Divergent Human Rights Approaches to Capacity and Consent

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Abstract

The institutional dialogue among the Committee on the Rights of Persons with Disabilities and other human rights tribunals has led to greater protection of rights. But not all courts and treaty bodies have accepted the Committee’s absolutist position on legal capacity. The chapter illustrates the multiple human rights-based approaches to capacity and decision-making, and describes how the Committee’s absolutism endangers many of the people living with moderate or severe dementia whom it supposedly benefits.

INTRODUCTION

The Committee on the Rights of Persons with Disabilities (CRPD Committee, or the Committee) has successfully influenced other human rights bodies over the past decade to strengthen their standards for the protection of people with disabilities. While some institutions have followed the CRPD Committee’s absolutist interpretations on issues of legal capacity and consent, others such as the Human Rights Committee and the European Court of Human Rights have declined to fully incorporate these interpretations into their own human rights approaches. Instead they have recognized the possibility that certain limitations may be justified by the interests of the individual in question or by the rights of third parties.

This chapter describes some examples of this divergence, and examines some of the arguments in favor of less absolutist standards, including reasons that have been articulated in dialogue between the Human Rights Committee and the CRPD Committee. The chapter proceeds in three sections, first by pointing out some of the features of the CRPD Committee’s approach (A); then by describing some of the interplay between the CRPD Committee and other human rights institutions (B); and then by illustrating the implications of the absolutist approach for people living with moderate or severe dementia (C).

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The CRPD Committee is the treaty body created by the Convention on the Rights of Persons with Disabilities. A human rights treaty body is a committee of independent experts, elected by the states that have ratified a particular human rights treaty, for the purpose of monitoring compliance with the obligations under the treaty. There are currently nine other treaty bodies at the global level, including the Human Rights Committee, which despite its generic name actually monitors compliance with the International Covenant on Civil and Political Rights (ICCPR). Among other activities, treaty bodies commonly engage in the review of states’ overall reports, the adjudication of “communications” submitted by individuals alleging a violation by a state, and the issuance of texts known as general comments, which address legal issues of substance or procedure under the treaty without being focused on any particular state. Treaty bodies’ interpretations of their governing conventions have been described as “authoritative,” given the bodies’ expert character and functions, but they are not legally binding in international law, unlike the judgments of international courts.

The CRPD Committee issued its first general comment in 2014, on CRPD Article 12, entitled “Equal recognition before the law.” The main theme of the General Comment is the Committee’s account of the right to legal capacity and the requirement of supported decision-making.

General Comment No. 1 calls for a shift from substituted decision-making, where outsiders make a decision that should be based on the best interests of the person with disability, to supported decision-making, where the person with disability receives support in order to make a decision freely. The core of this argument, referring to the disrespect and dangers involved in older systems of substituted decision-making, has considerable force. The argument is less persuasive, however, in the full generality that General Comment No. 1 actually asserts.

Tracing a path through the text of the General Comment illustrates the extreme range of its prescriptions. Legal capacity is the (juridical) ability both to hold rights and duties and to exercise those rights and duties (para. 13). Mental capacity, in contrast, refers to the decision-making skills of a person (para. 13). Actual deficits in mental capacity must not ever be used as justification for denying legal capacity (para. 13). An assessment of whether a person can understand the nature and consequences of a decision can never be taken as legitimate grounds for denying the person’s legal capacity (para. 15). That is prohibited discrimination (para. 15).
Instead, support must be provided for the exercise of legal capacity (para. 15). Nonetheless, taking advantage of support is wholly optional - a person with disability always has the right to refuse any support (paras. 19, 29(g)). In other words, a person who cannot understand the nature and consequences of a decision has the absolute right to make the decision without assistance, and have full legal consequences attributed to the decision. Moreover, the person has “the right to take risks and make mistakes” (para. 22).

