



Dementia in Critical Dialogue

CRITICAL DEMENTIA STUDIES

AN INTRODUCTION

Edited by
Richard Ward and Linn J. Sandberg



Critical Dementia Studies

This book puts the critical into dementia studies. It makes a timely and novel contribution to the field, offering a thought-provoking critique of current thinking and debate on dementia. Collectively the contributions gathered together in this text make a powerful case for a more politically engaged and critical treatment of dementia and the systems and structures that currently govern and frame it.

The book is inter-disciplinary and draws together leading dementia scholars alongside dementia activists from around the world. It frames dementia as first and foremost a political category. The book advances both theoretical and methodological thinking in the field as well as sharing learning from empirical research. Outlining the limits to existing efforts to frame and theorise the condition, it proposes a new critical movement for the field of dementia studies and practice.

The book will be of direct interest to researchers and scholars in the field of dementia studies and wider fields of health, disability and care. It will provide a novel resource for students and practitioners in the fields of dementia, health care and social care. The book also has implications for dementia policymaking, commissioning and community development.

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Critical disability and human rights approaches

Linda Steele, Lyn Phillipson, Kate Swaffer and Richard Fleming

Introduction

For people living with dementia, the COVID-19 pandemic highlights the pre-existing deep-rooted ageism and ableism, persistent social inequalities and precarity, and systemic problems of incarceration, violence, neglect and social isolation in care homes (Anand 2021; Dehm et al. 2021; Kontos et al. 2021; Peisah et al. 2020; Robertson and Travaglia 2020). These dire circumstances have been exemplified by media stories of people in care homes in nations such as Canada (Olson 2020) and Spain (Parra 2020) dying of COVID-19 or neglect after being abandoned by staff during the early months of the pandemic in 2020. The longer term neglect that has surfaced in the ‘shadow’ of COVID-19 (Sedensky and Condon 2020) has prompted renewed calls for recognition of human rights of people living with dementia and deinstitutionalisation of the aged care system, including through the provision of community-based housing, support and resources for people living with dementia (Herron et al. 2021; Knapp et al. 2021; Quinn 2021). These calls follow the longstanding leadership of dementia rights activists in the movement for greater recognition of equality, liberty and inclusion of people living with dementia (Dementia Alliance International 2016; Swaffer 2018) and increasing engagement with dementia human rights over the past decade by United Nations bodies (Devandas 2019b), civil society (Brown 2019; Flamm 2018) and scholars (Byrnes 2020; Cahill 2018; Green et al. 2022; Grenfell et al. 2022; Meenan et al. 2015; Mitchell 2018; Mitchell et al. 2021; Steele et al. 2019, 2021; Verbeek et al. 2021).

This chapter introduces lived experiences, critical disability studies scholarship and human rights as vital resources in understanding and challenging injustices associated with people living with dementia in care homes. We focus on challenging common, mundane and often invisible and taken-for-granted dimensions of care homes. Common features in the environmental design of care homes – dementia care units, locked doors and gates – give rise to confinement of residents with dementia and their separation from other residents and the broader community. These design features are compounded with negative and ambivalent staff and family attitudes

towards people living with dementia and their rights, lack of resources and supports available to people living with dementia, substituted decision-making laws to limit the movement, expression, autonomy, social experiences and well-being of people living with dementia in care homes, and government policies and funding structures that provide structural support and legitimacy to these arrangements (Steele et al. 2020, 2021). On the one hand, generally, these conditions are accepted as necessary and benevolent means of protecting people living with dementia, other residents and the general public (Dreyfus et al. 2018; Steele et al. 2020). However, on the other hand, human rights activism (Brown 2019; Devandas 2019b; Flamm 2018; Swaffer 2018) and scholarship (Green et al. 2022; Steele et al. 2019, 2020) have reframed the material, attitudinal, relational and legal dynamics of care homes as amounting to discrimination, segregation and incarceration that violate human rights to equality, legal capacity, liberty, and independent living and community inclusion. These two positions are often dialectically opposed, and the dominance of the former in government policy and dementia care provision makes it difficult to gain widespread support for human rights as a tool to guide transformation of the political conditions and everyday lives of people living with dementia.

