

PRACTISING SOCIAL CITIZENSHIP IN A CONTEXT OF COMPROMISED DECISION-MAKING CAPACITY: REALIZING AND PROTECTING HUMAN RIGHTS.

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Abstract

The UN Convention of Rights of Persons with Disabilities has provided a strong foundation for asserting a rights-based approach to practice for people with disabilities but people with dementia have often been excluded in these discussions. Specifically, within the interdisciplinary field of dementia studies a rights-based approach to practice is only just beginning to emerge. This approach moves toward a more politically and socially active stance for conceptualizing and responding to the dementia experience. Using the language of citizenship, there is increasing focus within dementia studies on challenging the tendency to dichotomize autonomy and protection, addressing stigmatizing practices, and finding ways to 'do' citizenship in the context of compromised decision-making. The purpose of this paper is to contribute to the further development of this approach by outlining a citizenship-in-practice framework and then examining the implications of implementing this approach in relation to understanding and assessing incapacity.

I INTRODUCTION

The United Nations Convention of Rights of Persons with Disabilities (CRPD),¹ has provided a strong foundation for asserting a rights-based approach to practice for persons with disabilities. Article 12 of the CRPD reaffirms the rights of persons with both physical and mental disabilities to enjoy legal capacity on an equal basis with others in all aspects of their lives, and puts the onus on the state to take appropriate measures to provide the *support* necessary for persons with disabilities to exercise legal capacity and realize their full human potential. The focus on a 'positive' right to support from the state (as opposed to the 'negative' right to non-interference) within Article 12 has established an important set of expectations around direct societal responses to the needs of persons with disabilities people with disabilities.

CRPD Article 12 has been heavily endorsed as a framework for guiding practice with younger persons with mental and intellectual disability, but less significantly less attention has been paid to Article 12 in relation to the needs of older adults with dementia. This is beginning to change, however, with the emergence of human rights based approaches to understanding the dementia experience.² Often using the language of

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¹ United Nations (2006) *Convention on the Rights of Persons with Disabilities* (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD).

² Deborah O'Connor and Ann-Charlotte Nedlund, 'Editorial: Citizenship and dementia special edition' (2016) 15(3) *Dementia: International Journal of Social Research & Practice* 1.

citizenship - social citizenship,³ active citizenship,⁴ and narrative citizenship⁵ e.g. - these rights based approaches posit that at least some of the loss and deterioration associated with a diagnosis of dementia (or major neurocognitive disorder as it is named in the DSM 5) is related to how persons with dementia are pejoratively understood and treated in their relationships with others and society at large. With the shift in focus from neurodegenerative loss to societal context, the importance of stigma and discrimination for shaping the personal experience of living with dementia takes center stage. Research is now beginning to identify the social experience of discrimination and stigma as comprising one of the most devastating and challenging aspects of living with dementia, an experience that can severely limit both functioning and quality of life for persons with dementia.⁶

While the importance of a social lens for expanding understanding is critical, it is also undeniable that the neurocognitive changes affiliated with dementia remain a powerful force for organizing the dementia experience. In other words, people with dementia will experience physiological changes and loss as a result of the disorder. Often, these changes will (at some point) lead to questions about the person's ability to make at least some decisions, creating ethical and legal tensions between balancing the person's inherent rights to independence and autonomy, with her or his rights to protection.

Notions of capacity or competence are generally invoked to help resolve some of these tensions.

At its core, the concept of mental capacity captures the simple intuition that we need to display a level of decision-making competence in order for our choices to be respected; it is a technical concept that assesses the following: can individuals understand and reason about the various options available to them? Can they understand the consequences of their decisions? Are their reasons internally consistent? Can they draw upon true as opposed to deluded beliefs?⁷

There is a burgeoning body of literature focused on understanding and assessing capacity. Over the past two decades, most discussions have begun to recognize the importance of moving from a global notion of competency to one which examines capacity as specific to a particular decision. Within this body of literature, there is clear consensus that this assessment of decision-making capacity (DMC) is complex and challenging: it is an area

³ Ruth Bartlett & Deborah O'Connor, 'From Personhood to Citizenship: Broadening the lens for dementia practice and research' (2007) 21 *Journal of Aging Studies* 107; Ruth Bartlett and Deborah O'Connor, *Broadening the Dementia Debate: Toward Social Citizenship* (London, UK: Policy Press, 2010).

