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To cite this article: Terry Carney, Christine Bigby, Shih-Ning Then, Elizabeth Smith, Ilan Wiesel & Jacinta Douglas (2021): Paternalism to empowerment: all in the eye of the beholder?, *Disability & Society*, DOI: [10.1080/09687599.2021.1941781](https://doi.org/10.1080/09687599.2021.1941781)

To link to this article: <https://doi.org/10.1080/09687599.2021.1941781>



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Published online: 12 Jul 2021.



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## Paternalism to empowerment: all in the eye of the beholder?

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### ABSTRACT

This article reports findings from the first set of qualitative data from a study aimed to further understand practices of decision support for people with cognitive disabilities and assess the impact of training supporters in an evidence-based practice framework. It poses questions about whether, using the *Convention on the Rights of Persons with Disabilities* (CRPD) as the benchmark, it is possible to identify purchase points for assessing the degree of shift from paternalism towards empowerment of the supported person. The study findings suggest that this is a highly difficult, nuanced and subjective task offering little on which to hang objectivity. Instead, we suggest CRPD realisation of the will, preferences and rights of the person supported may better be realised through training of supporters designed to enable greater *participation* by persons supported and greater *reflection* and *deliberation* on wise and effective ways of providing such support by supporters.

### ARTICLE HISTORY

Received 20 November 2020  
Accepted 8 June 2021

### KEYWORDS

Empowerment; paternalism; intellectual disability; support for decision-making; La Trobe Practice Framework; CRPD

### Points of interest

- The meaning of terms like empowerment, paternalism and capacity building are very difficult to define with any precision
- Whether support actually helps someone with a cognitive disability to achieve their will or preferences is hard to assess
- There are no easy ways of ensuring that support for decision-making stays on the path set out in the UN Convention on the Rights of Persons with Disabilities
- An alternative measure of meaningful participation in decision-making may be a better guide for assessing training of supporters

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## Introduction

Supported decision-making undoubtedly constitutes a paradigm shift from the centuries old model of substitute decision-making for people with a cognitive impairment (Bach and Kerzner 2010, Bartlett 2020, Quinn 2020, McCallum 2020, Kanter 2008, 560, Kohn, Blumenthal, and Campbell 2013, 1120). Support for decision-making covers both informal civil society programs or related practices that are the focus of this article, and legal *recognition* of support practices (see for example, Alston 2017, Stavert 2020) such as by authorising supporters to give or receive information to agencies on behalf of the person supported (Kohn 2021; OPA 2021). There are a multiplicity of ways in which support for decision-making programs have been delivered but a paucity of evaluations of program effectiveness (Bigby et al. 2017, Kohn and Blumenthal 2014, Kohn, Blumenthal, and Campbell 2013). Findings about the impact of a particular program necessarily are equally relevant across informal or legislated settings because programs tend to seek to improve the practice of support for decision-making, whether the supporter is legally recognised in that role or not. While it is possible that legally recognised supporters (in the few jurisdictions that have implemented such laws) may find certain tasks easier if authorised (e.g. to access medical information relevant to the decision), for many day-to-day decisions the legal status of the supporter does not affect the practice of decision support. Driven by a host of new value precepts originating from disability community drafting input into the *Convention on the Rights of Persons with Disabilities* ('CRPD'), support for decision-making sings from the appealing new song sheet of realising human agency through empowerment, rather than the traditional hymn-sheet of best-interests paternalism previously used by law and service-providers alike.

Yet, in law and program development to realise the CRPD, it is one thing to aspire to new values and quite another to put them in practice (Bartlett 2020). So, does adoption of a new paradigm of empowerment through supported decision-making herald meaningful, measurable or verifiable change in the lives of people with a cognitive impairment? And how is accountability for fidelity to purpose to be monitored. Or is this one of those subjective conceptual questions like the meaning of beauty – a quality that lies in the eye of the beholder, meaning that trust must ultimately be placed in the good judgment of those responsible for engineering the shift?

The answer to the first question matters to the legal community because a meaningful shift of philosophy is one of the reasons advanced for legislating supported decision-making (Then et al. 2018). It matters to disability providers because it informs their decisions about their levels of investment in training and in the way they shape the design and delivery of support.

The answer to the question of fidelity to purpose matters because policy reforms can degrade over time, or even render supposed benefits fictional. Some obligations in the CRPD arguably do lend themselves to quantitative measures of change (for a systematic review: Gómez et al. 2020), including some aspects of support for decision-making (Douglas, Bigby, and Smith 2020). However, the respective degrees of paternalism or empowerment impacting on the decision-making by people with a cognitive impairment relies on highly subjective interpretation of data about context, support and participation, as well as interrogation of imprecise and contestable concepts. The ability to 'identify' whether support for a decision is empowering or paternal is a fundamental first step. But doing so may prove easier said than done.

