

Introduction

The dialogue below occurred in a large hospital in Canada:

Physician: Have you [referring to the author's father] applied for a long-term care (LTC) bed?

Author interjected: No

Physician: I suggest you apply for a bed as soon as possible. You cannot wait until you are in a crisis situation to apply.

[The author and the physician began to exchange opposing views about LTC.]

Author's father: My wife and daughter can take care of me.

As a former carer (my father has passed), I ponder the above conversation on a regular basis. One issue that continues to trouble me is the variety of influences over any older disabled adult's decision-making regarding care, including influences of professionals such as physicians and (benign) carers (e.g., family members). Not all older disabled adults need or accept involvement of family members and friends in their care decisions but some do for a variety of reasons. In this paper, individuals who provide decision-making support are identified as 'supporters' and individuals who receive support are identified as 'supported persons'. Drawing from my experience as a carer-supporter, I explore what Article 12 of the United Nations Convention on the Rights of People with Disabilities (CRPD) can offer to older adults who live with significant cognitive and physical impairments. Article 12 recognizes equal right to legal capacity, which includes the ability to be a holder of rights as well as capacity to exercise one's rights (Pritchard-Jones 2019, 2). This paper argues that the State has an obligation to establish appropriate support measures for carers so that they possess the

necessary capabilities and strengths to provide decision-making support to older disabled adults who accept such support in care settings.

Personal reflections on the role of carer-supporter

Looking back, it is clear that decisions about my father's care were subject to numerous direct and indirect influences resulting from familial and formal care relations. Those relations were critical for his physical survival but also had the potential to either threaten or support his right to legal capacity. As his carer-supporter, I helped my father to access and interpret information necessary for decision-making purposes. At the same time, I tried to influence my father over numerous care-related decisions in the name of 'safety' or 'wellness'. I also attempted to resist undue influence of physicians and other well-meaning professionals while being mindful of the constraints within their organizations. I felt an overwhelming sense of disappointment when we were 'nudged' to make decisions that were convenient for the health care system but would not reflect the will and preferences of my father.

My role evolved as my father experienced more cognitive and physical changes and the external cultural and language barriers became increasingly difficult to navigate. At the beginning of his care journey, I functioned as his 'conduit' (Pritchard-Jones 2019, 2) for his will and preferences: with some assistance, he was able to process information and then decided. As his illnesses progressed, his care decisions became more complex and more urgent. It would be accurate to say that decisions about his care were not always 'his' decisions but 'our' joint decisions. However, he was not a passive recipient of simplified information and tried to push back (as illustrated in the dialogue above).

This experience made me reflect on the conditions necessary for older disabled adults to assert their right to make decisions in care settings. A productive way to

advance debates about supports envisioned in Article 12 is to recognize the influence of carers and supporters and explore mechanisms for enabling ‘good’ influences. While I use my lived experience as a point of entry to discuss the exercise of legal capacity as it affects older disabled people in care settings, this is an issue for many disabled people.

Right to Legal Capacity

Article 12 of the CRPD affirms disabled people’s rights to equal recognition before the law, including the enjoyment of legal capacity ‘on an equal basis with others in all aspects of life’ (Martinez-Pujalte 2019, 1). Examples of actions requiring the exercise of legal capacity include making a will, appointing a power of attorney, and bringing a legal action against another (Hall 2022, 278). ‘Decision-making’ is one essential aspect of the exercise of legal capacity but Article 12 in itself is not necessarily about making decisions generally (Hall 2022, 277). In my view, certain care decisions such as consenting to medical treatment or admission to LTC require the exercise of legal capacity.

The CRPD also affirms that ‘States Parties shall take appropriate measures to provide access to persons with disabilities to the support they may require in exercising their legal capacity’ (Martinez-Pujalte 2019, 1). The CRPD does not mandate a particular type or form of support that must be provided. In some situations, personal support may take the form of peer support or consist of assistance from family, friends or other formal or informal networks. In other situations, technical accommodations such as the provision of information in accessible formats, extra time to think, and/or assistive devices to facilitate communication, will be sufficient (Nilsson 2021, 18–19). Importantly, support measures must include appropriate and effective safeguards, which are intended to ensure that support respects the rights, will and preferences of the person and prevent abuse, conflict of interest or undue influence (Martinez-Pujalte 2019, 5).

Managing influence: A tentative pathway forward

Adopting a more relational understanding of autonomy is a promising start. Since not all influence is benign, actions will be required from States to ensure that autonomy is fostered and nourished, and that ‘good’ relationships of support are encouraged while ‘bad’ ones are discouraged (Keeling 2022, 41). Keeling (2022) is correct to note that the type and quality of the influence in the relationship must be acknowledged (48). ‘In all cases of support, there will be influence, from the way that information is simplified, to the “important facts” for basic forms of support, to situations as above where the supporter is the only person who can “translate” the will and preferences of the disabled person to the wider world’ (Keeling 2022, 48). Accordingly, we should address more holistically the question of what ‘good’ environments that facilitate legal capacity look like and how we can create them (Keeling 2022, 55).