⁴ L. Birk et al 'Shifting dementia discourses from deficit to active citizenship' (2017) 3(2) *Sociology of Health & Illness* 199.

⁵ Clive Baldwin, 'Narrative, citizenship and dementia: The personal and the political'" (2008) 22(3) *Journal of Aging Studies* 222.

⁶ Deborah O'Connor, Jim Mann and Elaine Weirsmas, 'Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship'" (2018) 44 *Journal of Aging Studies* 45; Kate Swaffer, 'Dementia: Stigma, language, and dementia-friendly' (2014) 13(6) *Dementia* 709.

⁷ Camilla Kong, *Mental Capacity in Relationship: Decision-Making, Dialogue, and Autonomy* (Cambridge, UK: Cambridge University Press, 2017) 11.

of practice for which many health professionals - including physicians⁸ and psychiatrists⁹ - often feel ill-prepared.

To facilitate a clearer and more informed process, a large body of research has been directed toward developing standardized tools for capacity assessment. These tools focus largely on *what* to assess from a neuro-cognitive perspective and some gold(ish) standards are emerging. However, there is still a long way to go¹⁰ particularly in relation to non-health-related decisions.¹¹

Beyond the focus on assessment content and tools, however, an even larger gap in knowledge is linked to the very limited attention that has been paid to considering the importance of the *process* for understanding and conducting the assessment. This is a particular issue given emerging legislative trends mandating the involvement of the person in decision-making to the extent possible, irrespective of capacity. For example, in England, the *Mental Capacity Act (MCA) 2005* is seen as ‘*enshrining a legal right to autonomy*’ for people with dementia even when they lack capacity, thus advancing civil and social rights through an emphasis on protecting liberty, promoting self-determination, and providing social rights to facilitate autonomy.¹² Similarly, in Canada, provincial legislation has been enacted that explicitly recognizes the rights of all people to be presumed capable, hence the focus is on assessing *incapacity* as opposed to capacity.

An emerging challenge then, is to understand what it means to exercise autonomy and rights in the context of impairment and disability.¹³ This is a particularly salient and thorny issue when considering the assessment of incapacity. The purpose of this paper is to take up this challenge by considering how a citizenship-in-practice framework can be used to facilitate an assessment of incapacity that is strength-based and empowering irrespective of findings about capacity. Drawing on the literature related to social citizenship, this paper will outline a citizenship-in-practice framework and then examine the implications of implementing this approach in relation to understanding and assessing incapacity.

II TOWARD A ‘CITIZENSHIP-IN-PRACTICE’ FRAMEWORK

Conventionally, discussions about decision-making capacity have been situated largely within the realm of cognitive pathology. The underlying assumption with this approach

⁸ F Skelton et al ‘Determining if an older adult can make and execute decisions to live safely at home: A capacity assessment and intervention model’ (May-June 2010) 50(3) *Gerontology and Geriatrics* 300.

⁹ L S Seyfried et al ‘Predictors of suicide in patients with dementia’ (2013) 7(6) *Alzheimer’s and Dementia* 567.

¹⁰ S Lamont, Y Jeon & M Chiarella, ‘Assessing patient capacity to consent to treatment: An integrative review of instruments and tools’ (2013) 22 *Journal of Clinical Nursing* 2387.

¹¹ Deborah O’Connor and Barbara Purves, eds. *Decision-making, personhood and dementia: Exploring the interface* (London, UK: Jessica Kingsley Publishers, 2009); Skelton et. al, (n 10); James Lai and Jason Karlawish, ‘Assessing the capacity to make everyday decisions: A guide for clinicians and an agenda for future research.’ (2007) 15(2) *American Journal of Geriatric Psychiatry* 101.

¹² Geraldine Boyle, ‘The Mental Capacity Act 2005: Promoting the citizenship of people with dementia?’ (2008) 16(5) *Health and Social Care in the Community* 529.