As sketched previously (Carney, Then, Bigby, Wiesel, Douglas, et al. 2019), the human rights lodestar for support for decision-making in the CRPD – fostering the fullest realisation of the 'will, preferences and rights' of people with cognitive or other impairments – conceals ambiguity and tensions between competing values and conceptions of the dignity of personhood and the good life. 'Will' speaks to long-term sedimented values (as 'read' by another if the person is unable to do so); 'preferences' speak to current expressions of wishes and choices; while 'rights' are abstracted from instruments such as the CRPD and its long list that includes participation, health, education and training. These conceptual differences and tensions can be mapped in many ways, including using tools familiar to philosophers, lawyers, social policy and disability studies, as well as the spatial lens of geographers (Wiesel et al. 2020).

This article extends the analytical frame by scrutinising the notional philosophical spectrum across which paternalism and empowerment are located, in an endeavour to locate 'purchase points' to serve as one possible way of assessing the effectiveness of the evidence-based, capacity-building La Trobe Support for Decision Making Practice Framework ('Framework') for *supporters* (Douglas and Bigby 2020, Bigby and Douglas 2020). That framework might be assessed in one of at least two ways. First, as we endeavour to do in the present article, it could be assessed in terms of outcomes in achieving real as distinct from artificial progression of CRPD 'will and preferences'. Alternatively, as the framework itself more modestly seeks to promote, it could be understood and assessed in terms of enhanced levels of *participation* of the person with a disability in the *process* of forming decisions over time; an aspiration more prominent in earlier human rights standards such as the *Convention on the Rights of the Child* ('CROC') (Molin 2020, 11).

While an extensive literature exists on conceptualising and assessing levels (or 'ladders') of participation, prior literature on the specific issue of paternalism and empowerment is scant. An ethnographic study of support for

decision-making for people with cognitive impairments in residential care in the UK found barriers that shifted the dial towards greater paternalism (Devi et al. 2020). Devi et al.'s study confirms earlier research that informal support for decision-making has generally not been done well, and that people with cognitive disability have very limited or no involvement in either the major or minor decisions that affect their lives (Bowey and McGlaughlin 2005, Antaki, Finlay, and Walton 2009, McKearney 2020b). Decisions may reflect the values of others, be made in haste, driven by resource issues, or be contrary to values and rights embedded in policy (Bigby, Bowers, and Webber 2011, Dunn, Clare, and Holland 2010).

### **A slippery conceptual landscape**

All laws, and many programs, can be traced back to some large and powerful conceptual influences, whether it be advancement of personal autonomy and freedom under liberalism, protection of the vulnerable by the 'harms limitation' of utilitarian liberalism (that one person's liberty of action ends where it harms another), or communitarian care and paternalism. A paternalist ethic of care first found expression in the common law's 13<sup>th</sup> century *parens patriae* jurisdiction to protect the 'best interests' of vulnerable groups such as children, people with mental illness and those with a cognitive impairment (Carney 1982) and has since been adopted in UN treaties such as CROC and family law legislation (Seymour 1994). Best interests also finds a dominant place in medical ethics and practice. In these settings there is a focus on understanding and weighing up various considerations on behalf of another person (or child) which lay understandings often reduce to 'benefitting' another, as discussed further below.

The CRPD sought to lay down new very ambitious benchmark values, including empowerment through support for decision-making in place of substitute decision-making. It too references some iconic bodies of conceptual thinking, notable for their breadth and intellectual pedigrees rather than their ease of translation into concrete operational guidelines. This is evidenced in rejection of an adverse substituted judgment form of paternalism, pursuit of personal empowerment, and resonance with writing on capability theory and capacity-building (in law and social work: Kjellberg and Jansson 2020, Carney 2017). But no international treaty, domestic law or program achieves its old or new purpose merely by virtue of writing it down.

New paradigms gain substance when they resonate with the actions and thinking of affected members of society. Those ways of thinking and acting are guided by often centuries long traditions and social values. Unless these ways of thinking change, 'law on the books' bears little if any relation to what happens in the lived lives of people. So it is with support for

decision-making. Bartlett sees widespread risk-aversion as the enemy of empowerment, suggesting:

We are in a society as a whole where the governing principle has been the identification and calibration of risk, rather than of freedom or autonomy, where the role of the state is to keep people safe, not to keep people free. With all that background, it is unsurprising that empowerment has lost out to paternalism (Bartlett 2020, 11).

In a similar vein Quinn points the finger at long-standing notions of rational cognition as the hallmark of personhood. This assumption of lack of agency and capacity consequent of cognitive impairment is identified as one of those indelible myths and fictions resisting transformation because they reflect *socially* embedded cultural values (Quinn 2020).

