide support to a person with a cognitive disability in their day to day living without formal oversight or documentation of when such substitution occurs.

3.1.2. ‘NEED’ FOR AN APPOINTED SUBSTITUTE DECISION-MAKER

In addition to a determination of a lack of decision-making capacity, most jurisdictions in Australia have an additional threshold issue – that the adult ‘needs’ an appointed substitute decision-maker or in some jurisdictions this is phrased as their ‘needs will not be met’ without the appointment of a substitute decision maker (*Guardianship and Management of Property Act 1991* (ACT) s 7(1)(c); *Guardianship and Administration Act 2000* (QLD), s12(1)(c); *Guardianship Act 1987* (NSW) s 14(1); *Guardianship of Adults Act 2016* (NT) s 11(1)(c); *Guardianship and Administration Act 1995* (Tas) s 20(1)(b); *Guardianship and administration Act 2019* (Vic) s 30 (2)(b); *Guardianship and administration Act 1990* (WA) s 43 (1)). This requirement seeks to ensure, that when judicial bodies are involved in particular

cases, the removal of an individual's decision-making rights is not arbitrary and less restrictive options – such as substituted decision-making power granted for a narrow range of decisions, rather than a plenary appointment – are considered.

Some legislation provides more guidance around how this assessment should be made, with common features in most jurisdictions including whether informal support networks are adequately meeting the needs of the adult (see, for example, *Guardianship and Administration Act 2000* (Qld) s 11B(4); *Guardianship and Administration Act 1993* (SA) s 5(c); *Guardianship and Administration Act 2019* (Vic) s 31(b)). Some also rely on the broader concept of adopting a 'least restrictive' approach which also accords with reliance on informal support networks being preferred over formal Tribunal appointments of substitute decision-makers (see, for example, *Guardianship of Adults Act 2016* (NT) s 11(2)(e); *Guardianship and Administration Act 1995* (Tas) s 20(1)(b); *Guardianship and Administration Act 1990* (WA) s 4(4)).

Examples of formal applications for guardianship or administration being refused due to a lack of 'need' are not uncommon (see, for example, *NNX* [2020] NSW-CATGD 34; *Preston* [2016] QCAT 52; *JNS* [2017] WASAT 162). This assessment is often made by a Tribunal based on the fact that informal supports are already in place or informal substitute decision-making already occurs within a person's family or support network, and are sufficient for the adult's needs. Many of the participants of the study reported here acted in an informal supporter role that sometimes moved into an informal substitute decision-maker role.

3.1.3. RISK TO THE ADULT IN MAKING THEIR OWN DECISIONS

In five jurisdictions in Australia, Tribunal's may consider the likelihood of adults who lack decision-making capacity making 'risky decisions'. In the ACT, Queensland and New South Wales, Tribunals can take into account:

whether the adult is likely to do something in relation to the matter [in which they lack decision-making capacity] that involves, or is likely to involve,

unreasonable risk to the person's health, welfare or property (*Guardianship and Management of Property Act 1991* (ACT), s 7(1)(b); *Guardianship and Administration Act 2000* (QLD), s 12(1)(b); *Guardianship Act 1987* (NSW) s 7(1)(b)).

In South Australia and Tasmania this consideration of risk to welfare is taken into account in different ways. South Australia incorporates into its 'mental incapacity' definition a welfare consideration so a person will only be found to have a mental incapacity if they are unable to look after his or her 'own health, safety or welfare or... manage his or her own affairs' (*Guardianship and Administration Act 1993* (SA), s 3).

In Tasmania there is no explicit mention of risk and welfare, but the legislation states that the Guardianship Board can appoint a guardian or administrator where a person has a 'disability' and is unable to make 'reasonable judgments in respect of all or any matters relating to his or her circumstances' (*Guardianship and Administration Act 1995* (Tas), s 20(1)(b)). This broad statement would likely encompass 'risky' decisions if they were viewed as 'unreasonable' choices.

This consideration of risk to an adult's welfare is explicitly excluded in some other Australian jurisdictions. For example, in the Northern Territory, the legislation states:

An adult does not have impaired decision making capacity only because the adult:

- (a) has a disability, illness or other medical condition (whether physical or mental); or
- (b) engages in unconventional behaviour or other forms of personal expression; or
- (c) chooses a living environment or lifestyle with which other people do not agree; or
- (d) makes decisions with which other people do not agree; or...
- (k) engages or has engaged in illegal or immoral conduct. (*Guardianship of Adults Act 2016* (NT), s 5(6)).

Similarly, in Victoria, section 5(4) of the *Guardianship and Administration Act 2019* states, 'it should not be assumed that a person does not have decision-making capacity in relation to a matter merely because the person makes a decision that, in the opinion of others, is unwise'.