For older disabled adults who accept familial and other relations in their care networks, ‘good environment’ includes well-supported supporters. To effectively respect the ‘rights, will and preferences’ of supported persons and prevent abuse, appropriate support measures should include assistance for their carers who are also their supporters. The idea that carers require support in the process of making care related decision is not new, for example in the context of LTC placement decisions (Davies and Nolan 2003). The critical point is that Article 12 should direct us away from carers making decisions *for* older disabled adults. Given the importance of safeguarding in the context of support, it is easy to make the case for appropriate level of supervision of supporters (Harding 2022, 312). There is an equally compelling case for improving the quality of support provided by supporters.

In addition to providing direct support to supported persons, we must consider how to augment the strengths and capabilities of supporters. The main reason is that it should not be assumed that decision-making support is easy to provide (Harding 2022,

303–4). It is necessary to distinguish between ‘good support interactions’ and ‘bad support interactions’ (Pritchard-Jones 2019, 3). Even if supporters do not have malicious intentions, they may not be able to support a disabled person’s exercise of legal capacity because they do not have access to correct legal information or legal advice. It is not realistic to expect individuals who have limited understanding of legal issues to support others in making decisions about them (for example, see recommendations in Law Commission of Ontario 2017). For example, supporters may not know how to challenge a finding of incapacity made by a physician or support an older disabled person’s challenge in a judicial or quasi-judicial forum. They may not be aware of any right to demand information from health care providers so they can help the older disabled person to understand the consequences of their decisions. Another example of how the state could support decision-making supporters is through universal access to practical and cost-effective resolution systems when there are conflicts. Tensions between different supporters are not unique and such tensions can make the supported person more confused and less able to make their own decisions, particularly when it comes to difficult decisions and life choices (Harding 2022, 305). In some cases, reliance on the formal legal system is not feasible (Lai 2020).

Finally, since family members or carers of older disabled adults are likely to be involved in making decisions about health care (Pritchard-Jones 2019), they in turn could be subject to ‘good’ and ‘bad’ influences from a plethora of parties involved in medical and social care. Some of these influences are institutional in nature. Hospitals may put pressure on family members of patients to apply and consent to admission to LTC homes (preferably those with the shortest waitlists) by threatening significant bills, even if those LTC homes may not be suitable for the older adults in question. There is an obligation on the State to — at the very least — establish the necessary procedural

protections and transparent compliant procedures so carers are empowered to support older adults by being their advocates. To put it differently, supporters may also benefit from appropriate and effective safeguards.

This understanding of Article 12 should not be construed as a stand-alone carer right to publicly-funded support. Some disability scholars are critical of the implications of the carers' rights movement (Soldatic and Meekosha 2013). Any support for carer-supporters should not replace or displace the rights of disabled adults to access decision-making support provided by the State. The issue here is that there must be multiple pathways for older disabled adults to benefit from universal access to decision-making support in care settings. One such pathway might incorporate support measures for carer-supporters so that they possess the strengths and capabilities to support older disabled adults in formulating and communicating decisions about care.

Conclusion

Despite the promise of the CRPD, some older disabled adults may have been excluded from decision-making regarding care, while others, often carers or family members, have the final say in the outcome. This paper argues that not only does the State have an obligation to provide persons with disabilities with access to support, but it also has a positive obligation to provide support to carer-supporters in order to operationalize the requirements of Article 12.

References

- Davies, Sue, and Mike Nolan. 2003. "'Making the Best of Things': Relatives' Experiences of Decisions about Care-Home Entry." *Ageing & Society* 23 (4): 429–50.
- Hall, Margaret Isabel. 2022. "Putting the Pieces Together: Article 12, 'Safeguarding' and the Right to Legal Capacity." In *Supporting Legal Capacity in Socio-Legal Context*, edited by Mary Donnelly, Rosie Harding, and Ezgi Taşcıoğlu, 273–90. Oxford: Hart Publishing.
- Harding, Rosie. 2022. "Supporting Everyday Legal Capacity: Navigating the Complexities of Putting Rights into Practice." In *Supporting Legal Capacity in*

- Socio-Legal Context*, edited by Mary Donnelly, Rosie Harding, and Ezgi Taşcıoğlu, 291–314. Oxford: Hart Publishing.
- Lai, Poland. 2020. "Disability's Encounter with Legislation and Governance: Long-Term Care Homes in Ontario." PhD Diss., York University.
- Law Commission of Ontario. 2017. *Legal Capacity, Decision-Making and Guardianship Final Report*. Toronto: Law Commission of Ontario.
<http://www.lco-cdo.org/wp-content/uploads/2017/03/CG-Final-Report-EN-online.pdf>.
- Martinez-Pujalte, Antonio. 2019. "Legal Capacity and Supported Decision-Making: Lessons from Some Recent Legal Reforms." *Laws* 8 (1): 4.
<https://doi.org/10.3390/laws8010004>.
- Nilsson, Anna. 2021. *Compulsory Mental Health Interventions and the CRPD: Minding Equality*. London: Bloomsbury.
- Pritchard-Jones, Laura. 2019. "Exploring the Potential and the Pitfalls of the United Nations Convention on the Rights of Persons with Disabilities and General Comment No. 1 for People with Dementia." *International Journal of Law and Psychiatry* 66. <https://doi.org/10.1016/j.ijlp.2019.101467>.
- Soldatic, Karen, and Helen Meekosha. 2013. "Disability and Neoliberal State Formations." In *Routledge Handbook of Disability Studies*, edited by Nick Watson, Alan Roulstone, and Carol Thomas, 195–210. Abingdon: Routledge.