Paternalism is a principle with currency not only in law, medicine and social services (notwithstanding the rise of person-centred individual budget models), but also with historic appeal for the lay public. Paternalism is a philosophical position justifying overriding of autonomous choices. It manifests itself as pursuit of the 'best interests' of another to avoid risk, promote beneficence (particularly in medicine, Beauchamp 2019), or facilitate the 'good life' of someone unable to choose for themselves (Elks 2020). These are quite laudable objectives, but the paternalism of substitute decision-making challenged by the CRPD is where it *substitutes for* or distorts the expression of an authentic expression of another person's right to autonomy. This is the *adverse* sense of paternalism challenged by the CRPD as a breach of the dignity and personhood of the person affected by substitute decision-making (Flynn and Arstein-Kerslake 2014) and this is the usage adopted in this article. A substitute judgment based on a determination of 'best interests', whether made by kith and kin or by strangers, is criticised as being no standard at all (a so-called 'empty vessel' waiting to be filled by the values of the person making the substitute decision) and a mere fiction – a label according a veneer of legitimacy to unrevealed processes of reasoning (Rodham 1973, Harmon 1990, respectively).

Empowerment is one of those cross-disciplinary terms that is very capacious and ill-defined (Perkins and Zimmerman 1995, Hur 2006). Legal writing on empowerment mainly concentrates on structural or human rights mobilisation of justice machinery for poverty alleviation and development (Banik 2009), or advancing public health of vulnerable populations (Footer et al. 2018). A rare helpful definition for present purposes is that adopted by Domingo and O'Neil:

Empowerment requires that people gain new resources (psychological, social, material or political) and, through these, the ability to make and enact strategic life choices (Domingo and O'Neil 2014, 13)

In the case of support for decision-making these potential gains in ability to 'make and enact strategic life choices' can take many forms, but those gains

can be ambiguous and thus contestable. For example, what we later term verbal 'scaffolding' by a supporter in narrowing options for consideration may either facilitate empowerment (making the decision a manageable one) or be disempowering and paternalistic (in denying the person an otherwise reasonable choice). Again, support to encourage a person with a cognitive impairment to entertain making decisions which widen social horizons and activities may have appeal to outsiders but be a distinctly uncomfortable experience for, and thus be resisted by, the person being supported (McKearney 2020a).

This highlights the crucial but unresolved tension *within* the CRPD benchmark between a person's long-term or more settled goals (their 'will') and their more changeable 'preferences' (Szmukler 2019, Carney, Then, Bigby, Wiesel, Douglas, et al. 2019). While commonly in close alignment in most everyday situations, examples like these illustrate how difficult it is to decide *which* goal to support – the longer term will or the currently expressed preference? This is not unique to the present cohort of people with a cognitive impairment discussed in this article. Another classic example is the life-long vegetarian who develops a dementia and now becomes greatly agitated when not offered the meat dishes provided to other residents of their aged care facility (Carney 2020). In the first example of expanded social horizons, either the now resisted future benefits of a wider circle of acquaintances or the comfort of sticking with the less confronting status quo must be chosen. Just as it is either a vegetarian or a meat dish in the second example. Respecting the injunction to reject paternalism and best interests in favour of expression of the will, preference and rights enshrined in the CRPD hardly advances the conversation in these difficult real life settings (which the literature referred to earlier suggests are shaped by the values of supporters in any event).

High order concepts such as empowerment, autonomy or paternalism thus may be useful wind vanes for establishing general directions of change, but they lack operational purchase for assessing micro-level impacts of programs. They point to general directions of supposed harms (paternalism) or benefits (empowerment) but lack the ability to confirm the actuality or the magnitude of any such change. While lack of concrete operational purchase is trite as a critique of higher order concepts, it does not necessarily follow that micro-level data are capable of injecting greater calibration and precision to the assessment of the degree of paternalism in evidence. As later explained, such greater calibration currently eludes our grasp.

## **Understandings of empowerment and paternalism from fieldwork**

### ***Study methods***

To shed light on concepts of empowerment and paternalism, this article draws on qualitative data from an Australian study examining practices of support

for decision-making by supporters of people with cognitive disability. The overarching aim of the study was to explore the impact of training in applying a framework built from evidence about components of effective support for decision-making (Douglas and Bigby 2020). The subset of data reported here are drawn from the initial round of qualitative data collection that explored decision support practices of supporters and experiences of decision-making by the people with intellectual disabilities they supported prior to training.

Participants were recruited through parent and service networks associated with the researchers and the 12 industry partners in the study which included disability support organisations and statutory bodies such as Offices of the Public Advocate from 3 Australian states. Participants comprised 55 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. These people were parents (33), other family or friends (5), or paid workers (16). All participants lived in the three most populous of Australia's eight states and territories – Victoria, New South Wales and Queensland. Dyads were interviewed between December 2016 and May 2019.