Forbidden regimes of substitute decision-making include systems where even a single decision is removed from the scope of a person’s legal capacity (para. 27). Supported decision-making must totally replace substituted decision-making, which cannot be maintained as a parallel option at all (para. 28). Supported decision-making must be available to all, no matter how high their support needs (para. 29(a)). The right to support in the exercise of legal capacity cannot be limited by a claim of disproportionate or undue burden; states have “an absolute obligation to provide access to support in the exercise of legal capacity” (para. 34). The individual must have the right to refuse support and to terminate or change the support relationship at any time (para. 29(g)). Individuals may never be detained in an institution or placed in a residential setting without their specific consent; that constitutes arbitrary detention and is prohibited (para. 40). Forced treatment by psychiatric and other health and medical personnel is always a violation of the right to equal recognition before the law, and indeed of the right to freedom from torture; the right to choose or reject medical treatment must be respected at all times, including in crisis situations (para. 42).

It might also be observed that in the General Comment the right to free exercise of one’s legal capacity apparently includes the right to make decisions that have consequences for others, indeed to exercise power over others. Persons with disabilities have wrongfully been excluded from key roles in the justice system as lawyers, judges, or members of a jury (para. 38). Actual defects in a person’s decision-making ability cannot be a justification for any exclusion from the right to stand for election or serve as a member of a jury (para. 48). States should guarantee the right of all persons with disabilities to stand for election, to hold office effectively, and to perform all public functions at all levels of government, with reasonable accommodation and support, where desired (para. 49). That is, support can be provided where the officeholder desires it - persons with disabilities, including those in office, have an absolute right to refuse all support.

The Committee on Persons with Disabilities describes these far-reaching conclusions as necessitated by “the human rights-based model of disability” (para. 3). For the Committee, there is only one human rights-based approach.

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4 This feature deserves a study of its own, but will not be further explored here. See also David Bilchitz, “Dignity, fundamental rights and legal capacity: moving beyond the paradigm set by the General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities,” *South African Journal on Human Rights* 32 (2016): 418.
The Committee’s absolutist rejection of any diminution in the right to exercise legal capacity in any circumstance is consistent with other absolutist features in the Committee’s interpretation of the Convention, and in particular with the Committee’s absolutist conception of discrimination. In Article 12, the right to legal capacity “on an equal basis with others” means on exactly the same basis; there is no room for justified differentiation. The Committee’s General Comment No. 6 on discrimination similarly sets forth an absolute conception of prohibited discrimination. There should be no laws that allow for specific denial, restriction, or limitation of the rights of persons with disabilities (para. 14). The Committee defines direct discrimination as including any less favorable differential treatment for a reason related to disability, regardless of motive (para. 18(a)). Direct discrimination must be comprehensively prohibited; the General Comment does not contemplate any circumstances under which differential treatment could be justified. In fact, the final version of the General Comment also eliminates any possibility of justifying facially neutral practices that have negative differential effects on persons with certain disabilities. Language in the first reading draft of the General Comment would have recognized that practices with differential effects do not amount to such indirect discrimination if they are “objectively justified by a legitimate aim, and the means achieving that aim are appropriate and necessary,” but the Committee deleted that clause on second reading. In the final version, only the separately listed requirement of reasonable accommodation includes a possibility of justification.

The absolutist notion of discrimination is not the usual human rights-based approach to direct discrimination. The Committee was doubtless aware of the discrepancy. It had previously been pointed out to the Committee by members of the Human Rights Committee, and the present author made a written submission to the CRPD Committee’s day of general discussion in preparation for General Comment No. 6, urging the Committee to align its definition with the standard definition in international human rights law. The submission quoted examples from the Human Rights Committee, the Committee on Economic, Social and Cultural Rights, the Committee on the Elimination of Racial Discrimination, the European Court of Human Rights, and the Inter-American Court of Human Rights, all defining direct discrimination in terms that require an inquiry into the objective justification for differential treatment. The CRPD Committee instead continued on its chosen path.