This chapter begins with one of the authors (Kate Swaffer) discussing the lived experiences of people living with dementia of incarceration and segregation and their acts of everyday and organised resistance to these circumstances. It then draws on analytical tools from critical disability studies scholarship that support an alternative way of understanding care homes in terms of dehumanisation, segregation and incarceration. Critical disability studies scholarship is the focus of discussion because it has directly engaged with institutionalisation, coercion and control and is situated in radical anti-oppression politics. Next, the chapter explores human rights as providing transformative tools to address the segregation and incarceration in care homes that we illuminated through lived experiences and critical disability theory. This exploration centres on four dialectics presenting the conventional and human rights approaches to: (1) inequality and segregation of people living with dementia, (2) decision-making on incarcerating people living with dementia in care homes, (3) conditions of people living with dementia in care homes and (4) community living as an alternative to care homes. The UN Convention on the Rights of Persons with Disabilities (CRPD) is the focus of the discussion in this section because dementia is a condition giving rise to cognitive and other disability and the CRPD is the international human rights instrument specifically for disabled people. We conclude by reflecting on possibilities for engaging human rights to bring about transformational change.

People living with dementia in care homes – Experiences and activism

The lived experiences and activism of people living with dementia are the impetus for this chapter's exploration of injustices of care homes. In this

section, one of the authors (Kate Swaffer) shares her personal reflections – as an aged care nurse, family member and person living with dementia.

In 1977, in Australia, while working in an aged care facility (then referred to as a nursing home), Swaffer's professional experience as a qualified nurse was that people living with dementia were segregated in four-bed wards within a nursing home, and if mobile, they were strapped or shackled to beds or chairs. The design of nursing homes then, now referred to in Australia as residential aged care facilities (RACFs), was based on a hospital design, with long corridors leading to wards, and few if any single rooms. For Swaffer, this RACF was the first in Adelaide that she knew of, to build a designated locked unit for people with more advanced dementia. At the time, Swaffer believed it to be an advance in dementia care, as it meant the restrictive shackles and harnesses were removed, and confinement was reduced as the residents had some liberties to move around freely within the locked unit.

Years later, Swaffer was faced with being a legal guardian for three people in her close circle living with dementia requiring assisted living, and with the best of intentions found placement for each person in a RACF. Each person she was responsible for placing into 'care' consistently complained about having been 'locked in jail'. Her father-in-law asked every time Swaffer visited, which was daily, from day one of placement and up until he died, 'why have you put me in jail; you promised me this would be my home?'. He also regularly asked for his own key to his new home. The three people living with dementia in Swaffer's close circle complained about the poor quality of the food; they complained about the lack of access to the garden or to the outside in general; they complained about the lack of allied health services such as physiotherapy or dental care; they complained about the way they were forced into a routine that was clearly for the benefit of staff, and not respectful of their own preferences and pre-entry RACF routines, not aligned with the information provided about their personal preferences. They also complained often about the restrictive visiting hours, the lack of meaningful and personalised activities and the lack of exercise of any kind.

As their legal guardian, Swaffer had promised and was legally obliged to support these three family members, and to ensure they were being well cared for with respect and dignity. However, it was evident that those under her guardianship were being physically and chemically restrained and restricted in their individual freedoms, within an institutional setting which equated to incarceration.

It remains easy for families and guardians to fall into the ruse of believing a person's safety is more important than their autonomy, and more important than their legal and human right to be supported to live in their community. To deal with the many breaches of human rights, it has been necessary to take a rights-based approach to residential care, especially for people living with dementia. The stigma and myths surrounding people living with dementia mean they are automatically deemed to have limited capacity to make their own decisions, and it is deemed acceptable to incarcerate them, leaving their care to inadequately trained staff.

Dementia Alliance International (DAI) is a charitable organisation run by and for people living with dementia. Founded in 2014 it has members in 49 countries. DAI is the first organisation in the history of the Conference of State Parties Conference (CoSP) on the Convention on the Rights of Persons with Disabilities (CRPD) to have hosted a side event specifically focused on dementia, and in particular dementia as a major cause of disability. This was done not only to highlight dementia as a disability, but to emphasise the many violations of the rights of people living with dementia.

In a statement made at this conference (Dementia Alliance International 2019), Swaffer who herself lives with younger onset dementia and is a leading international dementia rights activist stated:

Approximately 7 years ago the Dementia Envoy for the World Dementia Council Dr Gillings said people with dementia may need to take to the streets and march on the steps of parliaments. This is the beginning of that march, so that people with dementia are not left behind in the 2030 Agenda [for Sustainable Development Goals].

