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Supported everyday citizenship: widening the discourse to include persons living with intellectual disability or dementia

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ABSTRACT

In this article, we focus on supported everyday citizenship to widen the discourse of citizenship including persons living with intellectual disability or dementia. Support in everyday contexts is an essential aspect of social work practices. Supported everyday citizenship is defined as a relational concept for enhancing the social and political participation of persons with disabilities in need of welfare services. The idea can be traced back to five existing bodies of knowledge. These are (1) supported decision-making, (2) sociology of the everyday, (3) lived citizenship, (4) inclusive citizenship and (5) human rights. In this article, we approach supported everyday citizenship as a unifying perspective and lens through which the relationalities of persons with an intellectual disability or dementia can be understood in a welfare context. As such, the article adds to the current debates within professional practice and social work studies by exploring how supported everyday citizenship can be reconsidered and strengthen equal citizenship for persons who are service users.

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Introduction

Supporting everyday citizenship is an essential process in social work practice, but it can be a complicated one. Everyday citizenship means to engage in the mundane aspects of daily life, like getting dressed and exercising, with agency and a sense of belonging (Sund, Jaeger Fjetland, and Hanisch 2023). The process can be complicated for anyone with a cognitive disability, including people with intellectual disabilities or neurodevelopmental disabilities and people with dementia because of the individualistic understandings of citizenship that have been dominant in western cultures (Lid, 2020). Cognitive impairments influence upon the person's autonomy and cognition to varying, and in the case of most dementias, progressive degrees. This implies that people with a cognitive disability, including dementia, are likely to need support to enjoy everyday citizenship, including engaging in daily tasks like deciding what to wear and looking after oneself. We thus present and discuss different dimensions of citizenship for persons with intellectual disability or dementia in this paper, using particular examples. Citizenship here is not understood different than for the general public, the difference lies in the support dimension that is necessary for realizing citizenship for these persons.

A mundane activity like getting dressed is a basic accomplishment expected of citizens every day. To participate in society – to go to college, work, a care centre and so on – one must first get dressed in suitable apparel. Similarly, taking care of oneself (e.g. eating well, exercising, not smoking) is an important responsibility for denizens worldwide, as it helps to reduce demand on state resources.

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Any mundane activity that links us to the wider public sphere and collectives is best considered a facet of everyday citizenship, rather than simply an individual act of agency. We engage in them, in part, to be a ‘good citizen’. A point echoed in the literature on lived citizenship. Lived citizenship refers to people’s daily, mundane lives and how the political manifests within informal and domestic spaces, with ‘the political’ defined as any act, or usurpation, of human agency vis-à-vis one’s status, rights and responsibilities as a citizen (Kallio, Wood, and Häkli 2020). For example, a person living with dementia might take it upon themselves to modify their home to make it more accessible (this is agency). If they share the experience on social media and raise awareness (this is lived citizenship). We return to the idea of lived citizenship later but have introduced it now to explicate what ‘everyday citizenship’ means and to show its parameters.

The idea of lived citizenship takes no account of capacity or support needs and cognitive ability is presumed. Hence, this offering of ‘everyday supported citizenship’. The nature of support for everyday citizenship will vary and could include a trained advocate, education, professional practice, assistive technologies and individual devices such as mobility aids. Efforts have been made in social work scholarship to recognize and include persons with cognitive disability (Björne 2020; Fjetland, Gjermestad & Lid 2022; Sépulchre 2017), and policy exists to protect the human rights of people with cognitive disabilities (Gooding, 2013) including the Human Rights Treaty adopted by the United Nations (United Nations 2006). Unfortunately, there are deeply rooted barriers to implementing these policies into practice.