¹³ Kong (n 7).

is that decision-making is a reasoned activity and that there are certain cognitive capacities that are required in order to work through this activity. These include for example, an ability to understand material, to appreciate that it applies to one's self, to cognitively manipulate or use the information to come to a 'reasoned' decision, and/or to articulate a choice. An appraisal of cognitive functioning - which would include thought processing, perception, memory, judgement and intelligence - is an important part of the assessment of capacity.

Unquestionably it is important to understand cognitive issues that may interfere with decision-making. However, the sole focus on cognition is limited because it is premised on the flawed assumption that cognitive functioning can be understood independently and strictly as a function of the neurodegenerative change. Countering this assumption, convincing evidence is emerging that supports the recognition that how a person functions is indicative of both the degree of neurological change *and* that person's interactions with others, including how they are treated and perceived within their social context.¹⁴ This suggests that cognitive functioning is an outcome of both individual (neurocognitive) and interactional processes and, importantly, is not static. Rather, it is, at least in part, relationship and context dependent.¹⁵

A small but growing body of researchers and legal scholars are now taking the position that mental capacity must be conceived of as a relational concept:

...capacity assessments must also recognize the relational constituents of decisional capacity – how these can interact with and worsen biological factors affecting capacity. Most accept that physical accommodations are often necessary to promote the inclusion and autonomy of individuals with impairments, yet relational aspects – that is, the presence or absence of enabling, inclusive narratives – can equally affect one's decision-making abilities and practical agency.¹⁶

This work is largely grounded in the work of feminist relational ethics and challenges conventional notions of autonomy and independence. Using the language of relational autonomy, there is a recognition that most of us live in a condition of connections and interdependence throughout our entire lives so the tendency to dichotomize concepts like dependence and independence is overly simplistic and not useful.

Within the field of dementia studies, the focus on developing a relational understanding has had two, complimentary streams. The first, pioneered by the work of the late Tom Kitwood,¹⁷ positions personhood as relational and draws attention to the importance of

¹⁴ Deborah O'Connor et al 'Personhood in dementia care: Developing a research agenda for broadening the vision' (2007) 6(1) *Dementia: International Journal of Social Research and Practice* 121; Bob Woods and Rebekah Pratt (2005) 'Awareness in dementia: Ethical and legal issues in relation to people with dementia' (2005) 9(5) *Aging and Mental Health* 423.

¹⁵ Deborah O'Connor, 'Personhood and dementia: Toward a relational framework for assessing decisional capacity' (2010) 5(3) *The Journal of Mental Health Training, Education and Practice* 22.

¹⁶ Kong (n 7).

¹⁷ Tom Kitwood, 'Brain, mind and dementia: With particular reference to Alzheimer's disease' (1989) 9 *Ageing and Society* 1; Tom Kitwood, *Dementia reconsidered: The person comes first* (Buckingham, UK: Open University Press, 1997).

understanding the experience of living with dementia as a function of how one is treated by others. In other words, how competent a person with dementia looks and acts is often, at least in part, determined by how others see and treat him or her.¹⁸ This ‘relational’ understanding explicitly acknowledges the importance of one’s interpersonal relationships as both a precursor for promoting – or countering – the presentation of capacity, and as a lens for understanding and interpreting behaviours and decisions.¹⁹ While useful, this work is largely apolitical and focused on needs rather than human rights.

A second thread within dementia studies, one that draws its foundation more explicitly from political theory, uses notions of social citizenship to provide a foundation for conceptualizing a relational lens that is more directly human rights based. This lens extends understanding of the interpersonal to more recognize societal context. Once context enters the discussion, the importance of recognizing discrimination and oppression as a core aspect of the dementia experience comes to the forefront.²⁰

With the focus on stigma and discrimination, new questions emerge for understanding and exploring issues related to compromised decision-making when someone is diagnosed with dementia. A social citizenship lens offers a framework for beginning to consider these questions. Bartlett and O’Connor suggest that social citizenship is ‘...a relationship, practice, or status in which the person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible.’²¹ Operationalizing this definition draws attention to six components for doing social citizenship:

- Opportunity for growth;
- Acknowledgement of multiple social positions;
- Recognition of the importance of a sense of purpose;
- Participation rather than simply involvement in their own lives;
- The importance of a sense of connection and community; and
- Freedom from discrimination.²²

These components are both tier 1 and tier 2 human rights issues – they address both what needs to be protected (tier 1) and process issues (tier 2) in terms of how to go about realizing human rights. The remainder of this paper will draw on these components to consider how a human rights lens can be integrated into the process of exploring - and potentially removing - some aspect of someone’s basic rights to independence, self-determination and autonomy in a way that not only minimizes harm potential but ideally is empowering.