The different approaches to ‘risky’ decision-making by persons who have a disability or have some decision-making deficits demonstrates an interesting legislative division in Australia. Academic writing on the ‘dignity of risk’ highlights the lack of autonomy afforded to those traditionally considered ‘vulnerable’, it being recognised that over-protection, even if well intended, prevents people from living their lives the way they would want and fulfilling their potential (Perske 1972; Marsh and Kelly 2018). These protective limits are not imposed on most adults in society who are free to make unreasonable or bad decisions. For most individuals there is an expectation that they will have the freedom to gamble away life savings or engage in dangerous sports without significant interference from others. However, the same freedoms have not been applied to people with disabilities. The legislative differences that exist in Australia, demonstrate that notions of the ‘risk society’ continue to influence the way our society operates, including in the legal decision-making framework where some appointments for those determined to lack capacity can take into account likelihood of ‘risky’ decision-making (Bartlett 2020: 11). Here, we see some jurisdictions mandating Tribunals to adopt a much more protective stance, and others adopting an approach more consistent with the human rights driven preferencing of autonomy over beneficence. Our findings, discussed below, show that these different perspectives evident in the legal frameworks in Australia, are also shared by informal supporters of adults with cognitive disabilities.

3.2. SUPPORTED DECISION-MAKING AND THE LAW

In contrast to the legislation on substitute decision-making there is relatively little to say about domestic law and supported decision-making. This is because, to date, explicit legislative recognition of the concept and

practice in Australia remains rare. However, there has been some legislative movement abroad (Largent and Peterson 2021) and supported decision-making has a growing amount of academic literature dedicated to it and has influenced the recommendations of many law reform commissions worldwide (Then et al. 2018). Increasingly, government departments are implementing or aligning policies to recognise supported decision-making principles (see e.g. (National Disability Insurance Agency 2021); (Queensland Public Guardian 2019)). However, this has not been translated into significant legal reform in Australia. The exceptions in Australia are in the State of Victoria – where it is possible to formally appoint a decision-making supporter (known as supportive attorneys or medical support persons) – and to a lesser extent in the State of Queensland and the Northern Territory, where general principles mandate that a supported decision-making approach must be attempted before turning to substitute decision-making on behalf of an adult (*Guardianship of Adults 2016* (NT), s 4(4)(b); *Guardianship and Administration Act 2000* (Qld), s 11B, General Principle 10). In Queensland, due to the use of the word ‘support’ in other contexts, this has been, somewhat confusingly, given the name ‘Structured decision-making’ in General Principle 10 (*Guardianship and Administration Act 2000* (Qld), s 11B).¹ Other States’ legislation refer more generically to adopting a least restrictive approach (which accords with a supported decision-making approach) and taking into account the adult’s wishes. However, how this is implemented or regulated outside of Tribunal settings is unknown and the legislation itself does not provide a clear framework for implementation outside of those formal settings.

The picture this presents is increasing recognition and encouragement of the practice of support in decision-making by legislation. However, these types of

¹ Supported decision-making in this context should be distinguished from legislative recognition of general ‘supports’ that may be present for an individual. For example, in Queensland there the need to maintain ‘supportive relationships’ or ‘support networks’ (see General Principle 4 in s 11 *Guardianship and Administration Act 2000* (Qld)). While these supports may overlap with those providing support for decision-making, the scope of those relationships seem broader and also relate to social supports. It can, however, lead to some confusion in terminology used by Tribunals in those jurisdictions regarding what is being discussed and how the Tribunal categorises those activities – e.g. supported decision-making, informal substitute decision-making or other forms of support. See e.g. *MJP* [2020] QCAT 253.

laws give little guidance as to how such support should be provided by those who take on those positions – whether formally or informally. General human rights principles provide aspirational statements but offer little advice for formal or informal supporters who are involved in assisting an adult with a cognitive disability with the myriad of decisions they face in day to day living.

What legislation there is assumes that support in decision-making may be used to ‘stave off’ a finding of incapacity and maximise the capacity of an adult to make their own decisions for the longest time possible. As noted in section 2, this accords with the meanings normally attributed to the terms ‘substitute decision-making’ and ‘supported decision-making’ in legal frameworks in Australia. This is a more binary and perhaps less nuanced understanding than the definitions adopted by the UNCPRD committee. The literature to date has not demonstrated whether such support does actually shift the dial for when substitute decision-making is imposed on adults with cognitive impairments.

While movement in government policy and legal reform is laudable, there is limited evidence of how support in decision-making actually works in practice and how it interacts with substitute decision-making (Bigby et al. 2017). We do not know whether these triggers for formal appointment of substitute decision makers based on the ‘needs’ of an adult, an assessment of ‘lacking capacity’ for particular decisions or determinations of risk are similarly used as a guide or are reflected in how informal supporters and decision-makers work with or on behalf of adults with a cognitive disability. What we illustrate in this paper, is that within our small sample, ‘good’ support can assist in developing decision-making capabilities and may shift the dial in favour of increased decision-making and less substitution, at least for some decisions. We also show that the reasons for supporters moving from a support role to an informal substitute decision-maker is more complicated and often takes into account the implications of an immediate decision for the future opportunities for the person they are supporting.

4. MOVING FROM INFORMAL SUPPORT TO INFORMAL SUBSTITUTE DECISION-MAKING

4.1 METHODS

This paper draws on a sub-set of qualitative data from an Australian study examining practices of support for decision-making by supporters of people with cognitive disability. The overall aim of the study was to explore the impact of training in applying a practice framework (the La Trobe Support for Decision Making Practice Framework) about effective support for decision-making (Douglas and Bigby 2020). Participants comprised dyads of a decision-maker with intellectual disability and their decision supporter. Decision-makers were adults who self-identified as having intellectual disability and who were able to communicate using words and participate in an interview. Supporters were adults who knew the decision-maker well and provided support for their decision-making in various contexts. Supporters were interviewed between December 2016 and June 2020.

