

Article

Prioritising Supported Decision-Making: Running on Empty or a Basis for Glacial-To-Steady Progress?

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Abstract: Honouring the requirement of the Convention on the Rights of Persons with Disabilities to introduce supported decision-making (SD) has largely been a case of much talk and little real action. As a socio-economic right, actualising support is resource-intensive as well as being fairly uncharted territory in terms of what works, to what degree and for how long benefits last. This paper, drawing lightly on mainly Australian examples, considers unexplored (and sometimes unorthodox) approaches such as the ‘needs-based’ principle for setting social welfare priorities as possible ways of revitalising SD through progressive realisation, whether through civil society programs or under the law. It argues that pure repeal of proxy decision-making *on its own* is not viable in realpolitik terms so progressive realisation of ‘repeal with adequate support’ must instead be devised for SD implementation to progress.

Keywords: supported decision-making; socio-economic rights; progressive realisation; program priorities

1. Introduction

Article 12 of the *Convention on the Rights of Persons with Disabilities* (2006)¹ (‘CRPD’) is widely, but certainly not universally, understood in line with the views of the monitoring Committee as calling for the repeal of substitute decision-making regimes—such as adult guardianship or proxy decision-making for involuntary mental health patients—and for their replacement with supported-decision-making (‘SD’) which does not transfer *any* decision making away from the person. The repeal arm located in Article 12(1), (2) advances a civil right (elimination of capacity-based denials of legal capacity and autonomy), while the provision of support subject to ‘safeguards’ arm found in Articles 12(3), (4), arguably is a socio-economic right (and certainly is treated as such in the realpolitik of government). Like the socio-economic right to health (generally Tobin 2012; Magnusson 2017), SD however presently remains a fairly ‘empty’ right, even in first world economies. While there are many law reform blueprints (e.g., VLRC 2012; ALRC 2014; Law Commission of Ontario 2017), concepts and principles remain in flux (Carney 2014), legislation is scant,² and—despite a proliferation of legislative and non-legislative programs and schemes (Then 2013; Boundy and Fleischner 2013; Browning 2010; Power et al. 2013; Van Puymbrouck 2017)—there is no rigorous evidence of

¹ *Convention on the Rights of Persons with Disabilities* 999 UNTS 3. Australia was an original signatory when the CRPD and its Optional Protocol opened for signature on 30 March 2007, and ratified the CRPD in July 2008 (entering into force on 16 August 2008) followed by the Optional Protocol in 2009.

² Australia has been slower to legislate supported decision-making than Canada or Sweden (Gooding 2014; Gordon 2000; Law Commission of Ontario 2014). So far, other than a bit of dabbling in South Australia, Victoria is the only Australian state to legislate new ‘support’ measures which avoid conferring proxy decision-making power, limited so far to appointments which the person makes for themselves or in health and mental health: *Powers of Attorney Act 2014* (Vic) ss 87–89; *Mental Health Act 2014* (Vic) Part 3, ss 12–27; *Medical Treatment and Planning Act 2016* (Vic) ss 31, 32 [from March 2018]; also see *Advance Care Directives Act 2013* (SA), s 10(d); *Disability Services Act 1993* (SA) as amended, s 3A (Carney 2015a).

effectiveness (Kohn and Blumenthal 2014; Kohn et al. 2013; Carney 2015b; Davidson et al. 2015). Why is this so?

Have we lost sight of the bigger picture (or given it too little attention)? Such as that law has a patchy record at best in securing rights in general and socio-economic rights such as SD in particular; that neoliberal governance reforms and fiscal austerity have increased pressures on accessing scarce public resources (e.g., for the UK: [UN Committee on the Rights of Persons with Disabilities 2017](#); [UK Independent Mechanism 2017](#), pp. 22–27); that we have bold ‘capacity-building’ visions of how to harness the potential of informal civil society supports, but little understanding of how to operationalise the marshalling of that non-state ‘support’ (family or otherwise), and even less appreciation of associated ‘risks’ of hidden paternalism in the absence of appropriate safeguards? Or that there can be unintended consequences³ and that competition for access to finite resources carries risks of unfair and unequal outcomes, such as favouring the more powerful or more articulate in the absence of a needs principle or other means of ensuring proportional allocation? Alternatively, have we perhaps simply misread what SD realisation entails?