¹⁸ Steven Sabat ‘Capacity for decision-making in Alzheimer’s disease: Selfhood, positioning and semiotic people’ (2005) 39(11-12) *Australian and New Zealand Journal of Psychiatry* 1030.

¹⁹ O’Connor (n 15); O’Connor and Purves (n 11).

²⁰ O’Connor, Mann and Wiersma (n 6).

²¹ Bartlett and O’ Connor (2010) (n 3) 37.

²² Ibid.

A Recognizing Human Rights to Grow, Change and Develop

Conventional approaches for understanding the dementia experience often focus on maintaining or preserving aspects of personhood. While important, this lens fails to explicitly recognize that everyone, including those with dementia, have the right to grow and change. This includes the right to change one's mind, and to make different kinds of decisions (the vignettes appearing this paper are based on professional and research-based cases).

Mrs. Nolanger was diagnosed with dementia and decided to leave her husband of forty years. Her decision was attributed to her advancing dementia, and emphasis was placed upon supporting her and her husband in their own home. This included medicating her for depression and agitation. At no point did the health care team seriously query whether her decision to separate possibly reflected her own personal growth and development, that she had finally had enough of living with a man she described as selfish, irritable and who constantly belittled her. Three years later she was removed from a home that had become quite abusive.

An important aspect of an assessment of incapacity includes developing an understanding of the person's historical values, beliefs and judgments. This can provide important insights into decision-making. It is consistent with international trends toward the use of supportive decision-makers who are charged to incorporate the will and preferences of the adult into decisions rather than paternalistic practices of 'best interest' substitute decision-making.

However, what happens when someone with dementia begins to develop a different way of making decisions? Arguably, the default is to assume that any changes are a function of the dementia, that it is the diagnosis talking. Using a citizenship-in-practice framework, the challenge becomes to build an assessment that positions the person with dementia as a person with continuity pre-and-post diagnosis, *while simultaneously not precluding the possibilities of growth and change of mind.*

B Respecting Diversity in Personal Meaning-Making

Too frequently, one's identity as a person with dementia begins to supersede all other aspects of identity. Specifically, there is a tendency to treat people with dementia as a homogenous group, and a group that too often, is seen first-and-foremost as vulnerable and in need of protection. A citizenship-in-practice lens helps to counter this tendency by explicitly recognizing that all people occupy different social locations and these social locations are important for helping to situate personal meaning making.²³ In other words, one's position within one's familial, cultural and societal contexts are both relevant and important for understanding what is important to that person and how that person is responding to a particular experience.

²³ Ibid.

This has a number of implications in relation to the assessment of incapacity, one of which is to challenge how basic notions of ‘risk’ and ‘protection’ are used for understanding and taking action. In positioning people with dementia as a vulnerable, homogenous group, risk and protection are most frequently translated into physical terms and the goal becomes to keep the person with dementia physically safe from harm. There is a problematic assumption that the priority placed on physical safety is a shared societal value. The refusal to self-protect from physical harm is then seen as a demonstration of questionable capacity.

The following case exemplifies how understandings of risk and protection may be constructed differently based upon one’s specific social context.

Mrs. Harris is a tiny, very frail woman with deteriorating eyesight and memory loss. Widowed many years ago, she lives on a small pension in her one-bedroom basement apartment with her unemployed, middle-aged son. He has a longstanding history of serious mental health issues and has been noticeably deteriorating over the past several months. The police were called by the neighbours following a violent outburst by her son that left Mrs. Harris with a fractured foot and severe bruising. Mrs. Harris refused to press charges, declined the need for ongoing support, and promptly discharged herself from the hospital.