The data reported here are drawn from 11 parent supporters (nine mothers and two fathers) of adults with intellectual disability, who completed training in the La Trobe framework and took part in at least four interviews (pre- and post-training) and four mentoring sessions. The time period between interviews and training and mentoring was variable as it was very much subject to parental availability. The research focused on the the most populous Australian States of Victoria, New South Wales and Queensland and, consequently, all participants came from these States.

Participants were recruited through 12 industry partners in the Australian Research Council funded study and parent and service networks associated with the researchers. Recruitment sources included disability support organisations and statutory bodies such as Offices of the Public Advocate from the three Australian states.

The semi-structured interview schedules were designed to explore the nuance of supporters’ practices, and decision-makers’ experiences. Dyads were interviewed separately and nominated a myriad of decisions

to discuss, ranging from choosing what to eat, what to wear to living arrangements. Interviews lasted between 30 and 60 minutes, were digitally recorded and then transcribed. For this paper, where the focus is on transitions between support for decision-making and substitute decision-making by supporters, transcripts of the 11 supporters were coded inductively. This process allowed new thematic codes to be identified and applied following the initial coding. As the coding progressed, codes for each participant were compared and contrasted and discussed and refined among the research team.

The study was approved by the La Trobe University Ethics committee (and relevant Chief Investigator university ethics committees) and all participants gave informed consent. All names have been replaced by pseudonyms to preserve anonymity.

A limitation of this work is that data collected from informal supporters of adults with more severe or profound intellectual disability are not included in this subset but are explored elsewhere (Bigby et al. 2021). Comparing the sub-sets we note that our findings here are consistent with the reported findings of parents who support adult sons and daughters with more severe intellectual disability.

5. FINDINGS

5.1 DEVELOPMENT OVER TIME

This study tracked support dyads over a period of time and found changes in two aspects of supporters' perspectives. The first was supporter perceptions of development in the adult's decision-making capabilities. The second was self-reflection by supporters on their own actions in providing support.

5.1.1 DEVELOPMENT IN DECISION-MAKER CAPABILITIES

Some of the supporters noticed changes in the decision-making capabilities of the adults that they were supporting over a period of time. Often, this development in decision-making capabilities was surprising to supporters who were pleased to see it occurring.

He's making more and more decisions himself. Like, smaller ones but he's taking ownership of them a little bit more. So, in terms of what he wants to eat, where he wants to eat sometimes if we're not eating at home, what he wants to wear. (Joanne interview 3)

He's becoming more independent. So at day service, he's been unhappy with some of the things that have been going on, so he's gone direct to the manager and sorted it. And not consulted me at all. So I believe he's understanding that he needs to be the person who makes the decision and then acts on it. So he's not waiting for someone else to look out for him. (Kate interview 2)

Well, now she says to me, I'm going out tomorrow night, or I'm going out now, I'm just going to call my Uber and I'm going out to the [shops]. And for Noah and I, that was really not even something we were imagining six months ago. So that change has happened quite quickly. (Jody interview 3)

Consistent with evaluative findings in other support programs (Bigby et al. 2017), supporters often reported that increased participation or autonomy in decision-making had positive effects on the decision-maker including a growing and observable confidence in making some types of decisions. For example, Joanne described changes in the demeanour of her son who she supported:

He just beams. He's a different person. There's a smile on his face. His shoulders are upright and it's like, "I'm choosing this and I'm making it happen. I'm not waiting for someone else to lead me." ...you see it in his face and his body and the way he holds himself, carries himself. (Joanne interview 4)

However, as demonstrated by Kate and Jasper's relationship, this growing confidence can be negatively impacted quickly. Kate talked about Jasper's growing understanding of his ability to make decisions resulting in increased decision-making confidence over some types of decisions in his life – like choosing to opt out of or change the activities he wanted to participate in at his day service. However, this confidence was dented, when Kate had to step in over a decision made by Jasper (facilitated by another person) which in her opinion involved too much physical risk.

I think he can't tell the difference between a decision that puts him in a position of risk and any kind of decision, so you know, whether he – he's probably asking me more questions about should I do this, and should I wear these shoes? Should I tell him about – than he was before. So, he's checking in with me more than he did.... So, it's changed anyway. He's not as confident as he was. (Kate interview 3)

5.1.2 DEVELOPMENT IN SUPPORTER VIEWS

Alongside the perceived development in decision-maker capabilities was an apparent shift in the way supporters viewed and enabled decision-making by the adults they supported. This often manifested in supporters talking about actively stepping back from decision-making, trying to influence decision-makers less, and listening more to decision-makers. Sometimes this also manifested in attempts to find more opportunities for the decision-maker to participate.

All of the sample were parent supporters and some reflected on the need to move on from making decisions on behalf of a young child to respecting the autonomy of their now adult children.