This paper suggests that the answer to such questions is more ‘yes’ than ‘no’, and in addressing some of these themes, it sketches some ideas on how SD implementation may begin to be reimagined and the stalled progress rectified. In doing so it characterises the SD arm of Article 12 as a socio-economic right due to its capacity-building personal development and associated significant resourcing implications for supporters, meaning both that progressive realisation (and non-retrogression) tests must be met, and that there is salience to conversations closer to traditional welfare allocation (and priority setting) debates. Due to the tension in the link between the civil rights and socio-economic arms of Article 12 (and a realpolitik unwillingness of government to move on the civil rights front in isolation) it is also argued that the withdrawal or winding back of most proxies is contingent on delivery of *adequate* Article 12(3) support in those settings. In short it is contended that there is a neglected theoretical and operational indivisibility of the two types of rights in Article 12. Channelling Jenny Goldschmidt’s CRPD focus on pursuit of transformative equality and justice—engaging principles of equality, accessibility, autonomy, participation and inclusion ([Goldschmidt 2017](#))—this paper takes a broad brush look at new ways of realising CRPD substantive equality rights in the world of realpolitik, lightly engaging some concrete examples from Australia regarding possible priorities to be favoured.

2. Some (Re-)Conceptualisations?

When confronted with challenging issues it is sometimes helpful to strip out the technical detail to isolate the real shape of the underlying concepts. But first, some clarification of what SD involves.

2.1. SD as a ‘Relational’ Socio-Economic Right to Scarce Resources?

A short but simplistic answer to the question of the meaning of SD as expressed in Article 12(3) of the CRPD that ‘States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’, when read with the rest of Article 12, is that it is provision of any needed ‘support’ to enable people to exercise legal capacity to make their own authentic decisions. Article 12(3) follows articulation of the rights to ‘recognition everywhere as persons before the law’ (Art 12(1)) and to ‘enjoy legal capacity on an equal basis with others in all aspects of life’ (Art 12(2)). As is well known, the General Comment issued by the monitoring Committee for the CRPD reads Article 12 as requiring immediate withdrawal of any ‘substitute’ decision-making such as adult guardianship, or proxy-decisions such as under involuntary mental health powers ([UN Committee on the Rights of Persons with Disabilities 2014](#);

³ Disability history reminds us of egregious unintended consequences of lofty principles such as deinstitutionalisation ([Gooding 2016](#); [Wiesel and Bigby 2015](#)).

Arstein-Kerslake and Flynn 2015, pp. 5–6). This is mainly because of the egregious abuses associated with exercise of those powers, but also by implication in reading Article 12 as entirely concerned with civil rights which therefore do not permit progressive realisation.

As now explained, I read SD implementation within Article 12 as a ‘package’, and a package where civil and socio-economic rights are in some tension. On this reading, any imperative to withdraw substitute decision-making extends beyond proxy decisions made under the law (e.g., adult guardianship and mental health involuntary treatment) to also include any unconsented and ‘significant’⁴ proxy decision-making occurring in natural relationships in civil society (as with the paternalism associated with say a worryingly subordinated dependent or abusive relationship). And that the withdrawal or winding back of most proxies, especially outside mental health treatment, is contingent on delivery of *adequate* Article 12(3) support in those settings.⁵ This is because the right to SD is properly characterised as a socio-economic right (Carney 2015a). Fundamentally, then, SD as conceived in Article 12(3) is about ensuring that everyone has *access to* the necessary resources and assistive relationship(s) to enable full expression of their human agency as a *relational* being (see for example Herring 2016, p. 18; Gooding 2012, p. 435).

Despite the artificiality and deficiencies of taxonomies distinguishing say civil from socio-economic rights (see generally, Marks 2009) or first from so-called second or third generation rights (Tushnet 2016) and conceding the seamless relationships of such rights with each other, there *are* some useful markers. Socio-economic rights, such as to health or education, are often distinguished as imposing ‘positive’ liberties (claims on the state for expenditure or access to resources) while civil rights can be realised in a ‘negative’ or protective way, such as in describing civil rights to privacy or autonomy as the ‘right to be left alone’ (simply guaranteed by the state against interference with enjoyment). Although SD in the CRPD is only about ensuring equal access to agency as legal capacity, most SD programs to date offer a much wider spectrum of supports for greater agency in decision-making, so viewing SD *purely* as a ‘civil and political right’ (De Bhailís and Flynn 2017, pp. 17–18) is not persuasive. It is not persuasive because even though civil and political rights are not cost-free (protection of say the right to liberty, or freedom from torture all have machinery-of-enforcement costs), the resources to be marshalled to realise SD in *any* form are I contend both central to the right in question and are *very* much more substantial than those associated with civil and political rights. Like the rights to health or to social security, this *quantitative* difference in required resourcing is one of the characteristics that marks them out as socio-economic rights (attracting the correlative principle of progressive realisation). It is also that heavy resourcing implication that engages principles of *realpolitik*, which likewise presses for progressive realisation. I therefore find it no answer to deflect from engaging with this socio-economic character of SD, or its resource burden, by instead pointing to say the ‘myriad ways’ in which support can be delivered, or to requirements of personal tailoring of support to individual circumstances; for socio-economic rights share both of those attributes. It is the resourcing attributes, not these latter ones, which are critical in my analysis.