Critical disability studies scholarship and people living with dementia in care homes

Informed by the lived experiences of people living with dementia just discussed, in this section we draw on threads from critical disability studies scholarship to reconceptualise the circumstances of people living with dementia in care homes in terms of ableism, dehumanisation, segregation and incarceration, and the CRPD.

Critical disability studies scholarship challenges the conventional approach to disability as an individual, natural, medical lack and instead explores how disability is constructed as undesirable because it is contingent on social, political and economic norms (Goodley 2017, see also Chapter 14). Ableism is premised on the political rather than medical causes of difference along dis/ability lines, serving to hierarchise people and populations on the basis of their relative 'fitness' and the benefit or burden of the individual to the overall well-being and prosperity of the nation. This conceptual hierarchy of 'fitness' means only some people in society – rarely those who are disabled – are considered deserving of access to property, resources, and legal protections to sustain life and flourish, and ultimately to recognition as full humans. Ableism gives rise to ontological violence – denying to people with disability a legitimate right to be recognised as humans and to exist (Steele and Frohmader 2021). Material violence and injustice against disabled people are justified on the basis that they do not have what Judith Butler refers to as 'grievable' lives (Butler 2004). They are ungrievable because 'disability is an unwanted existence [...] Their pain cannot be comprehended because their disability renders their bodies and lives devalued and, hence, incapable of eliciting grief' (Steele et al. 2020; see also Spivakovsky 2018).

Bringing the concept of ableism to the dementia context illuminates how people living with dementia are profoundly dehumanised in society and through care homes. They are viewed as not meeting cognitive social norms which is sometimes referred to as cognonormativity (or able-mindedness by Kafer 2013). This failure to meet these norms is associated with continuity over the adult life course of memory, comprehension, communication and personality, and age-related social norms of youthfulness, independence and productivity. When people living with dementia are perceived as failing to meet these norms, they are viewed as unproductive, nearly dead and an economic, emotional and physical burden on others (Aubrecht and Boafu 2020). They are dehumanised in a very particular way: by being associated with waste and death (Steele et al. 2021, p. 322).

In a neoliberal context, disabled people are seen as economically unproductive and dependent on others (Erevelles 2011; Goodley 2017). Their bodies instead become sources of economic extraction through warehousing in congregate residential and service settings (Ben-Moshe and Stewart 2016). Applying these ideas to the dementia context, we become alert to how the framing of people living with dementia as unproductive and a burden on families and the community is subverted into a source of economic gain through cost-efficient neglectful care and warehousing in care homes.

In being cast outside full humanness and political and legal subjectivity, disabled people are denied status as 'legitimate knowers' who can give meaning to themselves and their experiences (Liegghio 2013, p. 123). This is compounded even further when dementia occurs in older age, and intersects with ageism to compound stigma and discrimination (Werner and Kim 2021). This denial can be understood as violence in two respects. First, disabled people are seen as non-agential, vulnerable and in need of protection and are denied the status as political actors, capable of exercising resistance to legal and medical authority and their living circumstances (Beaupert 2018). Second, others are legally and socially authorised to decide on what happens to disabled people's bodies and lives, giving rise to non-consensual interventions such as medical treatment and institutionalisation. These interventions are understood as legal and non-violent, where they would otherwise be considered illegal and violent if done against a full (non-disabled) human (Steele 2014). Bringing these insights to the dementia context, ageing, chronic and mental illness and disability intersect to produce a particularly intense brand of epistemic exclusion (Matthews 2016; Young et al. 2019). Non-consensual confinement and physical and chemical restraints in care homes are accepted as non-violent and just, and as necessary responses to people living with dementia's expressions of distress, boredom and resistance which are pathologised as 'Behavioural and Psychological Symptoms of Dementia' or challenging behaviours. Swaffer (2019) argues that BPSD does not exist, and has been used as a form of control, against people living with dementia.