One barrier is the ‘long standing heritage of Othering that social work has practiced’ whereby clients are positioned as vulnerable and professional staff as powerful (Chambon 2013, 127). A power imbalance that is clear in language. For example, common phrases such as ‘*the elderly*’ and ‘*the vulnerable*’ are othering and serve to perpetuate the idea that certain people are different and detached from the rest of the population. Another barrier is the lack of knowledge about lived experience, including the experience of being represented by others. People with a cognitive disability often need to be represented by others due to diminishing decision-making capacity (Holmqvist, Eriksson, and Tideman 2023). A practice that brings to the fore questions about the power and responsibility of the representative, but also issues concerning what it feels like to have limited autonomy and control over one’s life. However, to date, research has tended to focus on the experience from the professional’s perspective (Holmqvist, Eriksson, and Tideman 2023). Hence, in this article, we seek to broaden the analysis and discussion of what supported everyday citizenship means for people with cognitive disabilities, including dementia. Our intention is to reignite and advance the disability agenda in social work studies by providing a unifying perspective – namely, supported everyday citizenship.

This conceptual article discusses the meaning and application of supported everyday citizenship in relation to people with a cognitive disability, including people with intellectual disabilities or neurodevelopmental disabilities and people with dementia. This article has both an analytical and normative aim. Our rationale for focusing on people with cognitive disabilities, including dementia, is to give due consideration to capacity issues and to the significance of relations and professional ethics for everyday citizenship. There are, of course, similarities and differences between people with intellectual disabilities or neurodevelopmental disabilities and people with dementia. One similarity is that both groups are often subject to the biomedical paradigm – the language of ‘client or service user’, ‘therapy’ and ‘treatment’ are frequently used in relation to people with intellectual disabilities or neurodevelopmental disabilities and people with dementia. A significant difference is that a person is born with an intellectual disability – it is a congenital diagnosis – whereas a person with dementia receives this diagnosis most often later in life. Such parallels and variances are relevant because they indicate how the idea of supported everyday citizenship merits more attention, in both a theoretical and empirical sense. The discussion draws upon two empirical examples found in pedagogical material and research literature.

The article proceeds in three steps as follows. First, we begin by elaborating on the context. This involves framing disability through a citizenship lens before introducing the idea of supported

everyday citizenship through two real-life examples of persons with intellectual disabilities or dementia in a relational welfare context. Second, we explicate five bodies of knowledge that supported everyday citizenship can be traced back to. In this section, we expand on the relational aspect of the concept. Third, the idea of supported everyday citizenship is broken down and each of the three concepts are discussed in turn. Several important questions are raised here, including: what is meant by *supported*, in the idea of *supported everyday* citizenship and how this can inform traditional understandings of citizenship, and how practicable is supported *everyday* citizenship?

Framing disability through a citizenship lens

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is considered by many as a powerful starting point for re-framing disability in terms applicable to persons living with a disability. The CRPD understands disability in terms of ‘a long-term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder their [persons with disabilities] full and effective participation in society on an equal basis with other’ (United Nations 2006, 3). It applies to everyone, including citizens living with an intellectual disability or dementia. Implicit in the convention is the importance of the everyday, such as where you live and who you live with (Article 19). Relational support as a tool to enable a fully inclusive citizenship is what we propose and discuss in this paper.

Despite the global appeal of the CRPD – it has been ratified by 186 countries as of May 2022 – some scholars question whether it embraces the entire disability community. For Grue (2019) elaborations of disability implied in the Convention are dependent on normative comparisons between the lives of people with and without specific impairments or chronic illness (16). He argues that the Convention is ‘lacking in terms of true recognition of human diversity’ and its definitions of ‘impairment’ and ‘barriers’ are contestable and context specific (10). As with all attempts at describing a phenomenon, it takes place in relation to a ‘specific system’, such as the legal system, education, health care and the labour market (Michailakis 2003, 224). As such, it is important to be aware of one’s perspective and to ‘strive for better, more subtle distinctions’ (Michailakis 2003). Despite the perceived imperfections and criticisms of the Convention, it provides a vitally important role in promoting the status and rights of people with a disability in all areas of everyday life.

Implicit in the CRPD is a recognition that how we understand disability transforms how we respond to it (Series 2019). In recent years, framing dementia as a disability (as opposed to a medical condition) has been heralded as a panacea to the many social problems facing citizens living with dementia, including discrimination, lack of social care and suitable housing options (see, for example, Alzheimer’s Europe 2017; Steele and Fleming 2020). Framing dementia as a disability is by many considered a positive step because it helps to transform the identity of a person with dementia from a ‘patient’ to an equal citizen with rights and freedoms. However, it is not widely accepted or operationalized and may stand at odds with how dementia is perceived by people with dementia themselves.