The socio-economic right to support includes among other things any necessary resources associated with reading a person’s will and preferences when unable to verbalise choices, and facilitation of choice through provision of information or other assistance required in order to understand and select between options. This in itself can be costly and time-consuming to deliver. But as Jonathan Herring observes, its realisation also entails a radical paradigm shift. Writing about the role of law (but by extension also encompassing any SD program) under this re-conception, the object is explained as not so much to ‘emphasize independence, liberty, and autonomy; but

⁴ The qualifying caveats are necessary because everyone tacitly or expressly accepts a degree of paternalist influence by others over what might be termed the minutiae of everyday life and social interaction.

⁵ The adequacy of SD too is a subjective question, where reasonable minds will differ. My point is simply that not having any SD, or only having an empty ‘opportunity’ for SD to emerge within civil society settings such as family and other networks, without asking about the substance of that support, *fails* the test.

rather . . . to *uphold relationships and care*' (Herring 2016, p. 18). For the friendless this necessarily entails establishing or finding equivalents for missing relationships (e.g., recruiting supporters or finding other sources of advice and support), while the correlative 'safeguards' obligation of Article 12(4) calls attention to ensuring an acceptable 'quality' of those relationships, including avoiding the risk of a relationship of dependence or domination (Arstein-Kerslake and Flynn 2017). All of this explains why SD trials have proved to be so resource intensive (Bigby et al. 2017; Purcal et al. 2017), even though their goals and achievements were often quite modest.⁶ But of course it also highlights the matrix of socio-economic contributors to overlapping and cumulative barriers and disadvantages encountered by those to be assisted by SD, such as poverty or problematic behaviours compounding reliance on care, and heightening levels of 'control' or surveillance of their lives (for an introduction, (Goggin et al. 2017)). Despite what some may wish, the evidence so far is that SD simply cannot be delivered 'on the cheap', at low cost.

2.2. Conceptual Language for SD Realisation and the Role of Law

Metaphorical mapping of conceptual debates and choices arguably highlights some important distinctions between the legal or program outcomes sought or able to be realised for the lived lives of people. These distinctions I suggest are the difference between actual and token or symbolic realisation of SD as a socio-economic right.

Many laws and many debates focus on the *making* of orders or accessing services. These may be thought of as 'gateway' issues, since they are about how easy or difficult it is to pass through the gate, and because little if any attention is paid to what occurs once a person has gained access (e.g., there is little monitoring and few if any safeguards beyond the access point or 'time'). Involuntary civil commitment and adult guardianship laws for instance tend to be weighted towards the gateway issues of the *making* of a sound and procedurally fair order rather than what happens afterwards. Other laws and debates are about finding an access route to a desired legal benefit, service or resource. These may be thought of as 'pathway' issues, because the focus is on the ability (or not) of a person to become *connected* to the social good in question, with little if any attention on whether the good in question is beneficial or not, or for how long any benefit subsists (Community Treatment Orders in mental health exemplify provision of such a pathway—an opportunity to have priority access to community mental health resources, but leaving debatable what is actually provided, or its benefits, if any: (Segal et al. 2017)). Other laws and debates by contrast are about seeking to achieve or guarantee access to a resource for a person. These may be thought of as akin to 'ticket to service' issues, because the focus here is on *requiring* the state or other providers to actually *deliver* the service or resource in question (as exemplified in say a legally enforceable *right* to social security), or at least in showing the service arrived (see Tait et al. 1995).

Of these labels, I suggest that SD as conceived in Article 12(3) is a 'ticket to services' product. But is this ticket to service mainly realised by adopting a treaty or passing a domestic law? What is the power of such laws in delivering on this? The answer I suggest is rather deflating. Making a normative 'ought' statement is one thing; but *operationalising* it so it translates into changes to the lived lives of people is quite another. International treaties like the CPRD certainly are among the most powerful of normative statements. But treaties do not automatically become part of the domestic law of a country, and their normative position may have little traction with the public at large (or what is often termed the 'beltway' of everyday politics). They are not self-actualising and may not even change culture and values, for as Jenny Goldschmidt (2017, pp. 12–13) notes, rights have lost purchase recently; and if actively opposed by ordinary folk they may even result in a backwards step (constituting what would

⁶ Those modest aims—such as increasing understanding of the difference between substitute and supported decision-making or providing 'assistance with decision-making' rather than some theoretical purity of human agency which is beyond us all—are not necessarily objectionable. However, it highlights how difficult it is to define 'success' in realising the aims of SD, and draws attention to another 'cost-benefit' calculus when prioritising allocation of scarce community resources.

be a breach of the ‘non-retrogression’ test for implementation of socio-economic rights if the product of government action).