Critical disability studies scholarship provides tools to reconsider the places within which disabled people live. Disability residential centres,

mental health facilities and nursing homes which are conventionally understood as caring, protective and therapeutic spaces are reframed as ‘carceral’ (i.e. prison-like) spaces because they enable control and confinement *through* discourses and practices of care, protection and treatment (Chapman et al. 2014). Throughout their lives, some individuals are confined across a number of these sites, at times with seamless legal and systems transitions between them. Chapman et al. (2014) use the term ‘institutional archipelago’ to refer to the networked and interconnected nature of these sites of control and confinement. Bringing these critical insights to the dementia context, care homes can be understood as involving incarceration of people living with dementia, even though care homes are conventionally presented as benign and therapeutic settings. Moreover, if situated in the archipelagic context, care homes which house people living with dementia as well as older and younger people with other disabilities can be understood as one part of the bigger picture of control and confinement of disabled people, including if particular disabled people age out of or have support needs considered too great for other institutions, or if disabled people move into nursing homes when other institutional settings in which they were living close as part of deinstitutionalisation policies (Spagnuolo 2016). Thus, care homes are an important focus of critical scholarly work in conceptualising and challenging carceral control of people living with dementia *and* disabled people more broadly.

Critical disability theory also provides openings for disrupting and transforming these structural injustices. Liat Ben-Moshe (2013, 2020) explores the concept of abolition – a term conventionally associated with prisons – in the context of disability institutions. In popular discourse, the term ‘abolish’ means to put an end to something. In the care home context, its conventional meaning would suggest that abolishing care homes simply means closing down care homes, with no consideration of what comes next and of the alternative housing and support arrangements. However, in critical disability studies scholarship, abolition is more complex and is a process rather than an event – it is about building more just and equitable communities so institutions (for care, punishment, whatever reason) are unnecessary. We see in this approach to abolition the possibility of addressing many of the dynamics we have introduced earlier – the material conditions of segregation and incarceration as well as the cultural, legal and economic drivers that shape these material conditions.

Dialectic arguments and counter-arguments

In this section, we explore human rights as providing transformative tools that could be used to address the segregation and incarceration in care homes that we illuminated through lived experiences and critical disability theory. We do so with reference to the CRPD because this instrument directly addresses issues of discrimination, segregation and institutionalisation

as issues of inequality and structural injustice. While people living with dementia have historically not been the focus of analysis and application of the CRPD (Steele et al. 2019), there is growing momentum in the UN (Devandas, 2019a, 2019b) and civil society (Dementia Alliance International 2016, 2019) to utilise the CRPD in relation to people living with dementia, and specifically in the context of care homes.

Inequality and segregation: Biomedical difference vs equality

The term ‘dementia’ is derived from the Latin prefix ‘de’ meaning without and ‘mens’ which carries the meaning of brain, intellect, faculties and understanding. A common understanding of this is simply to be ‘out of your mind’. This label has informed and reflected the opinions of lay people since it was first used by Aulus Celsus who lived between 25 BC and 50 AD (Vatanabe et al. 2020). The identification of the causes of dementia as lying in identifiable and potentially understandable changes in the brain is relatively recent, dating back to the work of Alois Alzheimer in the early 20th century. The fact that this work is still far from complete and has not yet produced a cure for dementia, or a reliable means to prevent it, has left the views held by lay people relatively unchallenged. Some of the stigma surrounding dementia may in fact be informed by the biomedical view, underpinned by Cartesian thinking and the locating of personhood in the mind (Walrath and Lawlor 2019). In addition, both negative portrayals and publicity about dementia in the mainstream media have also historically contributed to public fear and a social construction of people living with dementia that is potentially both prejudicial and dehumanising (Behuniak 2011; Gerritsen et al. 2018).

One aspect of the lay view may be described as the belief that people living with dementia are so biomedically different from others that they must be obliged to accept treatment, irrespective of their wishes. A recent survey of attitudes to dementia involving interviews with 70,000 people from 155 countries (Alzheimer’s Disease International 2019) showed that the general public (averaged across the 155 countries) agreed to the statement that ‘It is better for people living with dementia to be forced into treatment with their doctor even if they do not want to go’ (male 47.8%, female 46.2%) (Alzheimer’s Disease International 2019, p. 51). Sadly, the general public’s belief was supported by that of the healthcare practitioners who reported that their colleagues ignore people living with dementia: 47.8% in high-income countries, 55.8% in upper-middle income countries and 43.5% in low-/lower-middle countries (Alzheimer’s Disease International 2019, p. 50).

