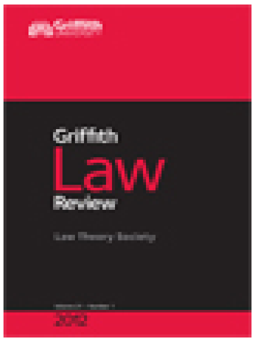

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Realising ‘will, preferences and rights’: reconciling differences on best practice support for decision-making?

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ABSTRACT
‘Will, preferences and rights’ is the new guiding principle for all support for or exercise of decision-making under the *Convention on Rights of Persons with Disabilities,* but its meaning is disputed and practice implications are poorly understood. This article explores key debates across disciplines and draws on grounded theory fieldwork findings to bring greater clarity to the principle within law, policy and practice settings. It is argued that the principle calls for a nuanced understanding which cautions against expectations that mere enactment into law or adoption within programs of support will prove to be a panacea.

KEYWORDS
Will preferences and rights; support for decision-making; CRPD; grounded-theory findings

I. Introduction

Interdisciplinary understandings of complex constructs can be challenging to reconcile. Reaching greater consensus on the meaning and practical implications of Article 12 of the *Convention on the Rights of Persons with Disabilities* (CRPD) on equal recognition before the law[1] – and specifically the concepts of ‘will, preferences and rights’ adopted in Article 12(4) as lodestar principles for guiding support for exercising legal capacity – is a case in point.[2] Article 12 restates the existing human right that everyone, regardless

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[1] Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) (CRPD) Article 12. The salient parts of State Parties obligations are:

1. … the right to recognition everywhere as persons before the law.
2. … legal capacity on an equal basis with others in all aspects of life.
3. … measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. … ensur[ing] that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. 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 … .

[2] Craigie et al (2019).

of level of abilities is entitled to equality before the law.[3] While Article 12 does not set out additional rights for people with disabilities it did, for the first time, describe the 'specific elements that States parties are required to take into account to ensure the right to equality before the law for people with disabilities, on an equal basis with others'.[4] This includes specific reference to State obligations to take steps to provide access to support required to exercise legal capacity for those who need it. While the term supported decision-making is not used in Article 12, it has become synonymous with an understanding of what Article 12 means in practice. This article explores the conceptual tensions around will, preferences and rights, drawing on fieldwork into capacity-building and effectiveness of support for decision-making practice to contextualise that discussion and reveal some of its practical complexities, such as the emotional labour entailed in its delivery.

Many health sciences professionals and providers of disability services, some but not all consumers, social policy hardheads cognisant of limited public resources, and sceptics of overselling the social capital capacity of civil society and the family, all can make a case for having been neglected or by-passed in the debates about Article 12. Rather these debates understandably have been dominated by lawyers and 'normative' disciplines, such as philosophy, since human rights treaties and standards are about what 'must' (in the case of civil rights such as freedom from torture) or ultimately 'ought' to occur (in the case of 'progressive realisation' of socio-economic rights like the right to health), rather than how to make it happen in practice. Although there is much common ground, as is often the case, the interesting issues are when there is disagreement, as we now show.

Much support *for* decision-making occurs at the everyday level and principally within the informal interpersonal relations in civil society and family or the more formal relations between clients and disability support workers at the front-line of service provision, rather than under legal mandate, since very few jurisdictions have enacted specific 'supported decision-making' laws.[5] The Australian Law Reform Commission ('ALRC') expressed Article 12(4) of the CRPD as support for decision-making reflecting the 'will, preferences and rights' of the person.[6] While Article 12(4) actually formulates it as 'rights, will and preferences' the ALRC instead decided to follow 'the spectrum of decision-making based on the will and preferences of a person, through to a human rights focus in circumstances where the will and preferences of a person cannot be determined'.[7] It is fairly common ground on either formulation that this is incompatible with the open-ended 'best interests' test of the common law,[8] even if will and preferences are unable to be ascertained despite best endeavours to read them (as for a comatose stranger). In these comparatively rare circumstances, the default 'backstop' is that decisions be informed by a 'best interpretation' of will and preferences,[9] drawing on whatever is known of the person but nourished by the 'rights' expressed across the CRPD. But this is where solid consensus crumbles into

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[3] de Bhailís and Flynn (2017), p 7.

[4] UN Committee on the Rights of Persons with Disabilities (2014).

[5] Then et al (2018).

[6] ALRC (2014), pp 75–85.

[7] ALRC (2014), p 76 para [3.53].

[8] Some jurisdictions have replaced best interests. Victoria adopts the phrase 'promote the personal and social wellbeing of a person', including regard for their 'inherent dignity', individuality, 'existing supportive relationships, religion, values' and respecting of confidentiality of information: *Guardianship and Administration Act 2019* (Vic), s 4.

[9] Donnelly (2016). General Comment #1 also turns to best interpretation only where, 'after significant efforts have been made, it is not practicable to determine the will and preferences of an individual': UN Committee on the Rights of Persons with Disabilities (2014) para [21].

uncertainty and disagreement. Thus while the ALRC treated will and preferences as a single *phrase* (and Victoria is following suit), each of those terms has a distinct linguistic meaning, potentially leading to a finer grained sequential process starting with acceptance of will before moving to preferences and then rights. Now that legislatures are incorporating this language,[10] the meanings of these terms have real world consequences for the practice of support for decision-making.

So what is 'will' and what are 'preferences', do they bleed into each other to any degree, and how do they express themselves? One issue here is whether will entails a degree of rational processing (as in free will or informed consent) or involves respecting a raw, unadulterated desire or '*natural* will'.[11] Another is whether the expression of will or preferences is (or can be) that of the affected person alone or instead is 'shaped' by social interactions with others. A key practical question is whether the social audience simply 'reads' another person's will or preferences (a face or literal process) or engages in a process of 'interpretation' of it. And if interpretation is involved, how is that interpretation to avoid being the (imposed) meaning of the listener rather than the real meaning of the speaker? Since expression of and actions on will and preferences are the stuff of social interaction and engagement over a period of time, questions also arise about the point where a social conversation ceases to refine and add value by more authentically representing the 'true' will (and any 'choice' or 'agency') of the person, by transforming into an unduly constrained, coerced or in-authentic expression.[12] For example, supporters' actions can open up new avenues or experiences that expand decision-making options in ways similar to the guided self-determination described by Crisp,[13] or their actions can be directive or manipulative, guiding decision-making in supporter preferred directions. Threading through all this is whether our difficulties stem from arguably flawed liberal conceptions of rights as individual autonomy, rather than a framing in relational and socially contextual form (as already done for abusive relationships[14]).