Even when normative statements of international law command widespread popular acceptance, as say with the ‘right to health’, and even when such propositions are incorporated in the ‘peak’ constitutional documents of nations (as is often the case with the right to health), the operational impact may be negligible or slight. Thus at best it can be argued that a constitutional right to health ‘changes the conversation’ of the body politic (DeLaet 2015), even though there is, as yet, no empirical evidence of its ability to generate *any* additional resourcing at all (Chilton and Versteeg 2016). This is true also of US jurisprudence, as hopes of substantive change following adoption of a ‘right to treatment’ in mental health were dashed by experience (Carney et al. 2008). Nothing lasting really came of US and Canadian court jurisprudence laying down minimum criteria for civil commitment (Fischer 2006, p. 158; Appelbaum 1994), the qualified rights of competent patients to refuse treatment, or the limited ‘right to treatment’ for those detained (see Case Comment 1973; Eisenberg and Yeazell 1980, pp. 468–69; Perlin 2011).

So how does all this conceptual mapping help to understand the policy challenges associated with the limited implementation of SD to date?

3. Some Policy Challenges

One thing that is crystal clear from the Australian pilot programs for SD is that, irrespective of whether they achieve the desired outcomes or not, programs of support piloted so far in Australia are very costly (Bigby et al. 2017; Purcal et al. 2017, pp 32–33, 49). So, in a real-world context, even though not everyone needs support (e.g., some in mental health) and costs will vary with the individual, some priority setting is inevitable: for no government has unlimited resources.

Now these priorities can either be set by default (through inaction or by responding to the most vocal pressure groups) or result from explicit policy choices. Australia’s introduction of provision for ‘plan nominees’ and support in its National Disability Insurance Scheme (‘NDIS’) is a (crude) legislative and program example of the latter. Appointment of a nominee and/or funding for support are both now seen as potential inclusions in personal plan packages, though the costs of any SD support mean its inclusion is rare and rarely is it fully funded. Further, the NDIS covers only small numbers of people (just 475,000 of the 4.3 million Australians with some form of disability: (Productivity Commission 2017, pp. 5, 16, 70)), and predominantly those with an intellectual disability and autism. This highlights some of the equity and distributional issues entailed when priorities are set in this ad hoc way. People with only marginally lesser needs than NDIS participants (or greater ‘complex’ needs such as associated criminal justice or poverty issues: (Steele et al. 2016)), simply miss out on either form of support. Skewing of access towards intellectual disability and autism results in inequality of access for otherwise apparently similar support needs of people with acquired brain injuries or mental illness/ psychosocial disabilities,⁷ while NDIS design features mean that older citizens with mild dementias miss out entirely due to its age ceiling (other than for people already in the scheme prior to reaching retirement age).

So firstly, what ‘does’ Article 12 require of governments? Is repeal of proxy powers alone ever acceptable in the absence of support, and would this ever be ethically acceptable to any government? And, secondly, if progressive realisation is either the proper reading of Article 12(3) or is the only realistic pathway ever perceived to be available by governments, are there any insights to be drawn from debates about the merits or otherwise of needs-based allocation of welfare resources? These two questions are dealt with below.

⁷ Mental illness or psychosocial disability is the third most common disability after intellectual disability and autism, but accounts for only 6% of NDIS scheme participants: (Productivity Commission 2017, p. 16).

3.1. Repealing Substitute Decision-Making First/in Isolation?

Whether expressly or by implication, many commentators have accepted that the most immediate priority is giving effect to the CRPD Committee's insistence on eliminating all coercive powers (repealing all involuntary mental health and guardianship laws). This also is not happening, so is it time to 'tell 'em they're dreamin' in the memorable line from the Australian film *The Castle* (Wikipedia 1997), or is the reason for lack of legislative action due to a misreading? I suggest it is a misreading of how Article 12 in general is to be operationalised,⁸ or at least that this is so in the world of realpolitik.

I argue that the first reason for such sluggish progress in either repealing laws like adult guardianship, or even adding some SD options to the statute book, lies in the neglected *indivisibility* of the civil and the socio-economic rights contained in Article 12. For legislatures (or indeed for social policy programs in general), winding back or eliminating most instances of substitute decision-making *needs to go hand in glove* with establishment of meaningful SD programs or arrangements. One way of demonstrating this for Australia is to pose the thought experiment of asking how life was for most such people (not involuntary mental health patients who were already under proxy treatment regimes) around half a century ago—*before* substitute decision-making laws were fashioned into something close to current guardianship legislation. This is interesting because in practice for many (or most) people, essentially there were *no laws at all*: the only options were the rarely used costly and cumbersome avenue of the inherent superior court protective jurisdiction; *automatic* property guardianship on becoming an involuntary patient; and—in some states such as Victoria—*administrative* procedures of medical certification of need for management (Carney 1982). This was the situation rectified by reforms introducing accessible least restrictive but substitute decision-making guardianship reforms, as recommended by an enquiry which sat between 1982 and 1984 (an Orwellian date, though not actually enacted until 1986: (Carney 1989)).