The conventional approach to people living with dementia as naturally different reflects a medical model of dementia, which can instead be viewed as ableism and countered by the human rights argument that people living with dementia are entitled to equality and non-discrimination. Equality and non-discrimination are central to the CRPD – as a general principle, a substantive right and a thread running through all of the other substantive

rights in the CRPD (UN Committee on the Rights of Persons with Disabilities 2018, pp. 1–2). Article 5(2) of the CRPD calls on States Parties to ‘prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds’. The CRPD’s definition of discrimination extends to ‘structural or systemic discrimination’ which operates at the population level and is not reducible to the experiences of specific individuals (Pyaneandee 2019). States Parties are not only obligated to respond and prevent discrimination, but engage in positive steps at the individual and structural levels to realise equality. In particular, there is the obligation to provide reasonable accommodations.

The right to equality and non-discrimination provides a political tool to unseat the assumption of disability as a natural basis for inequality *and* gives rise to the expectation of entitlement to the resources and supports to realise equality. The UN Committee on the Rights of Persons with Disabilities refers to this as an ‘inclusive equality’ approach. This approach moves beyond formal legal equality to include fair redistributive, recognition, participative and accommodating dimensions (UN Committee on the Rights of Persons with Disabilities 2018, p. 3). Indeed, the former Chair of the UN Disability Committee, Theresia Degener, explains that this is grounded in human rights as universal and incapable of restriction on the basis of disability (2016, p. 4). Degener proposes that the CRPD advances a ‘human rights model’ of disability that is premised on ‘transformative equality’ (Degener 2016). Transformative equality ‘targets changing these structures and systems with a variety of positive measures’ (Degener 2016, p. 17). This suggests that nothing short of structural transformation of society, involving the abolition of care homes and the development of alternative living arrangements, shifts in resource allocation to ensure economic equity, and cultural shifts in how dementia is understood in society more broadly will fully realise Article 5 (Degener 2016).

Article 5 provides a political tool to challenge ableism and ageism at the core of segregation and incarceration of people living with dementia in care homes, and their subjection to violence, neglect and indifference within them. In particular, this Article supports an understanding of the systemic nature of discrimination against people living with dementia and the importance of addressing the material, legal and cultural dynamics of this. The right to equality and non-discrimination for people living with dementia provides the foundation for rights to autonomy, liberty and community living which we now turn to discuss.

Deciding about confinement: Incapacity to make decisions vs legal capacity

People living with dementia are often regarded as incapable of making decisions for themselves and thus experience discrimination in being denied

legal capacity. The ADI report (Alzheimer's Disease International 2019) showed that there was widespread agreement from the general public to the statement that 'It is important to remove family responsibilities from people with dementia so as not to stress them' (M 60.4%, F 56.7%) (Alzheimer's Disease International 2019, p. 51).

It would be misleading to represent these views as universal; however, there are clear cultural differences. When asked about whether people do things for you that you could do yourself because they know you have dementia, respondents living with dementia in upper-middle-income countries (75%) (Alzheimer's Disease International 2019, p. 25) reported higher rates of others doing things for them, in comparison to high-income countries (59.1%) (Alzheimer's Disease International 2019, p. 25) and low-/lower-middle-income (50%) countries. The highest prevalence of others doing things for respondents living with dementia that they can do themselves was in the South-East Asian region (87.5%) (Alzheimer's Disease International 2019, p. 25). As the cultures in South-East Asia are known, traditionally, to have a high regard for elders, it may be that this reflects a particularly strong version of what is probably a common cultural attitude that doing things that people can do for themselves is a sign of deference towards older people. Other research also reinforces the motivations of informal carers of people living with dementia as being rooted in love, reciprocity, filial piety, duty and obligation, regardless of culture (Greenwood and Smith 2019). These also suggest that the motivation for taking over responsibilities from the person with dementia is often well intentioned.

We also see evidence of discriminatory denial of legal capacity in the involuntary placement of a person living with dementia into residential care. Evidence for this may be found in the agreement to the statement: 'If I had a family member with dementia it would be better to move them to a nursing home even if they didn't want to go'. This was the response given by 25% of people living in high-income countries (Alzheimer's Disease International 2019, p. 54). Respondents were also more likely to force someone living with dementia into a nursing home if it was not a member of their family.