These are neither abstract nor unimportant questions. They are at the heart of how support for decision-making should be structured in legislation, policy and everyday practice. Yet, to the extent that commentators have not neglected them altogether, answers to these questions differ in fundamental ways, as shown in the next Part. Part III then draws out the threads of our argument about the finely balanced and highly contextual challenge of understanding and applying will, preferences and rights as a lodestar for the practice of

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[10] The Victorian *Guardianship and Administration Act 2019,* addresses some of the sequencing and weighting issues:

> 9 **Decision-making principles**
> (1) A person making a decision for a represented person must have regard to the following principles –
> (a) … give all practicable and appropriate effect to the represented person's will and preferences, if known;
> (b) if … [un]able to determine the represented person's will and preferences, … give effect as far as practicable in the circumstances to what the person believes the represented person's will and preferences are likely to be, based on all the information available, including information obtained by consulting … relatives, close friends and carers;
> (c) if … [un]able to determine the represented person's likely will and preferences, … act in a manner which promotes the represented person's personal and social wellbeing; …
> (d) the represented person's will and preferences should only be overridden if it is necessary to do so to prevent serious harm to the represented person.

[11] Szmukler (2017), p 92.

[12] The most obvious source of such distortion is when undue influence is brought to bear, as recognised in GC1: UN Committee on the Rights of Persons with Disabilities (2014), para [22]. Undue influence however is no 'bright line' concept, with much room for debate about what it entails and when it is operative, much less how to avoid it.

[13] Crisp (2018).

[14] Kong (2015).

support. Part IV summarises our fieldwork-informed position of cautioning against expecting the new principle to be a panacea.

II. Disharmony of standpoints on 'will and preferences'

The philosophical, medical and social-relational literatures on will, preferences and rights are often in disharmony in interpreting these concepts, particularly will and preferences. This section highlights some key 'battlegrounds' in these debates, including a grounded theory reading of will, preference and rights drawn from our fieldwork.

On a purely straightforward reading it might be said that 'will' is the answer to 'what do I *want*', that preferences incorporate something of the answer to the question '*why* do I say I want it', while rights go more to the question of 'is that *meaningful* for you'. However, another reading might be that a want or desire is seen as the immediate 'preference', while will is a higher-order loading of more settled values. On the latter view for instance, a young adult's preference to move out of their parents' home can be interpreted as reflecting a will for independence; while on the first, perhaps just a 'willful' expression of adolescent impetuosity. But there are more sophisticated frames for thinking about it all. Whether or not to insist on an epistemic grounding is the first battleground: that is, whether the inquiry calls for showing real 'knowledge' grounded in understanding and connection to known facts about the person. This discussion is more than a mere philosophical debate, carrying consequences such as whether a stranger lacking deep knowledge can actually provide support for someone with cognitive impairment (or as discussed in Part IIC whether capacity-building investments can succeed here), or in what circumstances clearly expressed current desires can be overridden either as being in conflict with deeper settled life values of the person (the main focus of this article), or with their 'rights' under the CRPD (an issue we return to in Part IIIB).

A. A philosophically leavened human rights 'interpretive' reading of support

In arguably one of the more systematic but radical analyses so far, Paul Skowron rejects an epistemic reading of will and preferences under Article 12 of the CRPD because it searches for 'outcomes' reflective of some pre-ordained *true* will and preference (leaving out of account the way presentation of new options may facilitate expanded or better choices, or conversely suppress choice by injecting constraints). Rather, Skowron argues that Article 12(4) *always* involves picking and then applying a 'best interpretation' *process* (the process best capable of expanding and facilitating real choice), and that this is so even in ascertaining the person's will, or in establishing their preferences.[15]

As explained below, viewing the CRPD lodestar of will, preferences and rights as a 'process' sits comfortably with feminist relational readings of social life – with its spatial characteristic of interactions with social networks rather than solo decision-making, and its temporal feature of fluid and even recurrent conversations rather than instant decision-making.[16] But it is seriously at odds with mainstream CRPD scholarship in two ways. First in its reading of the CRPD Committee's General

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[15] Skowron (2019), p 126.
[16] Carney (2018).

Comment #1[17] ('GC1') as requiring a best interpretive process for *all* readings of another's will and preferences – rather than the much narrower ('fall back') approach which confines such 'interpretation' to those comparatively rare situations where will and preferences cannot be ascertained.[18] Second in its rejection of the view that an epistemic reading *is possible* in other, more common situations.[19] It is, however, unconvincing to think that the CRPD Committee ever intended or would accept that a 'best interpretation process' is required to read will and preferences in non-exceptional circumstances,[20] or that it would agree with Skowron by rejecting epistemic readings such as Szmukler's approach as applied in *commonplace* situations.[21]

To be fair, Skowron comes to his position not only through this problematic textual analysis of the UN Committee's GC1 (hardly more than persuasive) but more plausibly by discussing common everyday ways in which a person's will may be misunderstood ('I want to go home' while shopping being misread when its intended meaning was 'back to my home country' rather than stop shopping and go back to the house) due to 'assumptions' of the listener, or of 'backing down' having offended the listener with the first meaning.[22] However, surely this gives undue importance to 'clarificatory' components of normal conversational speech. It is true that: '[a] person's will and preferences change in response to their environment; and, because humans are extremely social creatures, they particularly change in response to interpretation by others',[23] but to go on to claim that '[t]his self-interpreting, responsive aspect of preferences is fatal to the epistemic reading'[24] is simply a bridge too far. For if that claim is to be accepted then *all social intercourse* is governed by the more elevated 'best interpretation' of will and preferences process outlined in GC1. It is a bridge too far because people *do* commonly accept at face value their understanding of a communication of another's will or preference (changeable as it may be); interrogation of it, or attempts to shift preferences, are comparatively infrequent outside relationships of dependence such as child raising (thankfully for human relationships).