Well, I have to keep on reminding myself that Sally is in fact a young adult. She's 25. And I think while she's still quite happy to be guided and she'll ask me questions and for advice, and so forth, she is a young adult with some quite strong points of view about certain aspects of her life. ... I suppose you come to the realisation that you don't actually have a child, you actually do have a young adult. So therefore you do need to treat that with some respect. Doesn't make it any easier when you're trying to negotiate day to day life, and getting things done in a timely fashion, and that's probably one of the biggest areas of tension between us. (Bernice interview 3)

I think too because Zara's ready for this change it then makes her more open. It gives her a measure of control back where hopefully we're valued supporters instead of, you know, parenting in the sense that you take – parents of small children take control of their children's lives. (Carol mentoring 3)

As recognised elsewhere (Booth Glen 2020: 124-125), and reflected in our data, sometimes moving away from the parental role to that of supporter was found to

be challenging. This was noted by Carol, who described still falling back into 'old habits of controlling the decision making' (interview 3); Jody, who acknowledged having to overcome her 'over-protectiveness' and 'relinquish control' (interview 5); and Frances who described how it was difficult to step back.

It's very hard, because mothers sort of take over things, and give up and just say, "I'll do it." But then me backing out a bit – it's just been a little bit – it seems how big and grown up he's getting, and his maturity and things... he likes to know that he can take control of stuff...he's sort of really maturing a bit, too. (Frances mentoring 6)

Jody also described the ongoing challenge of this transition especially when it came to understanding her daughter's will and preferences as compared to her own wishes for her daughter in the context of National Disability Insurance Scheme (NDIS) planning:

I would just highlight to you what is, and continues to be I think, the most difficult aspect of decision making for me. And I think that is making the transition from being the decision maker to supporting an adult who wants to make her decisions that aren't always the decisions I want made. So I would feel that on many occasions I see the bigger picture for Nat and the longer term goals more than she does. And I also feel that she often wants to make the easy, comfortable choices and have a good time, but not kind of challenge herself to stretch into goals that are more difficult for her...There was some things that I wanted for her that she didn't want for herself (Jody mentoring 1).

This transition was sometimes accompanied by the realisation that their adult son or daughter had not had many opportunities to participate in decision-making up until this point in their lives. This was the case with Bernice and her daughter Sally:

The rest of the week there's various recreational activities... you can choose activities, rank them from one to ten from this list, and over a period of time, I've determined that Sally doesn't like certain things so I don't even bother ticking those boxes. So it's sort of decision making by default. But I was just very conscious ... that Sally has not been an active participant in much of those regular cycle activities during a seven day period. So that was a big

reflection, just because it was triggered by the fact that I'd spent some time thinking and so forth about it. (Bernice interview 2)

Some parents, like Bernice, Joanne and Kate, talked about how actively working to provide more opportunities to practice making decisions had an impact on the decision-maker. Sometimes this was provided by the parent supporter directly, as with Bernice.

If we're talking about "What do you want to have for your lunch today? Do you want a sandwich or a roll – because they're both in the freezer?" – I think making a conscious plan, on my part, to give her those options, and not just for me to pull the bread out of the freezer and make a sandwich. Because the important thing is – and I think we talked about this before – is to provide Sally with practice decision-making. (Bernice mentoring 3)

Other times, this was assisted by other people, such as when NDIS funded support workers were introduced for the first time into Brendon's life. Joanne noted:

[W]e're coming up to a year with support workers, yeah. So I think that's opened up Brendon to express himself too because with them like they don't know him so they're asking questions, "what do you want to do? What's your choice?" so I think it's been really good to have them on board and give him another outlet, another way to say what he wants. (Joanne mentoring 1)

Other supporters, like Nara, talked about how they were actively stepping back from decision-making to allow more opportunity for the adult to make their own decisions, 'I have to slowly, slowly withdraw myself' (mentoring 2). Actively listening and taking account of an adult's views was also described by Joanne:

I think we are asking him more, and actually expecting him to answer, and not doing anything until he answers. ... And, I want him to feel that his opinion matters and what he has to say matters, and we're actually listening. We're open to listening and open to then doing something about it, if he says something. I don't know, perhaps in the past, he might have felt that, I don't know, maybe he didn't have a voice or he wouldn't be heard... I want him to make choices for himself and I feel that I think I have more insight into it. (Joanne interview 2)

However, as demonstrated by Nikki, some supporters voiced uncertainty about how much autonomy to give the decision-maker.

... probably I'm the prime person who assists Zac with making these decisions. But I've tried to back off a little bit at times. But then I also realise that when I do that, things start to break down a bit. And I'm never quite sure whether I have to let it break down for her to realise that, "Well, maybe I do need a little bit of extra help. Or whatever. I can do it by myself," she says. Or whether I let a service provider take over that role. (Nikki interview 1)

This challenge of balancing what the decision-maker wants or feels comfortable with in the short term against future opportunities or long term goals is also discussed further below.

5.2 MOVEMENT BETWEEN SUPPORT AND SUBSTITUTION

The participants often described moving from acting as a decision-making supporter to becoming a substitute decision-maker on behalf of the adult. This fluidity in movement between these roles appeared to occur for a number of reasons.

Some supporters moved into a substitute decision-making role based on pre-existing knowledge about the limitations in the adult's cognitive ability to make certain decisions. Another common reason for substitute decision-making involved when, in the supporter's view, some threshold of risk associated with the specific decision was reached. And lastly, some substitute decisions were made with a view to providing the adult with more opportunities in the future.