The semi structured interview schedules were designed to understand the nuance of supporters' practices, and decision-makers' experiences. Dyads were interviewed separately and nominated a wide range of decisions to discuss, ranging from choosing what to wear, to independent living arrangements. Interviews lasted between 30 and 60 min, were digitally recorded and then transcribed. The dyad transcripts were coded initially using the 8 steps, 3 principles and various strategies described in the framework (Douglas and Bigby 2020). An inductive approach to allow new thematic codes to be identified was applied following the initial coding. For example, new codes included, 'will and preferences negative' and 'will and preferences positive' which were then collapsed into 2 categories paternalism and empowerment. As the coding progressed, codes for each member of a dyad were compared and contrasted for the purposes of the analysis and discussed and refined among the research team.

The study was approved by the University Ethics committee and all participants gave informed consent. All names have been replaced by pseudonyms to preserve anonymity.

### **Limitations**

The study took a social constructionist theoretical perspective, focussing on the subjective realities of members of dyads of people with cognitive disabilities and their decision supporters (Bryant and Charmaz 2007). Accordingly, our analysis was interpretative and based on participants' subjective accounts,

recognising there are a multiplicity of truths about social phenomena. By interviewing dyads involved in decision making, comparison of perceptions was facilitated but these comparisons did not extend to others who might have been involved beyond the dyad. We note however, that information was sought from participants during the interviews about the role others might have played in decision support. By using face to face interviews, we attempted to build rapport with participants with cognitive disabilities but acknowledge the difficulties they may have experienced due to cognitive limitations in providing rich descriptions of their experiences or sophisticated insights into their feelings. 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.

### ***Heavily circumscribed 'choices'?***

The most striking aspect of the material coded on will and preferences is what is absent. The meat and potatoes of conceptual discussions of empowerment – the clear-cut binary of either respecting or overriding personal autonomy – is missing. In its place are rather ambiguous and difficult to read 'mid-spectrum' exchanges, largely shaped by forces *external* to the decision in question and often narrowing it to such an extent that choice evaporates, rendering it effectively a form of paternalism.

For example, Julia would have liked more discretion about whether and when to participate in work and training, but appeared reconciled to the inevitability of external pressures for a stable routine:

JULIA: Well, I would say that I always get to have a say, but I don't really feel like it actually matters what I say

INTERVIEWER: So what do you reckon? So we're thinking that you're sometimes happy with how much control you have? Or that you're often happy? Or never happy? Or always happy?

JULIA: Well, like, when I say, "I don't want to get a job", or, "I don't want to do volunteering", or, "I don't want to do this". "I've finished school. I don't want to do this thing", and they said that I have to do this course because I have to get a job, I have to get volunteering blah blah .... So I don't really feel like it's actually...

...

JULIA: Yes, because I have to do – like, when I'm here, I have to do what everyone else is doing. I can't not do it because I don't feel like doing it at the time, or because I'm too tired.

Simon's discussion of his ability to choose where to spend his time was even more constrained. In this instance a product of being joined into group activities facilitated by a support worker:

SIMON: I wouldn't say I've chosen. I'll go out with a group of us ...

INTERVIEWER: So did you choose to be part of that group?

SIMON: No, no.

INTERVIEWER: Who chose that?

SIMON: One of the people that I was with – what's her name -

INTERVIEWER: Like a support worker or ...?

SIMON: Yes, it's a support worker.

INTERVIEWER: So she chose it for you?

SIMON: Mmmm.

In situations such as these, the external constraints – whether set by carers, service providers or others – paternalistically remove most potentially empowering choices lying outside of any very narrow field remaining. The key question is whether this is attributable to unthinking paternalism (unconscious application of Bartlett's 'risk society' values) and thus potentially capable of being remoulded by appropriate training, or instead part of the unchangeable realities of life which are resistant to change.

Even an ostensibly gold standard instance of empowerment can be replete with nuance and ambiguity, as next shown.

### *Chasing a mirage?*

Jacob had been supported to make a decision to elect to have a vagal nerve stimulator implanted to control epileptic seizures. A video of the procedure was provided as part of scaffolding the information for him.

INTERVIEWER: ... So when you were deciding about getting the operation did you talk to mum about that? What did mum say? Can you remember?

JACOB: Yeah. I had a chat to her about it first and then us we had a DVD showing a TV show all about it and I'd watched this and then I thought to go to the hospital and get it.

INTERVIEWER: And did you watch that with mum?

JACOB: Just by myself. It's my choice.

However, a little later the conversation turned to the hospital briefing and Jacob was asked:

Did you talk to them about the good things and the bad things about having the operation?

JACOB: Well, the only thing they told me is just about the choice. That's what they told me. That's all.