Where Skowron is on stronger ground perhaps, is in stressing the relational and embedded character of social life. Martha Fineman and other feminist scholars take a 'relational' view of *all* human decision-making.[25] Decision-makers necessarily interact with their social network in making decisions through conversations and other social processes. But members of that social network or the public at large also necessarily constitute the *social audience* which recognises that person's will, by engaging in some 'process' of *reading* that will and/or preference and associated expression in a decision. That is certainly true of many decisions involving at least brief 'conversations' (ie decision-making with a 'transactional' dimension) where an interactive process of 'reading and contributing' takes place. It is therefore also a social site where the conversational partners may deploy the language of social influence; a spectrum of language which runs from subtle 'suasion'

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[17] UN Committee on the Rights of Persons with Disabilities (2014).
[18] Donnelly (2016).
[19] As argued by Szmukler (2017).
[20] Arstein-Kerslake and Flynn (2017); Arstein-Kerslake and Flynn (2016).
[21] Skowron (2019), pp 128–129.
[22] Skowron (2019), pp 129–130.
[23] Skowron (2019), p 130.
[24] Skowron (2019), p 130.
[25] Fineman (2013); Fineman (2004); Nedelsky (2011).

through to moral blackmail as the nearest neighbour to outright coercion. Influence that can prove particularly problematic for people for whom support in decision-making is required (Parts IIC, IIIC).

But not all decision-making is so socially embedded or prone to extensive 'second guessing' by others. For instance it surely is not representative of routine expressions of will such as going to the shop to buy an ice-cream. There are indeed straightforward situations where will and/or preferences can instantly be determined, just as there are socially transacted processes for making and then understanding another person's will and/or preferences, including through some *process* of interpretation. However, it is certainly true that the dilemmas and complexities of such human interactive processes are often encountered in practice in the provision of support for decision-making (Part IID below).

Rather than focus on the way will and preferences are operationalised in practice, however, health sciences professionals instead call into question what they perceive to be the medically illiterate formulation of the guideline itself.

B. A clinician's 'medical-contextual' reading of 'will, preference and rights'

Clinicians from the health sciences have long suggested that there is a disconnect between the clinical experience of certain disabilities and the approach called for under the UN Committee's interpretation of Article 12. Clinicians highlight the diversity of mental states and manifestations of those conditions in daily life. Depending on the condition, it may undermine the capacity to clearly express either will or preferences as with intellectual disability, or more complexly raise issues of authenticity of currently expressed will (as with psychotic delusions, or brain injuries causing a person to always live 'in the moment' without short term memory) and/or the ability to moderate expressed will against past preferences (as in a patient with dementia and a 'new personality and values', the permanence of which may warrant their acceptance, unlike those the product of shorter-term psychoses). As Galderisi observes of such conditions, 'the possibility to assess the person's will and preferences "coherent with a sense of personal identity" is very limited'.[26] Thus,

> During a manic episode, … a person may prefer to behave in ways that, outside that episode, would make her/him deeply ashamed, or concerned, or even guilty. When recovered, the person might ask those around her/him why no one did anything to prevent her/him from causing so many troubles. When acutely delusional, a person might wish to donate all her/his goods to someone else, and later on, when no more delusional, feel desperate for having ruined her/himself and the whole family.[27]

Such '[c]onflicts between different wills in different moments, and even among different rights'[28] have of course historically been managed paternalistically, by application of a 'best interests' conclusion that the person should be protected from *self*-exploitation.[29] Advance directives in general, and particularly those made prior to experiencing a dementia which results in a 'new personality', provide a different but major challenge to assumptions of consistency of beliefs, as discussed later.

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[26] Galderisi (2019), p 48.
[27] Galderisi (2019), p 48.
[28] Galderisi (2019), p 48.
[29] See Donnelly (2016).

For his part Szmukler has sought to reunite will and preferences with clinical realities through excavating philosophical reflections on ‘will and preferences’, thereby attracting strong criticism for retaining capacity assessments.[30] Rather than will being the raw expression of ‘wants’ with which this paper opened, Szmukler adopts a philosophical reading of will as ‘as a higher-order function reflective about values and what it would be best to do, as opposed to desires or inclinations – or “preferences”’.[31] While usually coincident,

> It is when they diverge and a person needs to make a serious decision that a problem may arise. The ‘will’, on this view, can be seen as founded on a person’s deeply held, reasonably stable and reasonably coherent personal values. In this sense, it is not the same as a desire, inclination, or a currently held ‘preference’, even a strongly expressed one.[32]

In such a contest, will – as so defined – prevails. Elaborating more recently on how such a conception of will might be operationalised, Szmukler essentially equates its written expression in an advance directive (legally designed to trump later loss of capacity, or in the case of a so-called Ulysses agreement, to trump harmful actions the person anticipates they may otherwise take in the future) with what may be termed its *social history* expression.[33] In other words, its expression through a well settled and evidenced repository of a person’s past ‘will’ (constituted as deeply held, stable conceptions of the good). Szmukler argues that both forms of ‘time 1’ manifestation of will presumptively trump any questionable ‘time 2’ contradiction of it.

There is much power in refusal to give any significantly greater weight to a person’s time 1 statement reduced to writing (an advance directive) compared to one which is orally expressed or derived from lived life expressions of will; a position equity jurisprudence adopted centuries ago in doctrines such as part performance and constructive trusts (where oral expression or past patterns of actions over-ride lack of ‘formalities’). There is also strong if more contestable merit in the clinically grounded identification of psychoses, and some brain injuries,[34] as resulting in a temporary or long-standing inability to align later (‘time 2’) appearances of will with those earlier (time 1) expressions of it. Yet, as Skowron recognises, room must be kept for the case where the past self arguably should not bind the future self.[35] And as was the case when debating the appropriateness or otherwise of an epistemic reading, it is the blurry boundaries around when currently expressed views are to be trumped by earlier and supposedly more settled views, and the messiness of the process of so deciding, that lingers most strongly.[36] Clinicians and other practitioners are indeed very familiar with these dilemmas around when to facilitate the person to change their preferences and when someone else should step in.

So are there more socially attuned framings in addition to the philosophical and clinical standpoints canvassed so far?

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[30] Flynn (2019); Puras and Gooding (2019).

[31] Szmukler (2017), p 93.

[32] Szmukler (2017), p 93.

[33] Szmukler (2019), p 39.

[34] Szmukler (2019), p 38.

[35] Further, Matsumura (2014); Herring (2008), pp 1622, 1637–1645.

[36] Earlier views generally are trumps under valid common law or statutory advance directives, though there are some exceptions: White et al (2018), pp 217–220, 239–240, 265–266.