5 Committee on the Rights of Persons with Disabilities, General Comment No. 6 (2018) on equality and non-discrimination, UN Doc. CRPD/C/GC/6 (2018).
7 General Comment No. 6, para. 18(b).
8 Ibid., para. 18(c).
9 See Submission of Prof. Gerald L. Neuman regarding draft General Comment on article 5, Equality and non-discrimination, available at https://www.ohchr.org/EN/HRBodies/CRPD/Pages/
Several states have attempted to preserve some exceptional use of substituted decision-making by accompanying their ratification of the CRPD with reservations, or understandings in the nature of reservations. However, the validity of such reservations has been challenged for deviating from the absolutist approach. The CRPD Committee’s concluding observations on Canada in April 2017 claimed that Canada’s reservation “contradicts the object and purpose of the Convention,” and did not comply with “the human rights model of disability.”\(^\text{10}\) Later the same year, the Special Rapporteur on the rights of persons with disabilities devoted a report to legal capacity, in which she asserted that reservations to Article 12 are incompatible with the object and purpose of the Convention and therefore not permitted, because they “hinder and/or deny the full and equal enjoyment” of CRPD rights.\(^\text{11}\)

### B THE DIALOGUE AMONG HUMAN RIGHTS INSTITUTIONS

Even before issuing General Comment No. 1, the Chairperson of the CRPD Committee called the attention of the Human Rights Committee to a passage in one of the latter’s General Comments from the 1990s, describing “established mental incapacity” as a permissible basis for denying the right to vote, which contradicted the CRPD Committee’s understanding of the subsequent Convention. The Human Rights Committee did not undertake a revision of the General Comment, but after deliberations on state reports it adopted concluding observations superseding that passage by a stricter standard for finding an inability to vote. The stricter standard allowed for individualized determinations of the relevant mental capacity, and did not impose the absolute prohibition favored by the CRPD Committee and later embodied in that committee’s General Comment No. 1.\(^\text{12}\)

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\(^{10}\) CRPD Committee, Concluding observations on the initial report of Canada, UN Doc. CRPD/C/CAN/CO1 (2017), para. 7.


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The Human Rights Committee also revised its approach to nonconsensual psychiatric treatment, in concluding observations adopted in March 2014. It recommended that “[n]on-consensual psychiatric treatment may only be applied, if at all, in exceptional cases as a matter of last resort, where absolutely necessary for the benefit of the person concerned, provided that he or she is unable to give consent, for the shortest possible time, without any long-term impact and under independent review.” Again, the standard was not an absolute prohibition, and it assumed that nonconsensual treatment might exceptionally be necessary for the individual’s own benefit.

The most extensive consultations between the two treaty bodies at this period occurred in connection with the Human Rights Committee’s adoption of its General Comment No. 35 on the right to liberty and security, which included a paragraph on involuntary hospitalization. Human Rights Committee members also benefited from meetings with disability rights advocates. The Human Rights Committee made several modifications to its draft to take into account concerns expressed by the CRPD Committee, but it became clear that the two treaty bodies disagreed fundamentally about the meaning of the right to non-discrimination and the limits of the right to physical liberty. There was also disagreement about whether the insanity defense in criminal law should simply be abolished without anything available to replace it. The Human Rights Committee ultimately declined to adopt the CRPD Committee’s absolutist definition of discrimination on grounds of disability as an interpretation of the ICCPR, or to regard involuntary hospitalization as always per se arbitrary detention. Once more, the Human Rights Committee tightened its prior standard, insisting that deprivation of liberty must be applied only as a last resort, accepting unconsented hospitalization that is proportionate and necessary “for the purpose of protecting the individual in question from serious harm or preventing injury to others.” The CRPD Committee countered by issuing a public statement, and subsequently “Guidelines,” reiterating its view that it is never permissible to detain persons with disabilities based on perceived danger to themselves or to others.

13 See Human Rights Committee, Concluding observations on the fourth periodic report of the United States of America, UN Doc. CCPR/C/USA/CO/4 (2013), para. 18 (citing articles 7 and 17 of the ICCPR); Human Rights Committee, Concluding observations on the third periodic report of Latvia, UN Doc. CCPR/C/LTV/CO/3 (2013), para. 16. The present author took part in the deliberations on the Latvia report, but not in the deliberations on the USA report, being recused by reason of his nationality.