And then:

INTERVIEWER: ... So what were some of the good things about getting it?

JACOB: Well, I just had to wait a few days until it came.

What initially reads as pure empowerment in making a life-changing *health decision* (one that Jacob clearly did value greatly) shrinks into valuing or otherwise his right to 'choose'. And then the conversation starts to appear as about a choice being made, not by weighing or appreciating the benefits and risks of the procedure (as informed consent to health care requires), but rather as taken on the basis of 'getting it over quickly'. This is captured in the final part of the exchange:

INTERVIEWER: Okay. Did they tell you what they thought you should choose?

JACOB: They did.

INTERVIEWER: Did they want you to have the operation?

JACOB: Well, it's just for me to choose about it and then I thought – I told them, "Yes, I want to go down to Melbourne."

Such emptying of the substance of what was at stake in the 'decision' received corroboration from his supporter, Catherine, when she relates that:

But ... we talked about it and Jacob saw a video of it and we just said to him, "Jacob, it's your choice, you know, if you want to have it, you know, go for it."

While it would be wrong to make too much of this exchange, it does suggest that empowerment and paternalism cannot readily be read from the expressed views of the person being supported (as a rights perspective would favour in designing accountability measures). It also brings home the importance of the form in which decisional choices are *presented*, as now discussed.

### ***Verbal scaffolding to empower through narrowing***

Supporters at times used verbal scaffolding to narrow the field of choice to enable the person being supported to engage with meaningful options when otherwise they might be swamped by an excess of choices.

This scaffolding is illustrated in the following comment by Alannah, the supporter of Jaxon, who talked about supporting him to choose a Barbie doll:

ALANNAH: So I might guide him price wise, because we might not want the \$69 one. So I might say, "Jaxon, you've only \$10 to spend, so these are the \$10 Barbies that you can pick from." So that narrows the field down. And then I might offer him little advice like, the main thing that he likes to do with them is brush their hair, so I might steer him towards the ones with long hair, because often they get little haircuts at home too, and he likes to do them up in weird sort of beehives

and all sorts of really intricate hair-do's. So then I might steer him in that direction too, like, "These ones have got long hair," so that I've narrowed the field down again, and then probably just let him mull it over.

Scaffolding was also evident in discussion of the choice of the destination for a reluctantly embarked upon but very empowering vacation trip to the iconic Australian tourist destination of Uluru for Simon. Applying lessons learned from a previous unfortunate travel experience (attributed to decision overload), his supporter Margaret explained:

So that's it, I suppose what I'm getting down to was I chose that because I knew that there'd be just a few things we could do that he would love to do that he wouldn't then be demanding to go and do something else because it was very simple and very isolated in the choices.

In the result, these more constrained choices proved fulfilling. As Margaret elaborated, this destination enabled Simon to be "[T]he man" because he was doing what his father had said when dropping them off at the airport "[N]ow Simon you look after your mum" "[A]nd he took it really seriously, bless his heart. So that was good." As Simon related it:

INTERVIEWER: Great. Did your mum ask you what choice you wanted to make, what you wanted to choose?

SIMON: I wanted to go to Uluru, and she said yes, go ahead. We booked on TAA. The plane. To get there.

Scaffolding in these two examples can be read as ultimately empowering in resultant outcomes. By removing the 'decision-overload', enjoyment of the purchased doll (Jaxon) and of the vacation trip (Simon) appears to have genuinely been enhanced. While the scaffolding support had paternalist overtones, it approximated to 'weak paternalism' (Dworkin 2020) in that the positive outcomes retrospectively justified narrowing of the decisional field. Despite some similarities in the techniques and motives of the supporter, however, the next set of examples illuminate deeper and arguably more problematic tensions that can arise between honouring will and preferences when the two do not coincide.

### ***Verbal gymnastics to exclude 'Un-achievable' choices***

A strong sub-text in much of the data was the difficulty of supporting realisation of what were perceived to be unrealistic wishes.

Dean, the supporter of Sean, ruminated on the dilemma of how to respond to such 'fantasies':

DEAN: So he will sort of say, "Oh I want to – next year I want to go to university. And I want to study film-making, because I want to make film commercials". Like well, okay, well you can't read. So that's not going to happen. And ...if you sort of

say “Oh okay; Yeah, sure”, he’ll sort of forget about that. It’s not clear. ... I’ve seen the sort of carers here go “Oh, okay. Well, Sean, if that’s what you want to do, well, we should look into courses that you might be able to enrol. Which I think is – he is expressing a wish – so what can we do to facilitate that. And I think – I assume they think – “well, it’s wrong just to say ‘well, no, you obviously can’t do that.”