C. A social-relational reading of Article 12 as social capital-building

No matter how will or preference ideally is to be understood, recognition and respect for a person's will and preferences depends on social actions of others. The social-relational situation of the person with a disability is therefore the key, as later elaborated from our preliminary fieldwork (Part IID). Capability theory scholarship (such as that of Martha Nussbaum[37]) emphasises such social realities of lived lives over conceptions of individuals as rationality machines, and of state responsibilities to promote and support development of key capabilities.[38] Article 12(4) of the CRPD, calling for support for decision-making, embodies this relational conception of personal autonomy.[39] In short, the individual qualities of a supporter or supporters, and their relational setting, matter.[40]

Writing about how traditional guardianship substitute decision-making can be transformed for older people with dementia, Quinn, Gur and Watson focus on what 'personhood' means, writing that 'although the stuff of our personhood is necessarily experienced individually, it is essentially a shared phenomenon'.[41] From this they observe that the CRPD is driving a shift away from protection towards 'support and social inclusion in the broadest sense', by 'search[ing] for ways to enable the voice of older persons to be revealed and supported' by way of means ranging from mere prompts or cues 'sparking' revelation of that voice or decision, through to full blown 'interpretation'.[42] Safeguards too, Quinn, Gur and Watson suggest, are less about precautions against removal of rights and more about the 'integrity of the process' for discovering will and preferences, such as occurs when the process is compromised by projection of a third party's misreading of will to displace the person's authentic will.[43] They recognise that the 'social scaffolding' of potential support provided by social networks accessible to a person varies greatly, however. For instance social networks tend to be smaller in size for people with intellectual disability (close family)[44] and to progressively contract and lose depth of knowledge of the person over time in the case of people with both developmental and acquired cognitive disorders, including dementias.[45]

In social capital language it is self-evident that the level of contribution by a social network, in interpreting a person's will and preferences and supporting its realisation, depends on many variables. These include the size of the network, frequency and duration of interactions with its members, and particularly the depth of understanding of support/interpretation issues and general skill set of its members (e.g. understanding of the rights of the decision-maker and the risks of inappropriate paternalism). Opening up for people with disability that 'zone of rich social interaction' associated with fullest expression of personhood,[46] whether by investing in programs which facilitate better access to existing networks, or building new networks or fresh sources of 'support', Quinn et al recognise is not a cheap exercise at all. That resource cost means realisation of Article 12(4) support

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[37] Nussbaum (2003); Nussbaum (2011).

[38] Gomez (2015), p 39.

[39] Series (2015).

[40] Knox et al (2016a); Knox et al (2016b); Knox et al (2015).

[41] Quinn et al (2018), p 54.

[42] Quinn et al (2018), p 55.

[43] Quinn et al (2018), p 55.

[44] Bigby (2008); Bigby (1997).

[45] Quinn et al (2018), p 58; Pozzebon et al (2016); Douglas (2019 in press).

[46] Quinn et al (2018), p 59.

cannot be achieved immediately, but rather is achieved ‘progressively’ over time,[47] and then is likely to be piecemeal and thinly resourced, favouring those with existing stores of social capital.

But even so, it is one thing to have aspirations to boost programs designed to create the rich spaces for support in exercising or interpreting will and preferences and quite another to establish whether and to what degree they succeed in realising their support aspirations.[48] Capacity-building is properly the top priority, but in short it is rather easier said than done;[49] though an ARC funded study is in the field to evaluate the degree and durability of capacity building delivered pursuant to the La Trobe model.[50] This is an important issue, because evidence about frequently touted measures such as creation of intentional friendship or ‘circles of support’ suggests that they cannot be created where they naturally do not already exist and that their contribution is modest even then,[51] raising real doubts about how to provide support to people who lack an existing family or support network. So perhaps lived experience offers some new insights?

D. Towards a grounded-theory reading of Article 12 as (emotional) labour?

Fieldwork data from the qualitative arm of our study of support for people with mild to moderate intellectual disability or acquired brain injury provides a practice perspective on these conceptual debates. Participants were adult members of dyads comprising a decision-maker with cognitive disability and their decision supporter, recruited in the Australian states of Victoria, NSW and Queensland. Qualitative data on practices of support for decision-making was collected before and after participation in a training workshop based on the La Trobe practice framework.[52] A quantitative arm, with a prospective random design, assesses the impact of this training. Decision-makers and supporters were interviewed about their relationship, about decisions that affected the person with cognitive disability and the process towards the final decision. Participants spoke about a wide range of decisions, from choosing what to wear to independent living arrangements. Regardless of the type of decision, the interview was designed to tap the nuance of supporters’ practices, and decision-makers’ experiences. In the following discussion we draw on data from six of 77 dyads interviewed prior to undertaking training (55 a person with intellectual disability; 22 a person with ABI). Our findings exemplify and expand on earlier research revealing how complex, nuanced and context-specific the process of support for decision-making is,[53] and thus how challenging it is to interpret will, preferences and rights in real life settings.[54]

One way of capturing some of this is through the metaphor of the labour market and the labour entailed for both the person being supported and the supporter in locating the will, preference and rights of the person they are supporting (the labour of caring). Just as

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[47] Quinn et al (2018), p 57; further Carney (2017a); Bartlett (2019).
[48] Kohn and Blumenthal (2014); Kohn et al (2013).
[49] Carney (2017b).
[50] Douglas and Bigby (2018).
[51] Bigby et al (2018); Douglas (2019 in press); Bigby and Araten-Bergman (2018).
[52] Further, Bigby et al, Australian Research Council Linkage Grant LP150100391 https://www.latrobe.edu.au/lids/research/effective-disability-services/decision-making.
[53] Jordan and Linden (2013), pp 1067, 1069; Knox et al (2016a); Knox et al (2015).
[54] Knox et al (2017).

in the labour market, provision of support calls for particular skill sets; the investment of time and energy; consideration of economic, emotional and any opportunity costs (alternative activities); and assessment of the nature of the work called for (its difficulty, risks, and sustainable benefits on completion). Likewise, there is equivalent labour for the person being supported – in the transaction burden of accepting/participating in the support; in assessing whether the support is 'needed' or will be worthwhile; and in opportunity costs of alternative investments of time and energy.

As we have seen, the task of reading and/or of interpreting a person's will, preferences and rights is challenging enough on both its linguistic and philosophical fronts. But those meanings we now show cannot be understood outside the lived relational life and features of the social settings in which recognition and respect for will and preferences is being understood. Crucially, this is mediated by the human qualities, skills and capacity of supporters for undertaking the work of support. Like life, our data suggest it is a mixed bag.