Of course, it is always problematic to ignore the cultural, organisational and other differences between historical eras, but since no-one found the then prevailing situation acceptable in the 1980s, it is surely difficult to argue that abolition of say guardianship laws *alone* would now be acceptable (the case for repeal alone is much easier to make in mental health where support may not be required). To the contrary, I contend that this is the whole purpose of the CRPD's inclusion in Article 12 of the *correlative* socio-economic right to support. Absent such support all that results from repeal is that state paternalism for all (under guardianship) is replaced, in the case of too many people for comfort, by civil society paternalism (by family or citizens who are generally well-meaning but unschooled in how properly to realise assistance and avoid paternalism). A paternalism that is less visible and less open to scrutiny, even if delivered by people theoretically likely to hold values closer to those of the person being assisted/subtly coerced, and even if unprotested by (i.e., notionally 'chosen by') the person. That is ethically unacceptable for most (some of course would judge it the lesser of evils). No government is likely to readily go down that path when that risk is judged excessive.

It is of course possible to argue that the remit of Article 12 as a whole is confined to realising rights of legal agency, meaning that the only way situations of domination trigger Article 12 scrutiny at all is where the person subject to paternalism turns to (or 'potentially' turns to) law to escape paternalism's clutches (as nicely argued by (Arstein-Kerslake and Flynn 2017, p. 27)).⁹ Only rights such as to independent living under Article 19 would then be accepted as genuine socio-economic rights in the CRPD on this basis. Even if this were to be accepted (contrary to my reading), the language of Art 12(3)

⁸ For analysis questioning the conceptual weaknesses of a strong reading of the CRPD on the basis of 'meshing' of articulated will/preferences and presumed autonomy goals, such as read from prior life history or 'diachronic identity' (Burch 2017, pp. 394–97).

⁹ The problem sought to be addressed is that '[i]n the informal sphere of familial relationships and services for daily decision-making ... many of the decisions made ... do not appear to have legal consequences or rise to the level of an exertion of legal agency. However, for many people with cognitive disabilities, some of the most damaging decision-making denials occur within these informal spheres' (Arstein-Kerslake and Flynn 2017, p. 24).

at the very least surely still sets provision of SD as a hard, *practical precondition* to any step to realise legal capacity, such as through repeal of guardianship (much perhaps as a right to a fair trial often requires funding for advocacy). Legislators and policy-makers certainly will not take unilateral repeal or other action in the face of the possibility of things being *worse* for affected citizens; so, repeal is not unconditional however we read Article 12.

While repeal of guardianship is easy, realising the correlative socio-economic right to support without incurring an all too common resultant paternalism and undue influence within the civil society settings which remain is not at all easy to address. Since it is rare indeed for people to *actually* ever make an entirely independent autonomous decision without taking into account external views of others (or community 'expectations'), merely removing barriers to autonomous decision-making as an end in itself cannot take us far at all; we need to know to what extent autonomy is *achieved* (Carney 2017c). Rather than such a starry-eyed consequential 'status' of self-actualisation, I would contend that the focus is better placed on a more modest notion such as the *means* by which people can be assisted to more fully and/or more often exercise their 'will' and/or 'preferences' (since the two are not necessarily the same: Szumkler 2017 IALMH paper summarised in (OPA 2017, p. 51)).

Seen in this light, the definition of 'success' in realising this Article 12(3) CRPD right to SD becomes quite debatable. Is it enough simply to 'try' to facilitate SD (a perhaps largely symbolic gain) or as argued below should there be insistence on a showing of progress? If so, how much progress and how durable should progress be? Is it enough that a new culture and language is adopted between the person being 'supported' and those around them (which may yield 'slow-burn' gains over time), or should, as suggested below, attention be on measuring change in the *number* and *type* of decisions *actually* being made? And, if so, can trends of expanded confidence in the number and magnitude of decisions being made be taken at face value without considering any (offsetting?) enhanced 'risk' of any unfortunate outcomes of those decisions? Surely not. Surely nor should the answers to these questions differ between SD schemes that are legislated as against being program or civil society initiatives (the range sketched in (Carney and Beaupert 2013)).

Since SD is something delivered to assist someone other than the supporter to realise their Article 12 rights, I argue that the contribution made by law and policy primarily must surely be on achievement of some minimum level of competence and understanding of SD by supporters, and where this does not exist naturally (as rarely it does) then it turns on the success and durability of capacity-building of SD among supporters. And since Article 12 is about ensuring/promoting optimal achievable equality, regard surely must then be had to the *substantive* as distinct from symbolic achievements of supporters in serving as the instrumental agents for realising optimal decision-making autonomy of those being assisted. This might for the purposes of the present discussion be translated into some crude conceptual labelling of the forms of SD. Labelling which deliberately here is pitched to be inclusive in the sense of catching not only SD under some legal auspice but also the much larger numbers of people receiving it under a formal civil society scheme, or the even larger numbers living and supported 'informally' by family or friends in natural civil society settings.