Dean’s solution to Sean’s lack of insight regarding his failure to acquire literacy skills despite extensive help previously, or of the way this ruled out university or film-making, was to pay lip service to the aspiration rather than engage directly. Dean’s rationalisation was because “*I think if you sort of point that out, he will become somewhat distressed. Like ‘Oh, I could learn to read...’*”

A not uncommon technique related by supporters was to narrow the field of choice so that choosing a potentially discomforting experience did not arise at all. As supporter Bernice related with regard to Sally who could cope with travelling on public transport but not with exposure to dodgem cars at a theme park:

[G]oing to [the theme park]. Now I know that she is absolutely terrified, based on past experience of dodgem cars, anything that’s sort of like vaguely controllable [would be fine] – but out of control, she would feel very uncomfortable.

Gregory’s ‘confusion’ about whether to take on another long endurance run across Australia was another example of narrowing choices by his supporter, Jennifer.

JENNIFER: I always find with Gregory, you don’t say what would you like to do? That’s too difficult. That’s like saying, why is the grass green? So if I present a few choices and say, these are some of the things you could do – “We could get the manager to speak to the support worker. You could have a discussion with your circle of friends. Or you could wait until you see your counsellor. ... So these are your choices as I see it” I said, “plus I think a good, long run might be helpful”. So he chose the good, long run and contacted the circle of friends.

This squarely reprises the ‘will’ versus ‘preferences’ dilemma at the heart of CRPD guidance on the way support is to ‘empower’ the agency of the person with cognitive impairment.

Understandably, in everyday settings those doing the supporting have to answer the practical question of ‘empowerment to do what?’ As these examples show, supporters bring and apply their own ‘social realism’ test about what is achievable (the goals seen as reflective of a true ‘will’) and put aside what may be passionately held ‘preferences’ of the person being supported. This ultimately is paternalism (weak paternalism) in another (and arguably unavoidable) guise. After all, none of us can get ‘everything we wish for’. There is always a reality check.

As revealed in the final group, support in *realising* will and preferences likewise ranges from less to more problematic in character.

### ***From wants to realisable action***

Among supporters a consistent theme was identifying and helping to translate wants into realisable change in the life of the person supported. In two cases the National Disability Insurance Scheme (NDIS) formal service planning meeting was identified as pivotal, enabling identification of 'likes and dislikes' (further, Carney, Then, Bigby, Wiesel, and Douglas 2019). But life goals risk becoming entangled with those of the supporter, as illustrated by Margot when she talked about Finn's goal of independence:

INTERVIEWER: So do you have a sense of Finn's life goals?

MARGOT: Yes, I do. Yes, we've done a bit – and the NDIS helped that. I had to do some planning with him and it ultimately it is to live independently. So everything we do is to work towards independence. Yeah, independence.

INTERVIEWER: So when did you realise that that was Finn's goal, or was that always your goal?

MARGOT: Maybe – well I did know I didn't want him living with me when I was 80, and I'm an older mum. I was 39 when I had him. So I did always know that oh, okay, so that might be something that perhaps the decision. But he's certainly been – now have I influenced that. That would be interesting. I don't know. But he certainly is right into it himself, yes. ... He wants to be independent. He wants to live without any hassle. I don't know which came first: the chicken or the egg. I don't know.

Knowledge of the person being supported can play a vital role in understanding expressions of likes and dislikes. Heath's renewed interest in another attempt at independent living was a case in point. As his supporter Michelle explained: *'he sat in the car one day, said to me, I'm ready to move out again. I just rolled my eyes and I thought okay. So my husband and I went and had a look at an apartment. Because he wants to share with someone else.'* However, on later visiting some cluster housing set up by families of people with a disability, Heath ruled it out, initially saying he was 'scared of' one of the existing residents. But this was not the true reason, as Michele explained:

But we had another discussion around that because Heath – Heath tends to – if you ask him why he doesn't like something or doesn't want to do something, he tends to try and find reasons that he thinks you will accept and that are not going to put anyone else in a bad light. ... Then I just kept saying to Heath, "Look, I don't think you're telling me the truth. I don't think you're being honest in your reasons". So I just kept pushing him and, in the end, he said, "That's not how I want to live". And I said, "well that's fine. It's all you needed to say."

Heath's wish to live independently but with just very few people thus was ultimately clarified as a basis for subsequent plans to turn his 'real' wishes into reality.

Commonly the expression of the will and preferences of the person being supported centred on less taxing issues, such as what particular work or other activity was preferred. Some of these were more easily read and then progressed. For example, Mikayla, the supporter for Paula, related that:

I guess that once she said she didn't want to do – it was the studies, the course, she wasn't enjoying that anymore, and then she came up with the idea of cooking. Then it was just a matter of finding a cooking class that happened on that particular day, and there wasn't that many options.