Because she denied that she was in any danger from her son, concerns were raised about her decision-making capacity. However, what became apparent in discussion with her was that she was actually quite aware of the risk of physical harm to herself, she simply did not prioritize this risk of physical harm to herself over her relational connection with her son. When asked, she was unequivocal that having him involved in her life was ‘absolutely’ more important to her ‘than anything’, even her own physical safety.

This case demonstrates the growing recognition that the emphasis upon self-determination and independence may be reflective of a particular Westernized, patriarchal value that is not shared by many women and those from other cultures. This is just one example of how socio-cultural positioning may influence meaning-making and sense of purpose.

A citizenship-in-practice framework for understanding and assessing decision-making capacity draws explicit attention to the diversity of socio-culturally laden values and beliefs that people with dementia bring into their experiences of living with dementia. These shape what matters to that person including what that person perceives as problematic and how they are considering both risk and consequences in their decision-making. In terms of the actual assessment, this suggests the importance of including questions directed at explicating how that person’s relational context and values are influencing his or her decision-making.

The importance of considering personal preferences, values and beliefs, is not restricted to a social citizenship-in-practice lens. For example, Moye et al²⁴ include this as an

²⁴ J Moye et al and ABA–APA Capacity Assessment of Older Adults Working Group, ‘A conceptual model and assessment template for capacity evaluation in adult guardianship’ (2007) 47(5) *The Gerontologist* 591.

important component of the assessment. However, with its focus on human rights, a social citizenship lens extends conventional guidelines to consider personal preferences, values and beliefs in two ways. First, it recognizes that these are shaped by broader socio-cultural contexts and hence need to be understood relationally. Second, and perhaps more radically, it encourages attention to power dynamics in the assessment process by recognizing that social positions are affiliated with power, marginalization and oppression. This suggests that for some, the opportunity to articulate personal meaning-making may be more practiced than for others. For example, Mrs. Harris' positioning as an Indigenous woman in a racially-colonized society may easily have silenced her in the presence of a male law enforcement officer. When applied to the conduct of the assessment, it highlights the importance of self-reflective questions such as: How are power dynamics limiting the ability of the person being assessed to express a personally meaningful choice or take action? How is the assessor addressing power dynamics in his or her relationship with the person being assessed?

C Promoting Active Participation

A third component of social citizenship-in-practice is the recognition that all persons have the right to participate in their own lives - and society at large - to the extent possible.²⁵ This component acknowledges the onus on the assessor to responsibly understand and respect both the remaining strengths and the potential limitations that are emerging as a result of the diagnosis. It has a variety of implications in both conducting and making sense of the assessment of decision-making capacity.

First, it sets the stage for considering how to meaningfully involve the person being assessed in the assessment process. Questions include: How is the time and setting of the assessment promoting - or deterring - active participation? Have steps been taken to minimize communication problems that limit involvement? In the fast-paced environment of modern social and health care, is the person with dementia being given adequate time to consider questions and respond?

John Liam worked his entire life as a logger in a remote area of the province. Now beginning to show signs of memory loss, his daughter was concerned about his ability to remain in his isolated community given its lack of support. He denied there were any concerns. When seen in the physician's office at the large metropolitan hospital, he was - probably quite understandably so - silent and disengaged. On those rare occasions when he did speak, he came across as belligerent and hostile.

A second set of questions that requires careful consideration relates to how - or if - to involve a support person in the assessment process. The importance of family in supporting persons with dementia has been widely recognized. However, recent research suggests that even with the best of intentions, persons with dementia may also feel silenced in the presence of the family member related to concerns about hurting their

²⁵ Bartlett and O'Connor (2010) (n 3).

care-partner, fear of reprisal in a situation of dependency, and/or a history of deferring to the more vocal other.²⁶ Furthermore, some tendency to accord higher credibility to the family member can be discriminatory to the person with dementia.

Drawing on a citizenship-in-practice framework for conceptualizing how to conduct the assessment includes exploring whether it would help or hinder to have a support person to be involved in process. This suggests that part of the process requires active questioning - for example, what is the preference of the person being assessed? However, it also requires careful observation for signs that the person is being silenced, whether intentionally or not.