15 Human Rights Committee, General Comment No. 35, para. 19.

Other treaty bodies and UN special procedures have varied in their approaches to such issues.\(^{17}\) The Committee Against Torture, the Subcommittee for the Prevention of Torture, and the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment have declined to consider involuntary hospitalization or nonconsensual treatment as always per se violations of the rights within their mandates. The UN Special Rapporteur on the rights of persons with disabilities has, not surprisingly, followed the CRPD Committee’s interpretation.\(^{18}\) The Working Group on Arbitrary Detention, which ostensibly applies the prohibition of arbitrary detention contained in the ICCPR and its analogue in customary international law, knowingly diverged from the Human Rights Committee’s interpretation of the ICCPR when it adopted “Basic Principles and Guidelines on Remedies and Procedures on the Right of Anyone Deprived of Liberty to Bring Proceedings Before a Court,”\(^ {19}\) condemning in all circumstances unconsented medical treatment, involuntary hospitalization, and substituted decision-making.

Meanwhile, at the regional level the European Court of Human Rights has issued a series of judgments over the past decade that pursue a non-absolute human rights-based approach to legal capacity, despite explicit reminders of the CRPD Committee’s understanding.\(^ {20}\) For example, the 2019 Grand Chamber judgment in Rooman v Belgium, upholding the current detention of a convicted offender for psychiatric treatment, explained:

> in the light of the developments in [the Court’s] case-law and the current international standards which attach significant weight to the need to provide treatment for the mental health of persons in compulsory treatment... it is necessary to acknowledge expressly, in addition to the function of social protection, the therapeutic aspect of the aim referred to in Article 5 § 1(e), and thus to recognize explicitly that there exists an obligation on the authorities to ensure appropriate

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\(^{19}\) UN Doc. A/HRC/30/37 (2015), para. 106. This is not the only respect in which the “Basic Principles” diverge from the Human Rights Committee’s interpretation of the ICCPR.

\(^{20}\) See, e.g., A.M.-V. v Finland, App. no. 53521/13 (ECtHR2017), paras. 74,90 (taking into account the CRPD Committee’s rejection of substituted decision-making but “mindful of the need for the domestic authorities to reach, in each particular case, a balance between the respect for the dignity and self-determination of the individual and the need to protect the individual and safeguard his or her interests, especially under circumstances where his or her individual qualities or situation place the person in a particularly vulnerable position.”); Hiller v. Austria, App. no. 1967/14 (ECtHR 2016), paras. 54-44 (finding that placement of an involuntarily hospitalized individual in an open ward was consistent with the requirement that the deprivation of liberty “must be scaled down to the extent which is absolutely necessary under the given circumstances,” and that his subsequent escape and suicide did not demonstrate a failure of state protection); J.D. and A. v United Kingdom, App. nos. 32949/17, 34614/17 (ECtHR 2019), paras. 82-89 (explaining that very weighty reasons would be required for differential treatment of people with disabilities, but maintaining the possibility of justification).
and individualized therapy, based on the specific features of the compulsory confinement, such as the conditions of the detention regime, the treatment proposed or the duration of the detention. On the other hand, the Court considers that Article 5, as currently interpreted, does not contain a prohibition on detention on the basis of impairment, in contrast to what is proposed by the UN Committee on the Rights of Persons with Disabilities in points 6-9 of its 2015 Guidelines ... 21

The same day another Grand Chamber judgment, in Fernandes de Oliveira v Portugal, addressed the duty of a public hospital to prevent a voluntary patient from leaving the premises and killing himself. The majority explained:

The Court considers that a psychiatric patient is particularly vulnerable even when treated on a voluntary basis. Due to the patient’s mental disorder, his or her capacity to take a rational decision to end his or her life may to some degree be impaired. Further, any hospitalization of a psychiatric patient, whether involuntary or voluntary, inevitably involves a certain level of restraint [which] may take different forms, including limitation of personal liberty and privacy rights ... [T]he Court considers that the authorities do have a general operational duty with respect to a voluntary psychiatric patient to take reasonable measures to protect him or her from a real and immediate risk of suicide.22

The majority rejected the mother’s claim of a substantive violation of the right to life, finding that there had not been sufficient evidence of risk to trigger this positive obligation. The majority had noted without explicit discussion the contrasting views at the international level on the permissibility of involuntary hospitalization.23