Some supporters are akin to highly specialised tradespeople, bringing high level skills and enjoying great job satisfaction. 'Karen' was a good example of an effective supporter. She supported her partner, 'Lee' a person with ABI who was able to clearly articulate his values and insight into his condition, but who lacked short term memory. Karen displayed sophisticated insight and deep intellectual engagement with understanding and resolving Lee's puzzling support needs:

> That's been a big lesson for me as well. We sort of have been learning from each other in letting him – not letting him, because he is his own person so I'm not in charge of him, but in having him sort of guide me and being his support person, he has to teach me how to support him I guess. So even though he comes to me with 'what should I do here', 'what should I do there' and blah, blah, blah, it seems to be more well, I need to ask more questions of him to figure out how best to help him get to a decision that he'll be happy with and that everyone in his support team will be sort of at least supportive of, even if they don't like it. It's at least not unhealthy or damaging to him and that sort of thing. So yeah, *it's a very, very kind of involved complex and super, super, super interesting kind of process I guess.*

Karen formed her relationship with Lee after his ABI injury and after residential living support had been organised, so her support for him took him as she found him, with the intriguing challenge of helping to find solutions for someone whose issues were largely a known quantity rather than someone who had changed over the course of their relationship. Despite being in an intimate relationship with Lee, at the time of the interview, Karen saw her role as a supporter as akin to a professional role whereby her own will and preferences were distanced to put Lee's at the centre – along with his rights. To do so she drew on her previous studies:

> I've done a lot of psychology kind of research and that sort of thing and the person centred approach of sort of deflecting back to him and making sure that even though I'm a guide that he can talk to and that sort of thing, ultimately he's leading me in the direction that he wants to go.

While Karen used her previous knowledge to help her to identify Lee's will, preferences and rights, other supporters performed emotional labour in order to manage their own emotions about decisions. Hochschild[55] developed the term 'emotional labour' in 1983

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[55] Hochschild (2012).

to explain the type of work that airhostesses and bill collectors performed on their emotions (or the outward display of emotions) to meet the professional emotional expectations – or 'feeling rules'. This included 'surface acting' whereby mannerisms, facial features and tone of voice would be manipulated. Alternatively, they would undertake 'deep acting' thereby changing their emotions to portray the 'appropriate' emotion.

'Nicole's' process of determining will, preference and rights involved both surface and deep acting. In contrast to Karen's post-ABI relationship, Nicole had been married to 'Frank' well before his ABI (from a motor cycle crash) which led to her now very strained marriage. His support needs called for rigid routines and (to her) excessive lead times in coming to decisions. As she related,

> So routines never worked for me, because I have to be flexible like that, constantly. Anyway that's just one of the issues that we have. So he's constantly asking questions, or just talking to me. I call it talking at me, for the sake of just verbalising out loud because it's easier than try and do it in his head, and maybe he gets some confidence from that, knowing that someone's listening in case that I can provide some input. But a lot of times he just repeats himself over and over and over, running around in circles. He kind of gets stuck in a loop a lot.
>
> So he finds it just useful to have it all there in front of him, and it's a process that he goes through. It will take over a week and if he doesn't start that a good week before, he's not comfortable.

In order to provide the support that she understands Frank needs to determine his will and preference, Nicole appears to manipulate her own feelings of annoyance at the time and energy that she's required to expend. Nicole found this emotional labour to be close to unsustainable:

> *I've got to try and think about whether or not I've got the time to help, or even if I've got the emotional strength or energy to deal with it myself at the time.* And I'm finding a lot these days that I don't, because I'm just getting so drained, physically and emotionally, that I just feel like I'm shutting down, and I'm struggling to make decisions now, because I have to switch off, emotionally, so that I don't just fall apart and I'm not going to have time to not be productive.

Nicole's way of coping with this excessively burdensome and draining labour was to reclassify much of it as no longer calling for support at all, but instead treat it as a decision that she herself would decide for Frank,

> *I'm a parent. I have to be. That's basically the way I see Frank as well.* I don't like to be an 'enabler' [sic], so I won't necessarily, except that's it and nothing can be done. … *At the end of the day they're not usually life or death decisions, so you can do your best and be happy and confident that you've done the right thing. And if not, it's not the end of the world.*

Nicole balances the value of a perfect realisation of Frank's will and preferences against the emotional cost of supporting such a process and its sustainability. From the perspective of understanding how will, preferences and rights plays out, the pressure of the social context has led Nicole into a routinised or 'default' stance of interpretive re-reading of Frank's will and preference in what she considers low-risk (not 'life or death') decisions.

The next set of examples raise another very important practical issue, of how to differentiate between 'apparent' paternalism which actually draws out new options and potentials for the person supported,[56] from actual imposition of the supporter's 'manufacturing' of a false will and preference. This is because facilitation or mere persuasion for one person can be outright imposition for another, depending on their disposition (eg stubborn or agreeable); a range of variance shared by people with and without cognitive disability. On the face of it, 'Samuel's' interpretation of support for 'Robert' who has an intellectual disability, appears to have risked the authenticity of the support, by reclassifying it from support for Robert's decision, to obtaining Robert's support for *Samuel's* preferred decision. Speaking about a decision to change Robert's personal trainer, Samuel said:

> I think it was going to be my decision – I wanted the decision a certain way but I want him to buy into the decision and make his own decision because I know that he'll have resistance if he doesn't make decisions. It's no different from him choosing a meal. If he doesn't want a meal he will get quite annoyed with it. *So yes you persuade him, you guide him, but at the end of the day he will say yes.* And we've had situations where he's chosen things we didn't want him to choose but we let him anyway. We think it's a bad decision but we let him anyway because he needs to do those things himself.

A little later in the discussion this was put more explicitly: 'So I'm trying to get himself to convince himself … I don't want to impose a decision on him because I know I will but I want him to think that it's his'.

Samuel seeks to preempt a critique of his 'persuasive' approach as coercive, by pointing out cases where Robert was not persuaded, and his preferences were respected. From this perspective, Robert's decision well and truly reflected his own will and preferences *after* he had changed his mind. However, such an interpretation overlooks the uneven power-relations at play in such a relationship, and the fine lines between best interpretation, persuasion and coercion in such a context. This case thus exemplifies how easily CRPD injunctions to respect will and preferences can be traduced by being transformed into a covert 'best interests' exercise whenever Skowron's 'interpretive process' is carried too far. Certainly, it is apparent from the data that *some* degree of interpretation is involved in most instances of support, but it is a fine line between realisation of will and preference and substitution for it.