5.2.1 RECOGNISING LIMITS ON DECISION-MAKING ABILITIES

All of the parents had known the adult they supported for all of their life. They had deep knowledge about the person, including both the limits imposed by their disability, and their 'will and preferences' in various aspects. The support they provided moved closer to substitution where the supporter perceived that the decision-maker did not have the cognitive capacity to engage meaningfully in the decision. From a strictly legal perspective,

this might be viewed as substitute decision-making on the basis of a determination of lack of capacity. As noted by Bernice, supporter of Sally, in reflecting upon the UNCPRD:

[The] UN Convention assumes that people are competent decision-makers and they can make all those life choices and be supported in making those life choices because they are equal citizens of the world or whatever. But the reality of it is that's just not actually how it works in some situations. (Bernice, mentoring 2)

Carol, supporter of Zara, talked about a decision made with an NDIS planner in relation to Zara's funding which excluded Zara. However, this was partly justified on the basis that she would not have understood the complexity of the decisions made:

And when I thought about it afterwards I thought 'oh, we didn't really consult with Zara'... But I still think in that case that was fine. I guess we could have asked Zara what [she] thought but we in fact didn't but that's an example of us making the decision for her because I don't think she would have understood the complexity of it. (Carol, mentoring 5)

While Carol did not involve Zara in the decision (which can be interpreted as substitute decision-making), she may have taken into account what she assumed would be Zara's preferences as opposed to her 'best interest' – thus treading the line of what constitutes allowable support (as opposed to substitution) outlined by the UNCPRD Committee.

Many supporters moved closer to make substitute decision-making where they believed – based on their past knowledge of the adult and their condition – that the adult's disability meant they did not have the understanding necessary to participate in decisions. For example, Samuel in talking about his son Robert said, 'The only thing is that his ID also means that he can't understand certain concepts, no matter how we look at it, contracts or decisions around ongoing expenditure, is not something I can teach him that easily' (mentoring 4). Similarly, Gavin in discussing the decision for his son Toby to contribute to a property and move in with Toby's brother stated how there was no real discussion with Toby about this:

Well, I guess we didn't really [discuss it with him]. We told him about it, we talked about it, but as I said, this is a very high-level decision. And he wasn't really able to make a decision about what would be in his best interest in terms of his only other thought was I will live with my friends. And it's not really realistic. Okay?...

[A]ll five of us are pretty happy with that decision and think it's in Toby's best interests. Despite the fact that Toby was really not able to make a decision about something like that. It's beyond him. (Gavin, mentoring 2)

As noted above, some of these might be interpreted as examples of support, as these parent supporters have not made decisions in a vacuum. Rather, despite lack of direct involvement by the individual, the supporter has kept knowledge of that person at the centre of their decision-making. However, others show parental supporters explicitly considering the decision-maker's future 'best interests', with less apparent regard for their wishes. These examples illuminate the difficulty in classifying something as support or substitution when UNCPRD understandings are applied in practice. In day to day living, identifying any clear line between 'acceptable' support and 'unacceptable' substitution – can be near impossible.

Kate commented on the challenges of having certainty around the capacity of her adult son to understand and be involved in decision-making and being authentic around when the decision could be his or be made by someone else:

He will never be the primary decision-maker for serious issues because he does not and never will have the capacity. His impairment is so severe that he is just not going to get there. And so the people that we put around him to help him make these decisions, will be making these decisions probably for him and they'll probably be doing the same thing that I do which is give him the information we think he understands and then try and make decisions which will minimise harm and improve outcomes...

So it's a moveable feast, particularly with people who are still growing, developing and learning... So with Jasper, giving him as much scope as possible to contribute but at the same time giving him all the scaffolding that he needs to make that contribution.

So again it's a very subjective thing. So of course we have all these strategies in place and you can pay lip service if you want to, but that's not me. I actually need to know what he can make a decision about and what he can't make a decision about and then if there's something he can't make a decision about we will make it for him and we will explain to him why we did that.

But I'm not going to pretend to him that he made the decision when he didn't, because I think that is inauthentic and absolutely not helpful. Because what happens is that he thinks his capacity to make decisions is greater than it is. (Kate mentoring 3)

Most of these statements were made in relation to decisions involving some level of complexity. Often these were associated with decisions that would have a significant impact on the adult's life, e.g. where they were to live, where they went and what they did during the week. Some of these statements may also be at odds with the recognition, discussed above, in at least some spheres of decision-making that development in decision-making capacity can and does occur and that complex decisions can, in some circumstances, be broken down to increase engagement with the smaller decisions within a larger decision.

The assessment by supporters that the adult they supported did not understand enough about aspects of a decision to participate and make their own decisions does, however, align with one of the legal 'triggers' that lawfully allows substituted decision-making discussed in section 3.1.1: lack of decision-making capacity for a decision.

5.2.2 RISK ASSOCIATED WITH DECISIONS

One category where supporters grappled with whether to take over decision-making was in relation to decisions that involved a level of risk. Whereas some supporters accepted, and indeed welcomed some level of risk into an adult's decision-making, others saw this as a clear flag for intervening and making substitute decisions. Similar to findings in other settings, risk was viewed as both 'opportunity and danger' (Wyllie and Saunders 2018: 585).