The German Federal Constitutional Court, which has often been influential in European human rights thinking, has also confronted the interaction between protection of life and legal capacity. In 2016, the Court held unconstitutional the absence from the Civil Code of provisions that would permit life-saving medical treatment to be administered involuntarily to patients who lack the mental capacity to “recognise the necessity of the medical measure or cannot act in accordance with that realization,” but who were too impaired physically to meet the standards for a civil commitment order.24 The Court addressed the contrary position of the CRPD Committee, asserting that a treaty body’s interpretations of its convention “have

21 Rooman v Belgium, App. No. 18052/11 (ECtHR 2019) [GC], para. 205 (citations omitted).
22 Fernandes de Oliveira v Portugal, App. No. 78103/14 (ECtHR 2019) [GC], para. 124. The Court did find a subsequent violation of procedural obligations in the proceedings to investigate responsibility for his death. Two judges dissented in part, arguing among other reasons that the hospital’s obligation to prevent suicide should have been defined more strongly. Fernandes de Oliveira (opinion of Judge Pinto de Albuquerque joined by Judge Harutyunyan). Although the two judgments were issued the same day, the composition of the two Grand Chambers differed.
23 See Fernandes de Oliveira, paras. 68-79.
24 Judgment of July 26, 2016, 1 BvL 8/15 (BVerfG), para. 103 (official translation), available at www.bundesverfassungsgericht.de/SharedDocs/Downloads/EN/2016/07/ls20160726_1bv000815en.pdf?blob=publicationFile&v=2. Under the relevant law, unconsented treatment could be directed only for patients who were legally ordered into a closed environment, and patients who were too physically weak to remove themselves would not meet the standard for such an order.
significant weight, but they are not binding under international law for international or national courts.”

It also argued that the Committee’s statements were vague and did not “give an answer to the question of what, according to its understanding of the text of the Convention, should happen to persons who cannot form a free will and are in a helpless situation.” For similar reasons, the Court has rejected the Committee’s reading of the CRPD as absolutely prohibiting the use of physical or chemical restraints for “persons who cannot (or no longer) be reached by means of communication and who pose an immediate danger to themselves or others.”

The German court’s opinions make explicit a problem that the CRPD Committee’s penchant for absolute rules repeatedly raises. The Committee demands immediate abolition of existing practices and institutions without providing implementable answers to the question of what should replace them. The issue can be illustrated in a hypothetical interaction between a member of the Human Rights Committee and a member of the CRPD Committee regarding the latter Committee’s position that the CRPD requires abolition of the insanity defense and normal criminal trials with support for persons with psychosocial disabilities. The first member asks whether that means that defendants with severe disabilities should be convicted and punished even if they cannot understand their trials, and whether they should be eligible for execution in countries that still retain the death penalty (which would be contrary to the Human Rights Committee’s current interpretation of the ICCPR). The second member replies that we need an entirely new understanding of criminal responsibility, which is yet to be developed. The first member concludes that it is no benefit to such defendants to dismantle existing protections completely before alternative solutions that respond to their situations have been found.

C DILEMNAS OF THE ABSOLUTIST APPROACH TO DECISION-MAKING IN DEMENTIA

The example that I will focus on here is moderate or severe dementia, which can involve what the Committee calls a high level of support needs. For people of my own age, this is a not-too-remote concern. According to the World Health

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25 Ibid., 2016, para. 90.
26 Ibid., para. 91.
27 Judgment of July 24, 2018, 2 BvL 309/15 (BVerfG), para. 92 (official translation), available at https://www.bundesverfassungsgericht.de/SharedDocs/Entscheidungen/EN/2018/07/rs20180724_2bvl030915en.html. Later, in relation to the right to vote, the Court contradicted at length the Committee’s interpretation of Articles 12 and 29 of the CRPD, and insisted that the treaty does not absolutely prohibit exclusion from voting rights of persons who lack “the cognitive skills necessary to make a free and self-determined electoral decision,” while finding unconstitutional a statute that imposed too broad a disenfranchisement of persons under guardianship as a violation of the constitutional provision against discrimination on grounds of disability. Judgment of January 29, 2019, 2 BvC 62/14 (BVerfG), paras. 69-77 (official translation), available at www.bundesverfassungsgericht.de/SharedDocs/Entscheidungen/EN/2019/01/cs20190129_2bvc006214en.html.
Organization, “[i]n 2015, dementia affected 47 million people worldwide (or roughly 5 percent of the world’s elderly population), a figure that is predicted to increase to 75 million in 2030 and 132 million by 2050.”