For simplicity, the 'substance' of such arrangements, on an evaluative spectrum from good to awful, might be badged as SD which is: (i) sensitive/substantive (i.e., SD at its optimal best); (ii) symbolic/empty (i.e., well-intentioned SD, but in name only); and (iii) abusive/oppressive (i.e., SD which is paternalistic substitute decision-making 'in disguise', whether by default or design (or as Matthew Burch evocatively puts it, '[w]hat happens when manipulation dons the mantle of support': (Burch 2017, p. 397)). The latter is of the greatest concern, not only because in practice CRPD autonomy enhancing is being contradicted, but also because in some instances it is the result not of lack of capacity of the supporter to do the right thing, instead involving deliberate abuse and exploitation of the person being supported (Arstein-Kerslake and Flynn 2017). However, the middle category is of concern too, since its symbolic window-dressing deflects public policy attention by conveying a false appearance of CRPD compliance. Only the first category passes CRPD muster, but so far there is no

evidence (other than unscientific anecdotal evidence) that *any* law or program *actually* is entitled to the label (though the same could of course be said of proxy decision-making).

So, what is entailed by priority setting and what ‘language’ maps the conceptual territory of laws and programs associated with that part of the challenge of ‘properly’ realising SD in the way sketched so far?

3.2. Setting Priorities for Allocating Limited Resources for SD

The second reason for sluggish progress in implementing SD (beyond the indivisibility point discussed in 3.1) I suggest may be due to a failure to address the realpolitik of implementing socio-economic rights in times of real or perceived austerity.¹⁰ Now I recognise that some will regard it as almost heretical to speak about setting ‘priorities’ for the realisation of human rights. Yet socio-economic rights have always provided for ‘progressive realisation’ by State Parties (especially in recognition of the challenges of developing states), subject to a correlative ‘non-retrogression’ obligation (not going backwards);¹¹ and it is hard to find examples even of wealthy countries not taking a similar progressive (i.e., staged) and/or selective (i.e., needs-based) approach to their realisation. Despite the jurisprudence on the obligation to ‘respect, protect and fulfil’ (Wills and Warwick 2016; Forman et al. 2016), progressive realisation of universal socio-economic rights does of course risk glacial progress at best or constant postponement to the ‘never-never land’ at worst, especially in the face of neoliberal fiscal austerity which constrains public funding options even in wealthy first-world economies.

Welfare policy seems particularly well adapted to addressing progressive realisation issues because it constantly engages with the competition and choices arising between the three principles of distributive justice for setting priorities about allocation of necessarily scarce resources: the competing principles of (i) equality (universal provision but at the risk of spreading resources too thinly); (ii) equity (proportionate return on prior contributions); and (iii) ‘need’ such as by means testing (see Carney 2006, chp. 4; Devereux 2016, pp. 168–78). The realpolitik of governing, especially in the age of neoliberal austerity, is that the needs principle will often be selected (and on its own) unless the case can be made for some selective *supplementary* application of a more costly principle, such as illustrated by Steven Devereux’s argument for supplementary provision of universal access to ‘essential’ services (Devereux 2016, pp. 178–79). In just this vein the right to health has been refined to stipulate a limited number of ‘minimum core obligations’ (the specification or measurement of which proves problematic: (Forman et al. 2016)), effectively elevating the core ahead of the right generally. Selective provision of a social good such as income or a service (such as by means-testing access or rates, or other forms of rationing) reflects prioritisation of the most pressing or acute need, including any redistributive pursuit of greater equality in access to the social good in question; though over the long history of welfare both ‘social investment’ (capacity-building initiatives) and needs-based programs are evident (see for example, Smyth and Deeming 2016).

Indulge for a moment engaging with the heretical thought exercise of asking how to isolate a ‘minimum core’ for SD, or how otherwise to provide a rank order of possible priority targets for early roll out of SD. Possible inclusions on such a ‘shopping list’ of possible steps towards realising the ultimate goals of the ‘support-with-safeguards’ principle of Article 12(3) of the CRPD might include:

- (a) addressing the most egregious breaches (perhaps people languishing under heavy drug restraints in care homes, though for an argument to cover family settings too, see: (OPA 2017, p. 38));

¹⁰ Targetting (priority setting allocation such as through means testing) is one of the three fundamental choices/tension in welfare provision (the others being universal provision and provision proportionate to say prior contributions or years of work/citizenship: (Devereux 2016)).

¹¹ For elaboration of these twin principles in the context of neoliberal shrinking of public resources, see the insightful discussion of the *International Covenant on Economic Social and Cultural Rights*, one of the two main ‘parents’ of the CRPD (Wills and Warwick 2016, especially pp. 640–46, 653–55).