Others were less straightforward, such as Tom's preferences about suitable work. This was because, as his supporter Alan explained:

[I]t's hard to explain what a job is that doesn't exclude him. So I guess he's committed to what he has experienced and what he would like to do from either watching TV or talking to friends. So no, we never really pushed him to a particular direction, only because again, we leave it pretty much as to what he thinks he would enjoy and prefer doing.

Arguably examples such as these come closest to actual empowerment or realisation of the will and preferences of the person being supported, as envisaged by the CRPD. This is because these supporters appear to have more information or skills to draw on in *reading* will and preference, as well as being in the more fortunate position that the decision in question is more amenable than others to more genuine empowerment, with minimal presence of paternalism. So, while these are commendably positive examples, it does not follow that the same would be true for a different decision.

## Discussion

The degree of confidence able to be placed in how adequately respect for will and preferences translated into support for decision-making in the study sample proved to be a mixed bag. In every instance discussed above it is clear that the conclusion drawn is entirely subjective, though many of the examples do convey authenticity.

Our readings of the decision-making as empowering or otherwise reflected a degree of face validity, thus imparting reasonable levels of confidence in the characterisation. This was particularly true of every-day decisions about activities but was far less so for larger questions. This is consistent with UK findings about the 'complexity' of support and their taxonomy of decisions, running from the 'spontaneous' to 'mid-term' and 'strategic' (Devi et al. 2020, 147–148, 152). Even when paternalistic 'guidance' from the supporter was detected in their support for making more straightforward choices, some confidence could still be placed in it being reflective of distillation of the higher order 'will' of the person supported (their long-term values and goals).

The paternalism still falls short of the philosophical position of weak-paternalism because it lacks any prospect of *actual* retrospective validation (the ‘thank-you’ blessing after the event) due to the level of cognitive impairment. But its face validity nevertheless ‘mimics’ or approximates that result.

However even face validity proved very problematic when higher stakes choices were in issue, as with Jacob’s health decision agreeing to implant a vagal nerve stimulator. As the qualitative narrative of his process of choosing unfolded, the characterisation shifted dramatically. It ran the full spectrum from an empowering to a paternalistic one – indeed at worst a paternalistic decision disguised as something better and more empowering than it was in reality. This casts doubt on the extent to which it is possible to correctly characterise where such a decision sits on the spectrum, meaning the purchase points for determining whether training of supporters helps to shift the dial towards empowerment is not made out. As a consequence fidelity to purpose also cannot be determined with any confidence.

The next question is whether the paternalism-empowering characterisation arguably remains too subjective and thus too labile an assessment to serve as the safeguarding component of support for exercise of legal capacity insisted on in clause 4 of Article 12 of the CRPD. The clause is not prescriptive of particular methods of safeguarding, simply calling for ‘appropriate and effective safeguards to prevent abuse’, with an implicit focus on checking measures restrictive of the exercise of legal capacity (i.e. paternalist substitute decision-making):

Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

Currently there are no safeguards at all for *informal* support for decision-making in the three study site jurisdictions. Indeed, for a case such as Jacob’s, his supporter (Catherine) would be legally empowered to make a *substitute* decision under Australian legislation establishing a pre-authorised ‘list’ of health decision-makers. While the resultant ‘standing authority’ removes any need for Jacob to satisfy the common law test of informed consent, it would come with some safeguards, including the ability to contest the decision taken and the requirement to consider statutory decision-making principles (White, Willmott, and Then 2018). So, in the sense that something is better than nothing, even a contestable subjective judgment call made by any third party entrusted with monitoring for fidelity of purpose – such

as one made by a public watchdog office like that of the Office of Public Advocate or a civil society 'nominated citizen' as under the *Representation Agreement Act* in British Columbia, Canada – could be portrayed as a worthwhile step down the safeguards path. Although imperfect, it might also be regarded as a sufficiently proportional protection of Jacob's 'rights and interests', as the CRPD clause requires. The La Trobe Framework takes a different route in seeking to do this through promotion of greater *self-reflection* and a more *deliberate approach to support for decision-making by supporters*, something the quantitative measures and other data suggests is realised for many but not all people exposed to training (Bigby et al. 2020 submitted; Douglas, Bigby, and Smith 2020).

The counter argument is that such protection is fictional (mere 'window dressing') because lacking in substance. This critique returns the focus to the sharp differences between will, preferences and rights, and the scope that this provides for rationalising decisions which in truth are being made on paternalist 'best interests' ground, as if they are a reflection of the authentic 'preferences' of the person. This risk of smuggling in the supporter's reading of the person's 'will' is greater for a person with cognitive impairment due to an intellectual disability than for someone with an acquired brain injury (ABI). For while both may currently have difficulty in expressing authentic long term life goals and values, a person with an ABI usually has a *past* life-course of such goals and values able to serve as a reference point; albeit a very flimsy one. For instance, Jacob's final decision to 'choose' to have a vagal implant may be read not as reflecting a real appreciation of the 'better life' the procedure gave him in no longer being so prone to seizures (his 'will'), but instead a traduced implementation of his 'preference' to get it over quickly. And Finn's life goal of independence may or may not have been a reflection of his own 'will' (and in his case also his 'preference') rather than that of his supporter Margot.