For example, Margot and Samuel, noted that letting their adult children make mistakes or take risks could ultimately be beneficial.

So 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 round the country... And I thought I had great success there. (Margot interview 1)

I've changed from no risk to some risk, because I know there's no such thing. So I'll allow him some risk so that he can learn how to manage the risks.'... Again, here, moving to sometimes now, because in the past I would say no, but now, things like shifting decisions away, shifting attention away, in the past I would always do it, now no. So actually take more risks, actually learn to take more risks, you learn that you can accept a risk. I know in the past, when he was younger, always when we don't want to make a decision, we'd always divert him. But now, no, we can live with that. (Samuel interview 6)

Many others acknowledged that some level of risk needed to be experienced by everyone. Frances and Nara noted the learning that comes from making mistakes or experiencing something negative (Frances interview 3; Nara interview 1), while Joanne and Kate emphasised the importance of allowing their adult sons to 'experience' things (Joanne interview 4; Kate interview 2) and the impossibility of keeping things 'risk free' (Joanne interview 4).

For others, risks in decision-making remained challenging and did lead to substitute decisions being made. The supporter's assessment of the level of risk involved and the short or longer term impact of such a risk eventuating could be perceived very differently by different supporters. This subjectivity inherent in assessing risk has been recognised in other contexts (Wyllie and Saunders 2018) and is evident amongst this sample too.

Many supporters stated that decisions by adults that involved short term, high risk activities would be overruled by them (e.g. Samuel, Joanne, Gavin, Kate). For example, where there was a chance of physical harm occurring. Gavin provided an example of this where he

refused to let his adult son carve a roast pork with an electric knife ('he just hasn't got the fine motor skills... So as a safety thing I stepped in and made a decision' (interview 2)). As mentioned above, Kate also made a substitute decision for her son regarding remaining completely independent at night. She commented 'The dignity of risk is important but not in a situation where you could kill yourself' (Kate mentoring 2).

Another more common example – provided by Carol, Joanne and Kate – was making substitute decisions around healthcare on behalf of adult children. As noted in section 3.1, this type of substitute decision-making is often provided for in Australian laws which have 'default' substitute decision-makers for health care recognised if an adult lacks decision-making capacity for a health decision. In most circumstances, the legislation would recognise a parent with an interest in the welfare of the individual as being the appropriate health care substitute decision-maker (White, Willmott, and Then 2018: 261-264).

However, more nuanced and disparate views as to substitutions were demonstrated when a longer term perspective was adopted – particularly around the future health and wellbeing of the adult and their independence. For example, Bernice discussed the long term impact of bad food choices on her daughter Sally when combined with a medication side effect of weight gain. In encouraging a more balanced diet Bernice sought to create a culture of healthy eating, often used the tactic of limiting the food options available to Sally: 'I spend a lot of my time giving her no choice, in some respects, but ensuring that she makes healthy choices as far as possible, preferably where there is plant food involved' (Bernice mentoring 4). Margot and Nikki also discussed making substitute decisions when it came to food choices, based on the cumulative impact of unhealthy eating on the wellbeing of their adult children. However, in other areas of her life Bernice had encouraged and enabled Sally to travel independently on public transport, despite the acknowledged risks of travelling alone:

Sally travels on public transport independently. Now, there'll be other families who would look at that choice...and just go that is a highly dangerous

option for you to take. But on balance...I think it's more important that Sally travels by public transport and is travelling independently then she steps into a taxi every second day... But I still can't, as a responsible parent ..., put Sally into a cotton wool box for the rest of her life. (Bernice interview 4)

A similar view was expressed by Margot in relation to independent travel by her son Finn and she rationalised the lower level of risk in the following terms: 'You have to make sure he's safe. But getting lost on public transport when you're available is all right' (Margot interview 1).

Kate described the conundrum where confidence in decision-making was higher than decision-making capacity:

The difference between ability and confidence is risk. That's what it is. And you've got to close that gap. How you close that gap, you fill it with other people, you fill it with processes or you somehow improve his capacity. Or you put him in situations where he doesn't get to make any decisions. So, that's a problem (Kate interview 5).

As demonstrated here, the views and justifications provided by some supporters regarding when substitution occurred did revolve around aspects of risk associated with potential decisions made by the adult being supported. As outlined in section 3.1.3, in some Australian jurisdictions, whether an adult is likely to make 'risky' decisions which may impact negatively on their welfare is a relevant consideration for a Tribunal in considering whether to appoint a substitute decision-maker. However, in a minority of States, these types of 'risk based' assessments are discouraged by the current legislation.

5.2.3 PROVIDING OPPORTUNITIES FOR THE FUTURE

The third area where supporters tended to move into substitute decision-making related to a theme that we have already reported in a different context: that parents in particular are worried that their adult son or daughter may have very limited life experiences or narrow views that, if fully respected, could limit the adult's life opportunities and wellbeing in the future.