Dementia is not one disease but an umbrella term covering a variety of forms of nontemporary significant decline in multiple cognitive abilities that significantly impair social or occupational functioning.29 Different categories of dementia may involve different types of damage to the brain and produce different typical patterns of cognitive impairment, and the same individual may also experience more than one of these categories. The most common form of dementia recognized at present is Alzheimer’s Disease. Other examples include vascular dementia (caused by strokes), Parkinsonian dementia, frontotemporal dementia, dementia with Lewy bodies, and other, less common forms.

My goal in this discussion is not to overgeneralize, and definitely not to conflate a diagnostic category with a present loss of ability. Nonetheless there are frequent consequences of dementia that many, perhaps millions of individuals will experience, and a doctrinal approach to decision-making by people with dementia cannot simply ignore those consequences when they do occur.

One symptom, particularly frequent with Alzheimer’s Disease, is progressive loss of memory function, causing increasing difficulty in forming new memories and retaining them even for short periods of time.30 In later stages, loss of older memories often follows, which may extend to the identities of close relatives. Another common symptom is impairment of “executive functions,”31 higher level operations by which the brain controls the carrying out of complex mental tasks.32 Deteriorating temporal and spatial orientation makes it more difficult for individuals to keep track of the passage of time, or to remember where they are going or even where they are.33 They often lack understanding or memory of their own mental limitations, and may become deeply suspicious of others.

Such declines in cognitive abilities with moderate or severe dementia seriously undermine the ability of the affected individuals to make decisions on their own
behalf, or even to follow explanations of complex matters by people attempting to support them. They can also lead persons with dementia to reject support.

Some people with dementia are fortunate enough to have close relatives whom they trust, and when they are no longer able to understand decisions that need to be made, they can engage in what the Committee would call supported decision-making. This may really amount to decision-making by the relative, with uninformed acquiescence. The foundation of trust may be destroyed for reasons caused by the illness, for example when the person can no longer recognize the relative, or when the person imagines that the relative is an impostor who merely looks like the relative. Under the absolutist approach, the person must be free to terminate the support relationship and make decisions without support at any time, which are entitled to legal effect, regardless of the danger they pose to the person’s own interest.

Other people with dementia are not so fortunate, and have no close relatives who care for them, and no close friends who would take on the support responsibility. Their support can only come from strangers, and they may be unable to recognize or trust strangers as their dementia progresses. Under the absolutist approach, they must be free to reject the support of strangers at any time, regardless of the consequences.

With moderate dementia, the person may retain older memories while having great difficulty in forming new memories or comprehending current circumstances. Physical ability and mobility often remain while mental ability is declining. Often individuals with dementia cannot recognize or remember their own mental impairments, and do not understand why they should not engage in activities that put them in danger. Ordinary daily activities of routine life such as cooking, walking outside alone, and driving become risky. People who retain enough skill to drive badly, but cannot remember that they are prohibited from driving, or why, endanger themselves as well as others.34 (Treating such drivers just like other drivers by punishing them for driving without a license, as the Committee’s approach to discrimination would suggest, is not a useful solution.) Simply taking a walk outside may result in “wandering” away from the home (which the person may not understand as home) and create a range of risks depending on the situation, such as getting lost, exposure to the elements, criminal attack, and dangerous physical conditions that the person does not appreciate.35

Countermeasures against these dangers, such as hiding the car keys, selling the car,36 putting complicated locks on doors,37 getting GPS finders in shoes,38 and

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34 See Desmond O’Neill, “Driving and Dementia,” in Law and Ethics of Dementia; Mace and Rabins, 36-Hour Day, 56-60.
36 Ibid., 59.
37 Ibid., 148.
38 Ibid., 144; see Julian C. Hughes, “The Use of New Technologies in Managing Dementia Patients,” in Law and Ethics of Dementia (arguing for balance between risks and benefits in tracking dementia patients who “wander”).