This conventional position can be challenged by Article 12 of the CRPD which is about equal recognition before the law. This involves persons with disabilities having their decisions recognised on an equal basis with others and being provided with the support they require to make decisions (also referred to as 'supported decision-making') (UN Committee on the Rights of Persons with Disabilities 2014, pp. 6–7). Supported decision-making must respect the 'rights, will and preferences' of disabled people (UN Committee on the Rights of Persons with Disabilities 2014, p. 4). Supported decision-making involves diverse strategies, including 'development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences' and facilitating advance planning (UN Committee on the Rights of Persons with Disabilities 2014, pp. 6–7). Underpinning

Article 12 is ‘universal legal capacity whereby all persons, regardless of disability or decision-making skills, inherently possess legal capacity’ (UN Committee on the Rights of Persons with Disabilities 2014, p. 6). Thus, converse to assuming people living with dementia are automatically unable to make decisions because of their disability, the assumption is instead that everyone *can* make decisions with the appropriate support and there is an expectation from governments that this support will be provided when needed (De Sabata 2020). The right to equality before the law is a ‘threshold right’ (UN Committee on the Rights of Persons with Disabilities 2018, p. 12) because having one’s decisions legally recognised is necessary for the enjoyment of other rights, such as liberty and independent living (UN Committee on the Rights of Persons with Disabilities 2014, pp. 8–9; 2018, p. 12). A key implication of Article 12 is that people living with dementia should be given the opportunity to decide where they live, rather than others deciding for them (UN Committee on the Rights of Persons with Disabilities 2017, p. 15).

Article 12 provides a political tool to challenge the epistemic violence arising from the conventional approach to people living with dementia as incapable of making decisions about where they live and what happens to their bodies, and as requiring others to make decisions on their behalf in order to protect them.

We now turn to discuss decisions to detain people living with dementia in care homes, and then the opportunity for them to choose where they live in the community.

Conditions of confinement: Safety and security of self and other vs liberty and freedom from violence

Fear of persons living with dementia is widespread. The ADI survey revealed that the general public (averaged across the 155 countries) agreed with the statement ‘A person living with dementia is impulsive and unpredictable’ (M 61.2%, F 65.8%) (Alzheimer’s Disease International 2019, p. 51). A substantial proportion of the general public take this further by agreeing that ‘People with dementia are dangerous more often than not’ (M 18.9%, F 20%) (Alzheimer’s Disease International 2019, p. 51) and ‘People with dementia pose a risk to their neighbours unless they are in a hospital or nursing home’ (M 17.2%, F 15.3%) (Alzheimer’s Disease International 2019, p. 51).

The conventional understanding of people living with dementia as safe and secure through confinement in care homes can be challenged by Articles in the CRPD that centre liberty and freedom from the violence and harm associated with confinement. Article 14 of the CRPD provides for the right to liberty and security of the person. It requires that States Parties ensure that people with disabilities, on an equal basis with others, ‘[e]njoy the right to liberty and security of person’ and ‘[a]re not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no

case justify a deprivation of liberty'. Deprivation of liberty occurs when individuals 'are confined to a restricted space or placed in an institution or setting, not free to leave, and without free and informed consent' (Devandas 2019a, p. 10). Deprivation of liberty is unlawful where there is no legal order in place permitting their confinement, and it is arbitrary (in the sense of being 'imposed in a manner that is inappropriate, unjust, disproportionate, unpredictable, discriminatory or without due process' (Devandas 2019a, p. 10)) if confinement occurs on the basis of disability because this is discriminatory (even if pursuant to law) (Devandas 2019a, pp. 10–11; see also UN Committee on the Rights of Persons with Disabilities 2015, pp. 1–2). Detention of disabled people that is based on 'danger to self or others', 'need of care' or 'medical necessity' will also constitute arbitrary detention for the purpose of Article 14 (Devandas 2019a, p. 11).

The UN Disability Committee has identified the right to liberty and security of the person as 'one of the most precious rights to which everyone is entitled' particularly for people with cognitive disabilities (UN Committee on the Rights of Persons with Disabilities 2015, p. 1). The UN Disability Committee has stated that individuals who are deprived of their liberty in violation of Article 14 must be assisted in their release from the premises, with provision of 'access to housing, means of subsistence and other forms of economic and social support' and 'compensation, as well as other forms of reparations' (UN Committee on the Rights of Persons with Disabilities 2015, p. 7).