- (b) addressing the most pervasive but more routine support needs (such as for a supporter or nominee/representative payee in social security);
- (c) prioritising the needs of the least visible and most vulnerable (such as people lacking friends or relatives, or overly reliant on a very ‘protective’ carer; or those who are criminalised or labelled with complex needs);
- (d) tackling issues where law or policy has the strongest track record in being brought into actual practice (perhaps by operationalisation of advance directives);
- (e) concentrating on groups fortunate to be more plentifully resourced (such as Australia’s NDIS population); or
- (f) picking the issues where the impact is most cost-effective (such as legislation allowing people to authorise someone else to convey information or access records on their behalf)?

I suggest a case can be made for putting almost *any* of the above items first on the list, and for choosing almost any subsequent running order of the remaining items. For instance calls have been made for more attention to be paid to the routine needs of large numbers of ordinary people (i.e., item (b): (Carney 2015a)) and concern expressed about neglect of the needs of people who are socially isolated (item (c)). But adapting Anna Arstein-Kerslake et al.’s observation that NDIS resourcing is already adequate to also properly fund SD, a start could very well be made with that population (noting however the authors difficult to avoid worry that SD may just become ‘another service’ controlled and delivered by others rather than by those being supported: (Arstein-Kerslake et al. 2017)). Reasonable minds will differ. Others may rightly urge keeping item (a) at the top of the list due to the depth of infringement of liberty and strong presence of actual or de facto coercion (actual in the case of involuntary treatment or restraint; often de facto where people are living in ‘total institution’ settings and/or feeling beholden to their carers). But there are several ethical and social values and standpoints potentially in play even here: of the just mentioned measure of diminution of individual autonomy; of the alternative measure of empowering or allowing ‘others to decide’ (the amount of paternalism or disempowerment); or by the measure of how much ‘harm’ is visited on the person (from consequential harms and risks¹²). So, in varying ways, prioritising any one (or putting others into a rank order for realisation) inevitably reprises the choice between, or weighting of, the just mentioned values of equality, equity and need (whether assessed by measurable variables like severity or more amorphous concepts such as ‘vulnerability’).

However, the problems are not yet finished. For knowing when Article 12(4) safeguards are called for involves yet another of those tricky ‘threshold’ questions. Certainly, as already argued, Article 12(3) extends a correlative entitlement to ‘support’ as the required replacement for some form of substitute decision-maker. In that sense, it provides the answer to the concern that reading Article 12 simply as outlawing substitute decision-making would merely return people to say Victoria’s ‘pre-1984’ situation of having neither an accessible substitute decision-maker (just costly and ultra-paternalistic Supreme court actions) nor any practical support (at least outside institutional or coercive orders). This would involve a return to what I have characterised above as the morally unsupportable position of being ‘free’ of substituted decision-making but with nothing but a theoretical (and unrealisable in practice) ability to enjoy autonomous decision-making unless blessed with access to ‘perfect’ natural or civil society supporter(s). But, as Linus Broström (2017) points out, there is a vast literature about the ease with which even the most conscientious and well-intentioned informal supports can rapidly degrade to operate paternalistically, under the thrall of forms of undue influence (Broström 2017). So finding ways to bring about the paradigm shift in values and skills of civil society members to genuinely realise ‘support-with-safeguards’ free of undue influence in the way envisioned by the CRPD, is a

¹² Indeed it was this latter lack of adequate safeguard protections against the risk of large social security debts that led me to focus on the ‘mass/mundane’ issues facing representative payee arrangements (Carney 2017a, pp. 10–13).

major empirical challenge in capacity building of supporters (Carney 2017c). But first there is the thorny question of where any bright line is set for 'undue' influence.

For its part, operationalising such a threshold of undue influence is very challenging. Common law principles of equity on undue influence could in theory make a contribution (Sloan 2012, chp. 7), but they do not readily lend themselves to simple application outside the higher courts. Concepts of vulnerability have been advanced by some in the related context of guardianship reform or elsewhere (Hall 2012 [as basis for guardianship]; Herring 2016, pp. 83–85 [inherent *parens patriae*], 243–49 [contracts]). Here the focus on webs of relationships and 'layering' of contributions to vulnerability (Luna 2009; Luna and Vanderpoel 2013) holds the promise of a richer calibration of individual and social-contextual dimensions (such as being socially isolated). However, vulnerability too remains a very woolly concept (Kohn 2014; Smith et al. 2010; Herring 2016, chp. 2, especially pp. 6–11). Vulnerability, then, is no generic standard or test, but one which calls for conceptual clarity between different formulations, along with specification in particular contexts (such as in quarantining special disability trusts: (Carney 2017b)). That specification may in turn be open to the criticism that it is a 'stark binary' capacity test in disguise, unless framed along the lines of Martha Fineman or Amartya Sen's 'universal vulnerability' or 'spatial/environmental' terms (for a detailed review: (Brown et al. 2017; Clough 2017), also the four articles underpinning [and fully republished within] her doctoral thesis: (Clough 2015)).