D *Creating a Context: Challenging Stigma and Discrimination*

As previously noted, stigma and discrimination have been identified as a key aspect of the day-to-day experience of living with dementia. People with dementia report being discounted, treated like children, and/or feared because of their diagnosis.²⁷ Some research suggests that it is these discriminatory practices, more than the actual decline of the diagnosis, that limit the capacity of people with dementia to remain active, productive citizens.²⁸

Within the context of understanding decision-making, too frequently a diagnosis of dementia becomes conflated with incapacity.²⁹ For example, one man describes with anger the reaction of his broker to being told about his dementia:

My broker – I’ve been dealing with her for 25 years and she doesn’t call me anymore. She calls my wife. For 22 years, she never even talked to my wife once. My wife answered the phone and she always asked for me, even on her investments. As soon as my wife told her [the broker]... [that I have Alzheimer’s], I guess. And the next thing you know, she [the broker] doesn’t [talk to me] – she doesn’t do it on purpose.... that’s just the way it is. [emphasis original]³⁰

This discounting is not simply at the informal level- rather it is often implemented into institutional policies and practices. For example, a common practice of Ethical Review Boards is to require that a family member, physician or substitute decision-maker give consent for someone with dementia to participate in a research study as a precaution to protect the person’s rights. The assumption here is that the person with dementia is not capable of making this decision by virtue of the diagnosis.

²⁶ Elaine Wiersma et al, ‘Creating space for citizenship: The impact of group structure on validating the voices of people with dementia’ (2016) 15(3) *Dementia: International Journal of Social Research and Practice* 414.

²⁷ O’Connor, Mann and Wiersma (n 6).

²⁸ Towako Katsuno, ‘Dementia from the inside: How people with early-stage dementia evaluate their quality of life’ (2005) 25(2) *Ageing and Society* 197.

²⁹ Susan Behuniak ‘The living dead? The construction of people with Alzheimer’s disease as zombies’ (2011) 31(1) *Ageing and Society* 70.

³⁰ O’Connor, Mann and Wiersma (n 6).

It should go without saying - and yet nevertheless arguably does need to be said - that *ALL* assessments of decision-making begin with the presumption of capacity. Assessors need to be vigilant about insuring that their practices always reflect this presumption, that they are not inadvertently enacting dominant discriminatory discourses.

III CONCLUSION

Drawing on a citizenship-in-practice lens positions the person with dementia clearly as a person with rights whose experience is being relationally constructed within a broader social context. The rights of the person with dementia include being recognized as an interdependent, socially-located person with growth potential and the ability to participate meaningfully even in situations where decision-making capacity may be compromised. This approach is congruent with CRPD Article 12 and the support paradigm³¹ - based on ideas of ‘shared personhood’ and an acknowledgement of universal reliance on myriad supports to ‘help us forge our own pathways³²’ - seeks to maximise the extent to which a person’s legal agency reflects her or his will and preferences, regardless of their perceived or actual mental capacity.

An assessment of mental capacity drawing on ideas of relational autonomy and social citizenship will differ in at least two fundamental ways from a more conventional assessment. First, this approach recognizes that capacity is not static; it is performed within a relational context. The important role of the assessor as an engaged and reflective participant in the process, rather than a neutral observer, is highlighted. Second, by attending to the person being assessed as a full citizen, this lens helps to insure that the person with dementia is able to maximize her or his potential - promoting competence, strength and agency instead of a performance based on societally-induced, internalised oppression.

³¹ Lucy Series, ‘Relationships, autonomy and legal capacity: Mental capacity and support paradigms’ (2015) 40 *International Journal of Law and Psychiatry* 80.

³² Gerald Quinn and Anna Arstein-Kirslake, ‘Restoring the “human” in “human rights”: personhood and doctrinal innovation in the UN disability rights convention’ in Conor Gearty and Costas Douzinas, eds. *The Cambridge Companion to Human Rights* (Cambridge, UK: Cambridge University Press, 2014) 36, 38.