This right could provide a political tool to challenge the carceral nature of care homes even where that confinement is framed as purportedly benevolent, and to demand the end to the incarceration of people living with dementia. Indeed, recent reports by the UN Special Rapporteur on the Rights of Persons with Disabilities (Devandas 2019a, 2019b) have recognised deprivation of liberty in relation to older disabled people.

Article 15 on freedom from torture, inhuman and degrading treatment and Article 16 on freedom from violence provide political tools to challenge the assumption of the inherent physical and psychological safety and non-violence of care homes, including specifically in relation to use of restrictive practices. Yet, in order for people living with dementia not to be confined and segregated through care homes, we must also unseat the assumption that their inclusion in the community is burdensome, as we now turn to discuss.

An alternative future of community living and inclusion: Social and economic burden vs independent living and community inclusion

Perceiving the person living with dementia as essentially different, incapable of making decisions and potentially dangerous lays a firm foundation for seeing them as social burdens and responding by isolating and incarcerating

them. This is consistent with the view of stigmatisation as a process which starts with the labelling of difference and stereotyping, both of which underpin the normalisation of both individual behaviours of ‘separation’ and eventually institutional forms of discrimination (Link and Phelan 2001). For example, people living with dementia responding to the ADI survey (Alzheimer’s Disease International 2019) reported that being excluded from socialising, hobbies or attending events is a widespread response. Respondents living with dementia in high-income countries (38.1%), upper-middle-income countries (57.1%) and low-/lower-middle-income (50%) countries reported experiencing this form of unfair treatment because of their dementia (Alzheimer’s Disease International 2019, p. 25). Respondents reported feeling ‘avoided’, ‘ignored’ and ‘ostracised’ in their social life due to having dementia where many of them ‘no longer get invited to social gatherings’ (71-year-old female from the United States of America) (Alzheimer’s Disease International 2019, p. 25).

The conventional understanding of people living with dementia as a burden on the community can be challenged by Article 19 of the CRPD which provides the right to live independently and full participation in the community. ‘Independent living’ means that ‘individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives’ (UN Committee on the Rights of Persons with Disabilities 2017, para. 16(a)). Being ‘included in the community’ has been explained as having access to support in order to ‘be fully included and participate in all spheres of social life’ (UN Committee on the Rights of Persons with Disabilities 2017, p. 4).

In recognising the discriminatory nature of institutionalisation, the UN Disability Committee has emphasised the circumstances that can force people into ‘choosing’ care homes, stating: ‘Institutionalization is discriminatory as it demonstrates a failure to create support and services in the community for persons with disabilities, who are forced to relinquish their participation in community life to receive treatment’ (UN Committee on the Rights of Persons with Disabilities UN Disability Committee 2018, p. 14). At a structural level, realising Article 19 includes repealing laws that restrict choice about where disabled people live, implementing deinstitutionalisation policies, and reallocating resources so as to have available a range of supports and accommodations for community living and participation. At an individual level, meeting the obligations in Article 19 involves freeing people from institutions and providing support to people with disabilities to make choices as to where they live (UN Committee on the Rights of Persons with Disabilities 2017, pp. 4–5).

The significance of Article 19 should not be understated; it provides a political tool for challenging not merely the incarceration in care homes of individuals living with dementia but the entire system of care homes, the systematic warehousing of people living with dementia and the institutional archipelago more broadly. It encourages us to be ambitious in activism and

critical thinking, and focus on demanding a world without care homes *and* where people living with dementia are included and supported within the community.

Conclusion

This chapter has offered some analytical and political tools to articulate and dismantle individual and structural harms experienced by people living with dementia in care homes. It has challenged the assumption that care homes are therapeutic, benevolent and benign by instead highlighting the carceral character of care homes and how they fit within broader dynamics of dehumanisation, discrimination, segregation, incarceration and violation of people living with dementia at the intersections of ableism, ageism and neoliberalism. Indeed, entry into care homes is also coercive as there are often few alternatives to institutional facilities when someone does require assisted living accommodation. By approaching dementia as a disability, the chapter explored how human rights and specifically the CRPD provide both a political framing of care homes as unjust and strategies to realise transformative change.