On other occasions the 'guidance' is more subtle and the decision-space more nuanced than that discussed in the first three cases, however. This is illustrated in the way 'Justin' (a person with intellectual disability) was supported by his carer ('Marion') to spend his birthday money on a laptop, immediately useful for his computer course, rather than 'blow it' on more trivial purchases while waiting for his mother to buy him a computer as a Christmas present:

> Because he would've just blown the money, and he wanted a laptop, he was going to ask his mum for one for Christmas, but I thought, well, this way, you've already got the money, and it's something that you really want. And once you said that to him, yeah, and he had some money left over as well to buy some other stuff that he wanted, and he was very excited and he goes, 'yeah, I didn't think of that'. 'It's just a suggestion, do you want to do that?' *'Yeah', so sometimes you just have to steer them in another way, because sometimes if they get money, they just want to blow it on, well, I suppose we're all like that, aren't we, sometimes?*

The difference between Marion's 'suggestion' and Robert's 'persuasion' seems to be in the degree of pressure placed by the supporter on the decision-maker. While both involve

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[56] Crisp (2018).

a degree of interpretation, and in both cases the final outcome may be similar – the decision-maker feeling that they have made their own decision – the process is different. Hence, the argument against 'persuasion' concerns not the extent to which the final decision reflects the decision-maker's true (but changing) will and preference, but the amount of pressure imposed on the decision-maker in the process.

However, processes of support for, and the resultant outcome of, a decision made can prove difficult to assess. 'Rachel', a person with intellectual disability, demonstrated very constrained preferences for *specific* forms of travel and participation. The unreflective endorsement and support of Rachel's preferences by 'Leoni' (her supporter) arguably came at the expense of Rachel developing or at least experimenting with richer and more diverse life experiences. Only 'arguably so' though, since this involves projecting our presumptive reading of what the good life may be for Rachael; and her true vocation and personal satisfaction may in fact lie on the narrow path her supporter is so strongly backing. Likewise, discrepancies between the decision-maker and the person providing support (or external commentators on it) may arise in determining the scope or importance of the decision; Nicole's assessment of decisions as 'not a life and death' decision may not square with Frank's assessment of them for example.

Deferring to a persons' rights did not necessarily provide the answer for at least one of the supporters. 'Katrina' is the mother of 'Svetlana' who was in her early 20s at the time of the interview and had expressed a desire to attend her general practitioner without Katrina being present. Katrina explained,

> I'm aware that it is difficult to transition from being a parent of a child to being a parent of an adult, *because she is not capable of being fully adult-like, but legally, she is of age and people expect her to make her own decisions and be responsible for herself*. So funny things happen like when you go to the doctor, the doctor wants to speak to her alone but I feel concerned that the doctor might not understand that Svetlana answers questions in the way that she thinks you want to hear the answer. So I'm very protective, I guess.

Despite identifying Svetlana's will and preference, as well as locating it within her legal rights, Katrina's concerns led her to override these and make a substituted decision in this situation.

As our preliminary analysis of the fieldwork discloses, some supporters devote much energy to understanding the authentic will and preferences of the person across most circumstances (Karen), others due to pressure of their environment or ability at reading will and preferences are able to devote much less time, rationalising this as being about supposedly more trivial aspects of the life of the person (Nicole); while others frankly admit that they do 'manufacture' a concocted will and preference in the image of the supporter, subject to the qualification that it is done with the best of motives (as with all paternalism) rather than for exploitive purposes (Samuel). In short, the fieldwork data bears out the complexity and nuanced character of the task of and need for support. This social messiness and complexity is unsurprising. For as Jonathan Herring observed of relationships of care,

> Inevitably within a caring relationship there is give and take. Some decisions will benefit one party more than the other, but other decisions will make up for that. This is how it is in real life in a *well-working caring relationship* and this is how it should be.[57]

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[57] Herring (2008), p 1647 (emphasis added).

The wickedly difficult question left hanging here of course is how to identify relationships that are *not* Herring's 'well-working caring' ones, and what to do about them. As explained later (Part IIIC) the straightforward part of the answer is to agree with the call in Article 12 (4) for regulatory or other safeguards against the kinds of power imbalance or practices that *unduly* constrain capacity.[58] But the highly complicated part is deciding in a case like Robert's whether Samuel has or has not exercised undue power and influence, and – if so – whether there are as yet any sufficiently effective measures to protect against it.

III. Towards a grounded understanding of will, preferences and rights

Three issues, in particular, stand out from the literature and the fieldwork. How to conceptualise the way will and preferences are expressed and how to understand any process of interpretation involved in that; where 'rights' fit in; and how to safeguard against risks of suppressing will and preferences given that support involves both facilitation and capacity building.

A. An epistemic or a process reading for will and preference?

The outcome of the contest between a more straightforward epistemic approach, which simply accepts or seeks out an authentic expression of (reasonably congruent) will and preferences, and Skowron's processes of deliberation and assessment entailed in locating substantive 'best interpretation' of will and preferences, is not clear-cut.

Like many contests, context matters. Someone experiencing onset of a mental health condition or cognitive impairment usually has a rich legacy of past realisation of preferences and values, and perhaps prior expressions of will. This legacy forms a basis on which conclusions can be drawn about their current expression of will and preferences. Someone with intellectual disability on the other hand is more likely to have entrenched routines, patterns of behaviour and narrow life preferences.[59] These are potentially at odds with alternative life possibilities, thus warranting the more careful presentation of and focused conversations about other options, as envisioned in the substantive 'best interpretation of will and preferences' model. Someone with a dementia may present either as a candidate for the simpler epistemic approach of acting on their current wishes, or for abbreviated acceptance of changed values (as in Szmukler's example of the long-term vegetarian now agitated in their 'new self' when denied meat). Someone with ABI, and changed emotional and behavioural patterns, may be a candidate for the more reflective substantive 'best interpretation' process, just as is the case when dealing with 'hard case' situations like coercion of someone with anorexia nervosa on the verge of death,[60] or other clashes between fundamental rights enshrined in the CRPD.

The latter approach also has greater 'real world' conformity to the way support for decision-making plays out in practice, where commonly both agency-denying and agency-enhancing options are foregone or provided in fair measure for both, depending in part on the nature and perceived 'risk' of the decision, its emotional labour burden

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[58] This is elaborated in GC1, but without much concrete guidance beyond emphasising that protections should be designed to reflect the person's will preferences and rights, and not preclude taking of risks: UN Committee on the Rights of Persons with Disabilities (2014), paras [22], [29(d), (h)].