Cases such as Sean's, Sally's and Tom's where 'unrealistic' expressions of 'will' regarding employment or social participation are ignored or narrowed – are even more complicated. Here clearly expressed preferences for unrealistic or unachievable goals are manipulated to negate certain 'preferences', but perhaps in realistic furtherance of CRPD articulated 'rights', such as the rights to employment or participation. Claassen's (2018) 'navigational agency' conception of the previously mentioned capability theory (with its focus on 'effective opportunities that people have to lead the lives they have reason to value': Robeyns 2006, 351) may be pertinent here. Actions of supporters to narrow the field of choice or type of content of options presented to the person being supported might still be construed as 'empowering' *provided* they preserve meaningful choice between 'different' *social practices of relevance* to their lives.

That certainly has some advantage in putting the spotlight on actual lived life experiences of the person supported. But ultimately it still leaves a subjective judgment to be made, both about *which* social practices are relevant and whether the person supported is making a real choice or not. So, it arguably doesn't advance resolution of a case such as Jacob's.

## Conclusion

Theoretical framing of concepts like paternalism and empowerment prove rather too abstract or 'slippery' to obtain much purchase on the lived experience of support for decision-making revealed by qualitative fieldwork.

While the qualitative data in this article demonstrated how subjective and nuanced is the task of assessing the degree to which *particular* decisions being supported are to be characterised as paternalistic or as empowering of rights will and preferences, it proved to be more than just reliance on the 'eye of the beholder'. It was found that some confidence could be placed in the assessments, especially when regarding issues of daily-living rather than more fundamental lifecourse issues. However, the extent of the shift away from Rodham's 'empty vessel' critique of best interests paternalism-informed *substitute* decision-making for people judged to lack rational cognitive capacities, towards CRPD-compliant support for decision-making informed instead by 'will, preferences and rights', proved to be hard to pin down when larger issues are at stake.

Reading empowerment through the lens of a person's will, preferences and rights entails application of hardly a less subjective a guide than reading it through the displaced lens of best interests. Its saving grace perhaps is that at least the tensions between will, preferences and rights can be rendered partially visible under close academic analysis. But in daily life and or everyday practice of disability support workers such subtleties seem to be beyond appreciation. And for larger lifecourse issues, subjective readings of the ultimate outcome of competing considerations prove to be quite fluid or changeable. In part at least this may be because of those deeply entrenched cultural values of the 'rational person' alluded to by Quinn (2020) or of Bartlett's (2020) culture of risk aversion.

Yet as Bartlett rightly says:

The reality is that for CRPD compliance to be achieved in anything like the form suggested by the CRPD Committee, fundamental political change is going to be necessary, within the political classes, among the relevant professional groups, and within society as a whole. That is a project that has barely begun. It cannot mean diluting the CRPD project, but if we are to see real movement, it must engage with the administrative realities and understand the reasons for the ideological positions the relevant actors start with (Bartlett 2020, 12).

Quinn optimistically refers to a host of disciplines challenging the validity of the narrow cognitive rationality precept, including neuroscience, clinical psychology, feminist/capability scholarship and behavioural economics among others, suggesting that this is “telling us loud and clear that cognition is just one part of a menu of capacities that most humans possess. ... that new discovery techniques are available and are evolving to enable us to divine the will and preference of the person, even in circumstances where we thought they were unknowable to us” (Quinn 2020, 41).

But it is this last claim that surely is both the largest challenge for operationalisation of the new paradigm of support for decision-making on CRPD terms, and the one which the data analysed here suggests cannot be made so glibly. Paternalism and empowerment are not just two qualities in the eye of the beholder, but neither are they yet ‘readily ascertainable presences’ either. The purchase points for an ‘outcomes’ measure of compliance are lacking. This is an unsurprising conclusion from the perspective of the La Trobe framework, which instead concentrates on training designed to lead to greater *participation* by the person supported and greater *reflection* and *deliberation* on wise and effective ways of providing such support by the person delivering it. Indeed participation, reflection and deliberation may also cleave more closely to the original rationale for support for decision making for people with a cognitive impairment (Arstein-Kerslake et al. 2017) and be more capable of being meaningfully progressed (Douglas, Bigby, and Smith 2020; Bigby et al. 2020 submitted).

### Disclosure statement

The authors declare that they have no financial or other interest.

### Funding

Research for this article was supported by Australian Research Council Linkage Grant [LP150100391]

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