Perhaps for some readers the approach to dementia and care homes taken in this chapter might be confronting or unsettling and the hurdles to change the status quo might seem overwhelming or insurmountable. However, we close this chapter by reassuring readers that this is not an inevitable response. For the past 40 or so years, addressing segregation and incarceration in residential settings has been a primary focus of activism and policy development in the context of disabled people more broadly, and much can be learned from successes and failures of these experiences. Moreover, in the past decade since the coming into force of the CRPD, a rich body of theory and practice has developed around supported decision-making and deinstitutionalisation (of large and smaller disability residential settings), particularly in relation to people with intellectual disability, thus giving strategies for change that could be developed in the context of people living with dementia. Ultimately, if we approach dementia as a disability, another reality of equality, dignity and inclusion is possible.

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13 The carnival is not over

Cultural resistance in dementia care environments

Andrea Capstick and John Chatwin

Introduction

To be means to communicate dialogically. When dialogue ends, everything ends. Thus dialogue, by its very essence, cannot and must not come to an end.

(Bakhtin, 1984: 252)

Within the dominant biomedical model of dementia, disorders of language (such as dysphasia, aphasia and perseveration) feature prominently among diagnostic criteria. In this view, changes in ability to produce coherent speech or understand the speech of others are considered to be a direct and inevitable result of neuropathology. The alternative psychosocial account of communicative challenges in dementia places emphasis largely on problems with social positioning that arise in interpersonal communication between people with dementia and 'healthy others', as Sabat (2014) somewhat problematically terms them. Less emphasis has been placed on people with dementia as social actors who create meaning and draw on contextual clues in order to give shape to their interactions. In this chapter, we draw on Mikhail Bakhtin's concepts of the carnivalesque, heteroglossia, polyphony and dialogism to analyse a series of interactions involving people with dementia in day and residential care environments.

We spent significant amounts of time in each care environment discussed below, getting to know the people who lived or spent their time there. One of the main outputs from the first study described below as Care Environment 1 was a short film about the local city market, made with two women at the day centre in question. The second project involved a number of people from Care Environment 2 in the development of a short film to be used in practitioner education. In the final study (Care Environment 3), the participants co-produced individual short films about subjects of personal interest to them.

We will not describe the three studies in detail. Instead we want to discuss how spending time with people in such environments has increased our

understanding of the communicative challenges faced, and the strategies employed, by people with dementia in group care settings.

Discourses on communication and dementia

We might identify three specific discourses on language and communication in dementia. They can be described respectively as dominant, alternative and emergent. The dominant biomedical discourse attributes all actions and behaviour of the diagnosed person to the progression of neurological disease. The alternative, psychosocial discourse recognises that communication with others in a social environment is also part of the picture. A more recent and still-emergent socio-political discourse recognises that much of the verbal and non-verbal communication of people with dementia is agentic, either as a protest against their situation or as a way of keeping a sense of personal identity alive in unpropitious circumstances.

Biomedical discourse

Within the biomedical standard paradigm, problems with language are among the criteria required for a diagnosis of dementia (American Psychiatric Association, 2013). In biomedical texts, the utterances of people with dementia are often reported as symptomatic of their condition. In this view, also, there is a typology of language disorders, including dysphasia (word finding problems), aphasia (absence of speech) or perseveration (repetitive speech) which are considered to be solely the result of neuropathology in localised areas of the brain, independent of any environmental factors. Studies of dementia conducted within this deficit-focused paradigm have typically examined language elicited through standardised clinical tests or as a part of interviews or conversations with a researcher (see, for example, Shao et al., 2014; Weakley and Schmitter-Edgecombe, 2014). The focus of research is generally on the prevention or management of 'inappropriate' forms of communication on the part of the person with dementia, e.g. 'verbally disruptive' behaviours in nursing home residents (Randall and Clissett, 2016).

Psychosocial discourse

An alternative model of communication in dementia is grounded in humanistic psychology. Here, it is pointed out that the psychological needs of a person diagnosed with dementia remain unchanged, and that the responses and actions of others to that diagnosis can have a significant impact on the individual's well-being and sense of identity. From this psychosocial perspective – since the environments in which people with dementia find themselves are often less than ideal – word-finding problems are also recognised, at least in part, as the result of stress and frustration, absence of