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disarming the stove\textsuperscript{39} are all questionable under the absolutist approach to legal capacity. Under that approach, individuals should always have the right to make their own decisions, with or without support, and to make later decisions inconsistent with earlier ones. People with dementia should have the right to leave the premises at any hour of day or night in any weather, as people without dementia generally do, and preventing them would be arbitrary detention.\textsuperscript{40}

Advance care planning and durable powers of attorney may provide partial solutions to some of the dilemmas created by the absolutist approach. These legal instruments, adopted prior to the onset of dementia or in its early stages or before one’s judgment is impaired, allow individuals to make choices for the future, or to designate people they trust to decide as they would wish.\textsuperscript{41} But these documents have limitations, and the absolutist approach undermines their usefulness.

To begin with, many people who are already living with moderate or severe dementia lack these documents. Prospectively, healthy individuals who have less income or live in less developed societies face barriers to acquiring instruments tailored to their preferences. Even with resources, specifying future courses of action is difficult when unforeseen problems or new alternatives may arise.\textsuperscript{42} There may also be cultural barriers to these forms of legalized future planning.\textsuperscript{43}

Next, the CRPD Committee’s General Comment appears to contemplate a highly restricted role for advance directives, only for individuals who cannot communicate their current wishes, such as those in a coma, or those whose ability to communicate is severely obstructed and who have no one who can interpret for them. Otherwise, the individual’s current preference is what counts, and the individual must be free to override a directive at any time, or terminate it, by expressing a contrary choice. And of course all choices can be made with or without support.

\textsuperscript{39} See Mace and Rabins, \textit{36-Hour Day}, 70-71.

\textsuperscript{40} I recall the eloquent plea by a member of the Subcommittee on the Prevention of Torture, at a consultation convened by the Working Group on Arbitrary Detention in September 2014, that individuals in group facilities cannot be simply allowed to go out in winter without coats. The Working Group nonetheless chose to follow the absolutist approach of the CRPD Committee. See “Basic Principles,” para. 106.


\textsuperscript{42} That reality is particularly vivid to an author writing in the midst of the COVID-19 pandemic.

Experts on the CRPD Committee’s jurisprudence also explain that advance directives and similar documents cannot be drafted so that they become effective when the individual’s mental capacity reaches a particular level of impairment. Making the legal effect of the document depend on a finding about functional capacity is said to be forbidden discrimination, and individuals cannot be permitted to adopt such an instrument.

As an “older person,” I do not want to be condemned to the uncomprehending freedom of action that some disability advocates on and off the CRPD Committee would impose on people with moderate to severe dementia. If it should come to pass that my memory and my reasoning abilities are so severely damaged that I cannot perceive obvious consequences of my actions, I do not want every insistent impulse to be indulged as an exercise of my absolutely equal right to take risks. Nor do I want my freedom to plan against such a future to be limited by the CRPD Committee’s vision of absolute equality and the irrelevance of functional capacity to the ability to perform every particular act with legally binding effect. Nor would I impose that state of affairs on others.

To be clear, I do not contend that the current wishes of a person with moderate or severe dementia are irrelevant, or that they should always yield to someone else’s estimate of the person’s best interests. Rather, I am arguing that there are situations of serious harm where the individual’s uncomprehending choice should not be given the exclusive focus that the absolutist approach demands.

Moreover, the failings of the absolutist approach in dealing with dementia are indicative of a wider methodological problem in the CRPD Committee’s construction of doctrines to implement its Convention. The Committee’s absolutism is not the usual human rights approach, and certainly not the only human rights approach.

D Conclusion

The advent of the Convention on the Rights of Persons with Disabilities and the work of the CRPD Committee have contributed greatly to the protection of persons with disabilities and to the human rights system. Other courts and treaty bodies have gained insights from textual and oral dialogue with the CRPD Committee and have revised their own interpretations of other treaties to reflect those insights, though not always by accepting its conclusions.

Regrettably, the CRPD Committee has adopted an unrealistic and rigid absolutist approach to issues such as legal capacity and discrimination, and has insisted that
this absolutism constitutes the only human rights-based approach. As the example of dementia illustrates, the absolutist approach to decision-making can undermine the rights of many people it purports to serve. One can only hope that the dialogue will continue and that the learning will be mutual.