[59] Ashley et al (2019 in press).

[60] Carney et al (2019).

on the supporter and decision-maker, and their own grasp of and commitment to agency as against paternalism. In these terms, the quality of support for decision-making is assessed not only on the extent to which the final decision reflects the decision-maker's will and preferences, but also the emotional labour and other costs that such a process involves, for both supporters and decision-makers. While a specific preference might be realised through an emotionally draining supported decision-making process, in the long run such efforts might involve a cumulative effect of eroding a decision-maker's social capital as a resource of support, and potentially also inflict damage on the decision-maker's confidence. However equally it cannot be overlooked that without effective training of supporters and meaningful monitoring and safeguards, this approach ultimately permits greater weight to be accorded to the views of people other than the person affected, whose current will and agency is then compromised on the basis of a supposed lack of compatibility with their 'real' preferences and/or with their 'rights'. It thus leans further towards the social engineering and paternalism associated with the best interests and substitute decision-making regimes which have so fallen from favour under the CRPD.

That said, such deeper inquiries into or reshaping of the will and preferences of the person, can of course be defended on a philosophical basis under the so-called 'thank you' theory of soft paternalism (that the person subsequently gives retrospective 'endorsement' to the overriding or modification of their then stated will or preference).[61] But soft paternalism justifications are contested,[62] are beyond the scope of this article,[63] and for our purposes ultimately stand or fall in the evidence of impacts, good bad or indifferent, as revealed in the lived lives of those supported.

B. Where do 'rights' fit in?

The place of 'rights' *within* the constellation of will, preferences and rights is not straightforward. Again, there is some common ground, in regarding it as a backstop resorted to when will and preferences cannot be ascertained or do not provide a sufficiently complete picture to guide making or respecting decisions. And of course it is infused by the overarching object of Article 12(3) in supporting the realisation of the person's legal capacity. But there is less consensus on how rarely or otherwise considerations of rights should be in play, whether those rights ever 'trump' discerned will and preference (serving as an override rather than filling a gap), and about what the 'content' of those rights might be. Nor is there any ready consensus about whether scrutiny of will and preferences should extend to non-disabled members of the community who are brow-beaten or morally blackmailed into expressing their view, and if not, how this can be consistent with the 'equality' principle of Articles 5 and 12 of the CRPD. For its part, the ALRC's decision-making principles strictly confine a rights override to situations 'where [it is] necessary to prevent harm'[64] and for it to be informed by respect for a long list of CRPD rights, including those of

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[61] For an overview: Dworkin (2017). The 'thank you' theory initially applied to mental health civil commitment combined diagnostic accuracy, level of suffering, treatment availability and the irrationality level of the objection: Stone (1975), pp 69–70.

[62] For a review of the validity of the distinction between 'soft' and 'hard' paternalism first advanced by Joel Feinberg in 1986: Hanna (2018).

[63] Deeper philosophical consideration would need to consider the 'relational' turn embodied in 'maternalism' formulations: Sullivan and Niker (2018).

[64] ALRC (2014), p 77.

inherent dignity, non-discrimination, liberty and security, freedom from torture or cruel, inhuman or degrading treatment, physical and mental integrity, liberty of movement, independent living, privacy, home and family, and participation in political and public life.[65]

Returning to the perspectives on will and preferences, Skowron's expansive role for 'best process' *interpretation* of will and preferences could be portrayed as simply an *extension or by-product* of CRPD rights, given his focus on the CRPD Committee's GC1. While the approach of treating substantive interpretation as part and parcel of all conversations in theory better meets the equality principle, in practice it elevates the power of the listener/supporter to impose their own value interpretations on the person being supported. Rather than rare, such 'trumping' of authentic will and preference may become commonplace; and rather than being explicitly (if vacuously) explained as a 'best interest' override, it is further hidden away as merely being part of necessary interpretation.

Of course, it can properly be countered that no-one with a deep understanding of the values and principles of the CRPD would countenance such a return to the very paternalistic and discriminatory practices the Convention is designed to redress. But as our fieldwork data revealed, dilemmas abound in the daily experience of provision of support for people with a cognitive impairment. Because this is an informal civil society space or at the front-line of service provision, where the emotional labour of support is borne by ordinary citizens or low paid support workers with various life pressures, it is not realistic to expect ordinary citizens to acquire finely attuned understandings of CRPD principles.[66] Rather it is to be expected that their understandings will be superficial at best, with a wide range of opinions about when a supporter's views on what is 'right' (ie a moral not a CRPD reading) should be applied and to what degree it should displace the views of the person being supported. Some will hold or will be receptive to learning about 'equality' and other principles of the CRPD, but for most supporters, any rights perspective relies for its expression on the content and effectiveness of safeguards and capacity-building, as now discussed.

C. Safeguards, facilitation or capacity-building?

As Szmukler observes, 'interpretation' of will and preferences cannot be left entirely unchecked:

> 'Interpretation', especially in difficult cases, may require support for the person – sometimes very substantial – as well as a number of safeguards. For example, the decision must involve people who know the subject well; an independent advocate should be available; where there is a dispute, referral to a court or tribunal must be available.[67]

Skowron too appreciates that 'interpretation' of will and preferences is potentially very fraught in practice, because the superficially 'better' process paradoxically may be more controlling. An example is a person with intellectual disability who has always been very dependent on family[68] and either is unconfident about asserting an independent

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[65] ALRC (2014), p 79 para [3.67].

[66] Thus U.K. support workers drew on their own understandings in taking a broad moral view of support rather than the narrow legal view of substitute decision-making responsibilities: Dunn et al (2010).

[67] Szmukler (2017), p 94.