In the context of the European Union, persons with disability have been referred to as ‘invisible citizens’ (Morgan and Stalford 2005, 98). This is because societal conceptions of family, work and community tend to exclude persons with disability. According to one disability scholar, persons with intellectual disability experience ‘civil death’ in that other people assume responsibility for their civil and social rights (Quinn 2015). Similarly, ‘social death’ – when someone is deemed dead socially when they are alive – is a phenomenon also associated with persons with dementia (Brannelly 2011). Thus, the neglect of persons with disability is both political and practical, limiting personhood and everyday life opportunities for these citizens. The concept of supported everyday citizenship provides a new perspective on inclusion, and in particular, inclusive citizenship. Building on Lister’s idea of inclusive citizenship and the idea of citizenship as a ‘momentum concept’, meaning that the concept must be constantly reworked to realize its egalitarian and anti-

hierarchical potential (Lister 2007, 49), we here attend to the concept reworking and redefine it in a disability perspective.

Supporting everyday citizenship in professional practice

Supported everyday citizenship can be defined as a relational concept for enhancing the social and political participation of persons with disabilities in need of welfare services. By *relational*, we refer to support provided in a relation between a person who receives services and person (s) who organize or provide (s) that service. Support may also be provided by friends and family members. To enable supported everyday citizenship for persons with intellectual disability or dementia, relational support needs are understood as and facilitated in the best interests of the service recipient (as opposed to the organizer or provider). Supported everyday citizenship is, however, about more than recognition of difference it is also about personhood and equal status. Included in not only everyday decisions but also how to provide support in everyday situation. Such support is often provided by professional service providers. Therefore, supported everyday citizenship also concerns professional ethics.

Relationality has always been a critical concept in social work studies. Work on care ethics by Tronto and others underlines the importance of interpersonal dynamics in care giving practices. Critically, the idea of ‘relational citizenship’ goes beyond the ethics of care because it presupposes that people become citizens through social interactions (Pols 2016, 177). In this context, relationality draws attention to the nature of citizenship of persons vis a vis the state – that is, having rights as well as responsibilities as citizens. Take for example, empirical work conducted in Finland on lived citizenship and the ‘relational modes of practicing political agency’ (Kallio, Häkli, and Bäcklund 2015, 101). This work advocates for bringing groups of people together for participatory work in spaces that are meaningful locally, rather than ‘official’ places. As these authors argue: ‘the everyday environments that are meaningful to children and young people differ greatly from those where their participatory agencies are institutionally supported’ (20). In the context of supported everyday citizenship and persons with intellectual disabilities or dementia, relationality relates to the daily modes of practice, dynamics and interactions in welfare spaces.

Supported everyday citizenship is thus a concept in which human factors are central. Scholars have pointed at the history of exclusion persons with disability have experienced and consequently been calling for the development of citizenship in relation to disability (Sépulchre 2017; Waldschmidt and Sépulchre 2019). Such work highlights the need to consider ‘the complexity of personal and social situations of persons with disabilities’ rather than see individuals in isolation (Sépulchre 2017, 954). For persons with disabilities who use welfare services ‘the distance between law and lived reality, between ideal and practice relations’ is vast (Hirschmann and Linker 2015, 2). Hence, any development of citizenship in relation to persons with disabilities must factor in the daily relational dynamics between a person who receives services and person(s) who organize or provide(s) that service. Foregrounding this relationality, we would suggest, is key to understanding and advancing citizenship in the context of persons with intellectual disabilities or dementia in need of welfare services.

Empirical examples of supported everyday citizenship

In the following examples, supported everyday citizenship is presented as lens through which to understand the relationality between a person who receives services and person(s) who organize or provide(s) that service. The first example concerns an adult man – Jan – possibly in his 40s, with an intellectual disability living in his own home in Norway. Here, our interest is in the relational dynamic between Jan and his two professional service providers. The second example concerns an adult – Jamie aged 94, who is no longer able to express a consistent preference about their gender due to moderate dementia. Jamie lives in a nursing home in Canada. The

example is about the professional dilemmas that care practitioners face when a person is confused about a key aspect of their identity – namely, gender. Our focus is on the person being represented and their representative – Jamie’s daughter. Both examples are about appearance and have been selected to highlight the complexity of supporting everyday citizenship in professional practice. Our intention is not to cast judgement on formal care practices but to highlight the citizenship negotiations and struggles of persons with intellectual disabilities or dementia in a relational welfare context.