These worries were previously reported as factors in parental strategies of support that made provision of support difficult (Bigby, Douglas et al. 2021 ([parental strategies])). In this paper, it is also recognised as a situation where support can transition into substitute decision-making. The rationale for this is largely driven by a more paternalistic approach where supporters can imagine a range of possibilities – which they consider to be beneficial and important – that could be open to the adult if they were introduced to experiences and people that they might otherwise opt to decline.

Sometimes this was described as being achieved through persuasion – slowly introducing options/ideas over a period of time – but sometimes this manifested in substitute decision-making against the wishes of the adults. In one rare example, this substitute decision-making included manipulation and lying by the supporter to get the result the supporter thought was best for the adult (see also Bigby, Douglas et al. 2021 ([parental strategies])).

In some circumstances, supporters relied on past experiences with the adult in which a new experience – while uncomfortable at first – led to a positive and beneficial engagement that the decision-maker enjoyed. This past experience justified the approach of ‘pushing’ the adults to engage beyond their comfort zone and to make substitute decisions around some activities. Supporters, including Jody and Nikki, discussed such an experience with their adult they supported:

‘I know that she didn’t want to go to [the arts program] and now she loves it, that informs me a little bit to think that I do have to stick to what I think is best sometimes and overcome her resistance and reluctance because it is in her best interests and it is worth doing.’ (Jody interview 2)

[A dance group for people with Down Syndrome] was being introduced ... and I said ‘Well, let’s go.’ ‘No, I don’t know.’ I said ‘Well, let’s go, let’s go for three weeks.’ Okay, so she went for three weeks. I said ‘Now you can decide, is it something you think you might like or you don’t like?’ Whereas before she would say no, but she wouldn’t know whether she liked it or not liked it... So they have to experience it in some way before they can actually make ... a proper decision I think.’ (Nikki mentoring 3)

The quotes in this section demonstrate that supporters felt justified to make substitute decisions now to enable more choice for adults in the future. This was well articulated by Samuel, who supported his son Robert:

And the other thing is that my ultimate goal, which I guess is also what you hope to see, is that my ultimate goal is for him to manage himself. ...that’s my ultimate goal no matter what I do. So if a decision that I do now helps him get there, then I’ll do it. If not, then no. So that’s my ultimate goal, no matter how we look at it. (Samuel mentoring 4)

As noted elsewhere, the formulation of these long term or life goals can be heavily influenced by or enmeshed with what parent supporters wish for their children (Carney et al. 2021). This reasoning or rationale for substitute decision-making seems the most unaccounted for in the legislative criteria examined in section 3 of this paper. The parents’ presumption of what might be in an adult’s longer term best interests – or even longer term ‘will and preferences’ – means that an adult’s immediate preferences may not be respected. Instead, parental supporters often moved into a substitute decision-making role with the aim being to maximise the chance of achieving a larger goal – i.e. greater independence, more choice and life experience in the future. There is a tension raised here as substitute decision-making is occurring with the aim of building the future decision-making capacity of the adult receiving support. It is difficult for this type of substitute decision-making to be accounted for in legislation in any nuanced way.

Whether such substitution accords with the underlying purpose of the UNCRPD and other human rights principles is an interesting question that is not easily answered, being so dependent on those who have knowledge of the adults and what they want or are likely to want for their future selves. This issue also goes back to the difficulties faced by substitute decision-makers – whether informal or legally appointed – who wish to act in accordance with the UNCRPD principles. The tension in how to determine a person’s will, preferences and rights where there may be a conflict between a person’s immediate preferences (to remain within

their comfort zone) and their long term goals (to live more independently) have been described elsewhere (Carney et al. 2019; Szmukler 2019; Carney et al. 2021). The findings here show in very practical terms how this plays out in relationships of support, while also demonstrating that a supporter can be intrinsically involved in helping adults to ‘imagine’ a different life and set up long term goals.

6. DISCUSSION

While laws in Australia increasingly recognise or encourage support in decision-making, law is a blunt tool, and there will always be reliance on informal supporters and informal substitute decision-makers (as well as those formally appointed to these roles who lack knowledge of what the law requires or choose to ignore or interpret the law in their own way) to actively work with adults with cognitive disabilities to increase their participation in decision-making. The practices of supporters do not always align with the intentions of law.

Our data shows the capability of adults with intellectual disabilities to increase their level of decision-making and also the reflection and relinquishment of control by some supporters who have traditionally acted as substitute decision-makers. We see evidence of the ‘better’ types of support being able to shift the tipping point for the move to substitute decision-making and increase an adult’s own decision-making. However, this is a two-way street. Some adults were able to demonstrate new decision-making skills, but this was normally in tandem with supporters altering their own behaviour, i.e. pulling back from taking over in decision-making; genuinely seeking the views of the adults and acting on them; exploring options together and allowing the adult to make some mistakes. Yet the findings also show the deep understanding and long standing history these supporters had with the adults, and how difficult this might be to cultivate outside of these types of relationships.