Turning to the risk of contravention of CRPD autonomy maximising values by civil society actors in ordinary relationship settings, it is again important to take a grounded real-world approach. Arguably all citizens are prone to adapt behaviour and choices to some degree in response to forms of external influence (Herring 2016, chp. 2). So, it is only when influence is judged to be a form of 'undue' influence that it becomes of concern legally, ethically, or socially. But as just shown, there probably is no bright line test which identifies the threshold beyond which concern is properly raised. At best there sometimes may be some assistance to be derived in posing a crude counterfactual, such as by comparing the lived-life autonomy enjoyed by someone under as against a person without guardianship or its companions. For surely it is unacceptable to argue that it is 'better' that a person enjoys *less* autonomy, or is subject to more paternalism in a civil society setting, than would be the case under say guardianship.

Might all of these worries about finding and prioritising resources and resolving design and safeguards issues be contributing to the very slow progress being made towards realising the legislative or program 'package' for SD as I argue is conceived in Article 12 of the CPRD? Does it not help to understand in realpolitik terms if no other, why legislatures such as Victoria have combined some minor 'easing back' of civil committal powers in mental health with the enunciation of rights to nominate supporters (*Mental Health Act 2014* (Vic), s 24)? A measure sure to be criticised by the CRPD Committee for its failure to repeal involuntary treatment but which it seems has already proved rather empty on the supporter side due to low take-up (Brophy 2017), as evidenced by the presence of nominated supporters at just four per cent of committal hearings (MHT 2016, p. 15). How can Victoria be faulted on a 'priority of needs' basis for at least *starting with* an area as rights-sensitive and fraught as mental health (especially if that support is not forthcoming in the way envisaged)? For self-evidently this is a strong candidate for inclusion on any hypothetical 'minimum core' for progressive realisation of the right to SD.

If this analysis has purchase, where does it leave Article 12 'repeal in conjunction with adequate SD' in the longer term? With a *de facto* status quo and glacial progression for much of the duration? Surely if simple repeal of substitute decision-making without more is not an option on ethical grounds or because it is unattractive to government realpolitik, and only the resource-intensive 'repeal & replace' avenue is open, as argued above, then the answer is 'yes.' Now this undoubtedly is an unsettling conclusion. But it is nothing other than the standard approach regarding implementation of other socioeconomic rights such as the rights to housing, to health, or to social security.

4. Conclusions

This paper was stimulated by the apparently glacial progress made in the decade since the CRPD enunciated the right to support. It has explored—well more accurately perhaps it has ‘lightly sketched’—some less orthodox conceptual and distributional frames (such as welfare’s ‘priority of needs principle’) as possible ways of injecting greater momentum into the implementation of SD by looking at it through a different lens than that of what might be termed the ‘capacity-analysis’ literature.

In doing so I am mindful that some may object that a lot of ‘below the radar’ support programs and pilot schemes have already been generated internationally (e.g., [Power et al. 2013](#); [Van Puymbrouck 2017](#)), or that SD resourcing costs are overstated, so we should remain patient. Others will object that even if progress is inadequate, it would be positively sacrilegious to isolate particular beneficiaries or to contemplate progressive realisation of what was framed as a universal entitlement. Both may be right. And there are no doubt other lenses which could be applied, such as a justice-reinvestment analysis (for an overview [Brown et al. 2016](#)) designed to boost resources available for SD by earmarking and reallocating savings from lowering the load on say the already costly adult guardianship and mental health machinery (while remaining alert to avoiding the past failure of deinstitutionalisation to hypothecate similar ‘savings’ while States congratulated themselves on their purist ‘reforms’: ([Mansell and Ericsson \[1996\] 2013](#); [Caplan and Ricciardelli 2016](#), p. 33)). However as I have previously written about the right to health, even John Tobin’s optimistic book about actualising the right to health closes by writing that: ‘Following Lauterpacht,¹³ it can safely be said that if economic and social rights are at the vanishing point of human rights law, as a surprising number of jurists and philosophers still seem to think, then the right to health is at the vanishing point of economic and social rights’ ([Tobin 2012](#), p. 371).

The worry tackled in this paper is that the socio-economic right to SD risks dropping below even that vanishing point; hence canvassing of some rather heretical paradigm shifting thought experiments as a way of assessing progress to date and the way forward. Rather than pessimism about Article 12 in general and SD in particular ‘running on empty’, I suggest that the slow but measured progressive realisation so far is also the course to stay for the future. After all, isn’t that the history of pursuit of substantive equality, with its messy needs priority and other principles ([Fredman 2016](#); [Goldschmidt 2017](#))? If so, does it not become even more imperative to know when SD serves to build capacity, for how long benefits subsist and at what economic cost, as a current study is designed to reveal (further, [LIDS 2017](#))?

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¹³ Adapting the wry 1952 comment by Sir Hersch Lauterpacht about the limited normative power of the international law of war (‘if international law is the vanishing point of law...the law of war is the vanishing point of international law’).

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