In terms of research ethics and integrity, it is important to note that these are not *our* empirical examples. Both cases have been selected from publicly available, open sources, and are used here to exemplify the points we want to make about the complexities of supporting everyday citizenship in practice. We do this in line with the European Codes of Conduct for Research Integrity, which focuses on research (i.e. knowledge creation and conceptual development) as a common enterprise and involves drawing on the work of the community of researchers. For this article, we found it useful to think about the complexities of supporting everyday citizenship by drawing on available sources of practice. As with the first example, we recognize that transporting it from a pedagogical context into a theoretical one might have ethical implications. However, we will argue that because it is an example that is used in social work education it is relevant to use the example to develop the concept of supported everyday citizenship.

To the first example about Jan then. This is a film vignette which comes from a digital teaching session about service delivery to persons with an intellectual disability living in their own homes made by NAKU (NAKU 2022). NAKU is a Norwegian national centre of competence on services for persons with intellectual disability. NAKU develops and offers a range of training resources for providers of services for persons with intellectual disability. Through this provision, NAKU aims to serve as a hub connecting policy, research and practice. The example is the content of one of the film vignettes made for an e-learning programme called ‘My home – My workplace’ (NAKU 2022). The film and e-learning programme are available at <http://naku.no/node/1341>. The programme focuses on challenges related to interactions between persons with intellectual disability and their staff as seen from both perspectives. Persons with intellectual disabilities were involved as willing co-researchers in all stages of the project, including the development of the constructed film vignettes (Hellzen, Haugenes, and Østby 2018).

The specific film in question features Jan getting ready to go out to a party. Two service providers are in Jan’s home assisting him to get ready. The first service provider, a woman, gives him his tie and says that he now must take a shower and shave. Jan responds that he does not want to shave, he wants to grow a beard. She refers to an agreement he has signed in which it states that he is supposed to shave. She leaves, at which point a second service provider, a young man enters the apartment and asks if Jan is ready for party and assists him with the tie. He takes a closer look at Jan and notices that he has not yet shaved. The same interaction is repeated, the service provider refers to the agreement and Jan responds that he wants to grow a beard. However, this time the persistence of the service provider is even stronger, saying that he is not allowed to go to the party without shaving first. At the same time, the service provider performs an expression of power, putting his arm on the shoulder of Jan, turning him around and moving towards the bathroom.

In the film, there is no explanation as to why the service providers find a written agreement more important than Jan’s will. Nor is it clear whether the part in the agreement about shaving was initiated by Jan or the service providers; we suspect it was the service providers wanting Jan to appear ‘decent’. The film was made for service providers to stimulate learning about professional knowledge and professional ethics. As such, the emphasis is on the role of the service provider and exercising judgement in a given situation. The relational dynamic is curious though, as there is nothing ‘wrong’ with a man wanting to grow a beard; it is a personal preference about appearance. Jan, as a man, wants to appear as many other men, with a facially gender-specific look. In a non-

welfare relational context, Jan would be free to grow a beard. Yet, the service providers working for him do not pay attention to his expression of subjective will. Jan is opposing making it clear what he wants. By doing so, he is also claiming subjectivity, claiming his voice in the situation and seeking to take power over the former agreement.