A striking feature of our findings about the movement of supporters’ actions along the spectrum between supported and substitute decision-making is the lack of prominence accorded to the criteria set down in

law as a basis for possible appointment of a substitute decision-maker (see section 3.1). This, however, is unsurprising. Writing about socio-legal findings on how people decide to use an enduring power of attorney in dementia care in Britain, (Harding and Peel 2019: 678) conclude that an ordinary person’s understanding of such legal instruments ‘derives not solely from its doctrinal legal underpinnings, but rather is constructed through dialogue between and within the different registers of everyday interaction, ... and legal rules’. That interaction, which they label ‘polyphonic legality’ seems particularly apt in explaining our findings about the divergence between what the law defines as a basis for substitution (establishing not only incapacity and need, but usually also ‘risk’) and how informal supporters rationalise moving to substitution. Their ‘register of everyday interaction’ proved to be vastly more prominent than any legal register, which was distant at best. We found additional and far more nuanced instances of substitution occurring, such as to provide greater opportunities for self-determination in the future. Supporter’s imagined a future that they thought the adult could not yet imagine for themselves. Indeed, the apparent inability for current legal frameworks to recognise or account for the complexity, nuances and ‘messiness’ of real life experienced by individuals is a good example of ‘intersectionality’ (Grabham et al 2008). Our results demonstrate the mis-match between law ‘on the books’ and daily life for supporters and people with intellectual disabilities.

On the intriguing issue of long term goals and immediate preferences – an argument could be made along the lines of Harding and Taşcıoğlu that ‘substitute’ decisions by parents can actually be viewed as existing along the spectrum of support and should be viewed as a supported decision. They argue that decisions that look to be substitute decisions, can still be compatible with rights under article 12 of the UNCRPD if the adult’s ‘wishes and preferences have been at the heart of the choices made’ (Harding and Taşcıoğlu 2018: 12-13). While this may be arguable and is consistent with an interpretation of support that we have discussed above, it does not solve the tension that exists where an adult expresses a wish for one thing but has this denied on the

basis that what is then experienced will be 'better' for the adult in the longer term and may accord more with the adult's long term goals. This type of weak paternalism by supporters can be difficult to justify (Carney et al 2021) and is very much dependent on how well the supporter's version of the adult's long term aims tracks onto the adult's actual – rather than presumed – goals in life. This is particularly so when supporters are so involved in determining what those long term goals are and how they are articulated in the context of programs like the NDIS (where they may also be appointed as formal nominees) (see Cukalevski 2019: 8-9)). As recognised in the context of support workers in supported accommodation services, there is a risk that informal supporters will make substitute decisions in an attempt to ensure the adult lives a life similar to them (i.e. 'a life like ours': Dunn, Clare, and Holland 2010). Education and training in frameworks like the La Trobe practice model for support in decision-making are useful to increase a supporter's reflection and critical assessment of their own influence in decision-making and to reduce projections of ideals onto adults that they support (Carney et al. 2021). However, as shown here, this continues to be a difficult task for some supporters.

What this study also demonstrates however, is that the issue of risk and how to manage it remains fraught and very subjective. Similar to the findings of Wyllie and Saunders who found those working in Victorian Guardianship system had differing levels of risk aversion or methods of negotiating risk, we similarly found that amongst informal supporters/substitute decision-makers that risk was a 'subjective and situational construct' (Wyllie and Saunders 2018: 588). In the informal support setting, the move to substitute decision-making was dependent on the supporter's views of level of risk. As this small sample demonstrates, different supporters have different levels of comfort around risk to the adult, and this is highly dependent on the individual involved and the circumstance presented. Management of risk – whether short term or longer term – in decision-making remains a wicked problem for which there is no easy answer.

7. CONCLUSION

Our research has sought to compare whether the trend for recognition of decision-making support in legislation and the legal conditions for the appointment of a substitute decision-maker in Australian law are reflected in the everyday practice of people who informally support and sometimes make substitute decisions for adults with intellectual disabilities.

What we have found is that the decision-making capabilities of adults with intellectual disabilities can be seen to shift over a period of time and the work of informal supporters can be effective in moving the dial regarding when a supporter finds it necessary to step in and make a substitute decision. This type of capacity building of supporters can complement direct work with young people and adults with intellectual disability via self advocacy groups to build their skills and confidence in decision-making (Burke et al. 2018; Anderson and Bigby 2017).

While determinations of incapacity and the 'need' for a decision to be made are legal conditions that are often reflected in when informal supporters moved to make substitute decisions, the additional considerations of risk and future opportunities proved to be much more nuanced factors taken into account by supporters. While the issue of risk is a relevant to the Tribunal appointment of a substitute decision-maker, the legislation does not meaningfully account for when supporters make substitute decisions (sometimes against the wishes of the adult) to ensure an adult's future opportunities and life experiences.

Legislation certainly has a place in promoting and normalising the practice of supported decision-making in Australian society. And steps to embed principles of supported decision-making more clearly would be welcomed in State, Territory and Commonwealth legislation. However, laws can only do so much. As noted by Harding and Peel, 'By changing formal law, we will certainly change something, but we will not always succeed in changing the whole polyphonic legality' (Harding and Peel 2019: 693). Instead, it will be the 'informal register' of the individuals who actually provide the support, and the quality of support they provide that will result

in meaningful change in the lives of the adults they support. Training and education of supporters has a role to play in equipping supporters to provide 'better' support but, importantly, our society must recognise the complexities and subjectivity inherent in undertaking this role and the difficulties faced in day to day life by informal supporters and substitute decision-makers.

8. REFERENCES

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