[68] Generally, Van Asselt et al (2015), pp 45–46.

view (perhaps because family undermined confidence in the past) or indeed is just very comfortable in continuing to live their life as it has always been experienced:

> When someone shows a certain amount of independence, then a controlling or abusive carer might always ask 'are you really sure that you want to do that?' They will not ask this question when the person acts in ways that heighten their dependence on the carer. In the right conditions, especially if the person is heavily dependent for a long period of time, this pattern of questioning may be enough for self-doubt to undermine someone's will to be independent. Indeed, if they are dependent on the supporter from a young age, they may never develop a will for independence in the first place.[69]

So asking the interpretative question about whether that is what the person wants can be either boon or bane. Consequently, scrutiny of the quality or authenticity of the support cannot halt at the end of the epistemic driveway (which treats asking the question as a marker of 'best interpretation'), for to do so is to remain 'blind to whether or not the person was presented with options that hold open the opportunity for the person to *change* their mind about their will and preferences'.[70]

So a more *substantive* process of interpretation is called for. This is because safeguards need to recognise and reduce the risk of 'manufacturing' false readings of will and preferences.[71] However, integrity of process is no fixed commodity, the presence or absence of which establishes a bright line between outcomes of will and preferences that should be honoured and those that miscarry. Returning to one of the questions earlier in the article about whether the same scrutiny is applied to processes as between a person with a disability and the equality baseline applied in the case of a non-disabled person, we find that the answer is that 'it all depends'. It all depends on the context or nature of the decision.

A non-disabled person who nevertheless is 'a bit of a pushover' who is easily manipulated or prevailed on by another person to accompany them to a weekend football match against their real wishes, will immediately have that decision respected as authentic (when it is not). But that same person, under an identical process, who is prevailed on to wager their life savings on their first ever bet on an unknown horse at that weekend's races, will come under close social scrutiny and pressure to rethink both the outcome and the process adopted. This we suggest is no different to the way supporters go about helping people with cognitive disabilities to make decisions. Some are able to invest heavily in understanding and advancing will and preferences (Karen in our fieldwork), some are obliged by circumstances to decide the smaller aspects of life akin to attending the football match above (Nicole), and others from the best of motives in reality resolve the dilemmas by projecting their own values onto the person being supported and create an inauthentic will and preference (Samuel).

Yet of course ultimately motive is irrelevant, since the test always is the impact on the person being supported to make their decision. Failure to ascertain and advance a person's will and preference is as harmful to *that person* if done for a good motive as for bad. But in practice there are finite limits to how much time or energy ordinary citizens can expend on presenting alternatives in ways that will be understood, and reasonable minds will differ on

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[69] Skowron (2019), p 130.
[70] Skowron (2019), p 130.
[71] Quinn et al (2018), p 55.

the subjective judgment about what is ‘too much’ or ‘too little’ by way of developmental experiments pushing boundaries of what may prove to be acceptable new alternatives. So once again it seems that what may be termed the ‘messiness of lived life’ is the core of the difficulties about realisation of Article 12 at the civil society level. This does not diminish the force of the critique that government and society at large are doing too little to realise the Article 12 obligations which crystalised on ratification of the CRPD; rather it reinforces how challenging is the task of devising practical and effective ways of doing so – a principal aim of the quantitative arm of our current study.

IV. Conclusion

Understandably many commentators accept that the best that can be achieved is to require (and trust delivery of) a process of assistance in decision-making that operates on what ‘in good faith’ the supporter(s) believed to be the expression of the person’s will and preferences.[72]

As Szmukler observed in discussing the ‘folk psychology’ or common-sense way people receive and interpret expressions of will and preferences, and their congruence and harmony (or otherwise), this is an acutely tuned human capacity, in that:

> We cannot help but see intention and hear meaning when observing the behaviour of, or listening to, another person. However, … this practice is not amenable to a set of objective, codified principles or standards of rationality. Nevertheless, we know whether a word, for example, is being used in the ‘right’ way.[73]

Yet however refined the folk ability, and however well it serves us in everyday life, this same instrument is the source of the very abuse to be protected against by ‘safeguarding’ under Article 12(4). Or as Quinn et al write:

> If the process requires more than just interpretation but actually help to reconstruct the self, then how do we guard against the ‘manufacturing’ of the self by third parties (even unintentionally)?[74]

As Scholten and Gather argue,[75] this risk is heightened in the exclusively civil society sphere in which support for decision-making operates, by comparison with the juridical setting of substitute decision-making (however unsatisfactory that may be). We therefore do not agree with commentators who contend that safeguards are not needed because they are too subjective and insufficiently deferential to the readings of will and preferences able to be made by members of the social circle of the person.[76] In our view, it downplays difference as between abled and disabled to leave safeguarding entirely to natural social processes.

As this article reveals, understanding and applying the CRPD’s new gold standard principle of honouring ‘will, preferences and rights’ involves resolving numbers of theoretical debates and practice dilemmas. The first is the tension between will and preferences, a tension complicated by the inclination for particular ways of thinking about these concepts to appeal to a greater extent to particular disciplines or professions, with health science

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[72] Series et al (2017), p 139.
[73] Szmukler (2017), p 94.
[74] Quinn et al (2018), p 55.
[75] Scholten and Gather (2018), p 229.
[76] Compare Flynn (2019).

professionals, law and human rights, and philosophical inquiry just three of the conceptual approaches contending for attention. Three differing perspectives also became evident in thinking about support for decision-making: a ‘safeguards’ perspective concerned with preventing outright violation of rights and departures from Article 12 of the CRPD; ‘best practice’ frameworks that are concerned with understanding what support for decision-making would look like in an ideal world; and the ‘actual’ experience, which is full of compromises as with any kind of labour, and is neither fully a violation of Article 12, nor its ideal implementation. While each of these perspectives might call for different legal and policy mechanisms – and perhaps also different scholarly disciplinary treatment – they are all informed by similar tensions surrounding the dynamic nature of ‘will’ and its complex relationship with ‘preferences’ and production of decisions; by the ambiguities and fine lines separating what constitutes reading, interpretation, persuasion and coercion of will and preferences; as well as by the impact of contextual factors such as the nature of disability, social settings and the nature of the decision itself. One common illustration of this difficulty from the fieldwork was working out whether a supporter was ‘expanding horizons’ of choice or acting paternalistically. Where to place support on a continuum from authentic realisation of will and preference through to its ‘paternalist manufacture by the supporter’, also proved to implicate many subtle issues, including contextual features of the decision and social environment, motivation and human capital of the supporter, outcomes for the person supported, and the nature of emotional labour entailed.

The preliminary engagement with these issues in this article has tested to the limits our ability to reconcile the many different complexities of the individual circumstances of those people owed the duty of support. Just as it is naïve for the public to assume that ‘passing a new law’ will easily resolve complex issues, so too is it naïve to gloss over the difficulties by pretending that will, preferences and rights is an easily understood or self-executing principle, the mere recitation of or lip service to which principle will prove to be a simple panacea.

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