The second example comes from a published case report about gender dysphoria – a marked incongruence between one’s experienced/expressed gender and assigned gender (American Psychiatric Association [APA], 2013). The case centres on Jamie who is described in the report as:

(A) 94-year-old biological male with a history of gender dysphoria and moderate cognitive impairment. Jamie had been living as a woman since the age of 80. She was married to a female for 66 years, and her wife passed away when Jamie was in her late 80s. The couple had one daughter together. Jamie lived at a long-term care facility and was referred to psychiatry after she began expressing confusion to the staff regarding whether she was male or female. The staff wished to have some direction in how to approach this patient’s gender role— what pronoun should they use? Should her clothing and haircut be feminine or masculine? (Marshall, Cooper, and Rudnick 2015, 113)

In the report, the situation is presented as a clinical scenario and the questions posed by staff are regarded as clinical ones. Further, the account seems to be based on a ‘binary biomedical perspective on sex and gender’ as ‘having an inconsistent gender identity is categorized as pathological (a ‘confused state of mind’) (Baril and Silverman 2022, 120). As Baril and Silverman (2022) point out, ‘this case brings to light the forms of ableism/cognitivism at play in discourses on dementia, associating it with a lack of agency and decision-making power’ (120). We have selected it as an empirical example of supported everyday citizenship as it brings to the fore the important issue of representation due to diminished capacity.

In a clinical setting, the next of kin is typically assigned substitute decision maker, even though they might find it challenging to support the person they are representing. In Jamie’s case, which predates supported decision-making protocols, the staff were aware that the daughter had difficulty accepting her father’s identification with the female gender: ‘her daughter’s wish for her father to live as a male did not seem to reflect Jamie’s values and beliefs when Jamie was still capable of making such decisions’ (Marshall, Cooper, and Rudnick 2015, 116). Nonetheless, she was afforded the power to represent Jamie if a choice had to be made about how staff should approach her.

In the report, there is no explanation (other than next of kin) as to why Jamie’s daughter was the designated representative. It is quite probable that she was Jamie’s formally appointed representative, which means that she had the formal right to make decisions on Jamie’s behalf. However, this form of representation does not mean that decisions must be in line with the person’s wishes (Holmqvist, Eriksson, and Tideman 2023). Nor is it clear whether any other representative or form of advocacy were considered – like, for instance, a trusted person from the trans community or a professional advocate. Like the first example, the report was written to stimulate learning about professional knowledge and professional ethics. As such, the emphasis is on how best to intervene in a given situation. The choice of representative is interesting though, as it highlights the power given to other people due to diminished capacity.

How we look and present ourselves in public is a concern for most of us, and the example of Jan and growing a beard illustrates how everyday citizenship maybe contested over mundane issues like subjectivity expressed through personal appearance. Recognizing Jan’s subjectivity would imply that the afore made agreement is set aside by the professionals paying attention to Jan communicating his wish to dismiss this agreement. As such, the interaction illustrates why and how professional ethics is of importance for supported citizenship. In contrast, Jamie is seen as confused (and disempowered) because they ‘do not fit into binary gender categories in a stable manner’ (Baril and Silverman 2022, 121). Further, the daughter yielded considerable power as next-of-kin in the decision-making process.

Tracing the idea of supported everyday citizenship

As illustrated by the two examples, citizenship is contested in professional care relations. The idea of supported everyday citizenship supports the advancement of citizenship of persons with intellectual disabilities or dementia in need of welfare services. It is a relational push-back to the oppression and exclusion that this group has historically endured (see for example, Hirschmann and Linker 2015). Supported everyday citizenship is a new concept, but it can be traced back to five existing bodies of knowledge. These are (1) supported decision-making, (2) sociology of the everyday, (3) lived citizenship, (4) inclusive citizenship and (5) human rights.

First, supported everyday citizenship can be traced back to the concept of supported decision-making. Supported decision-making ‘refers to the process of supporting people to make decisions and so promote autonomy and prevent the need for substitute decision making’ (Davidson et al. 2015, 61). It is an established concept in law that recognizes a need for practical assistance to support people with disabilities in decision-making (Blanck 2021). As a legal concept, supported decision-making offers a way of providing substantive rights to people with intellectual disability or dementia (Gooding, 2013). Moreover, according to the CRPD article 12, member states party to the convention shall offer persons with disabilities support to exercise their legal capacity (Demic et al. 2024). As such, it is a particularly useful tool for enabling people to be in control of both everyday and major decisions in their lives – in respect, for example, to guardianship (Arstein-Kerslake 2016) and end-of-life decisions (Watson, Wilson, and Hagiliassis 2017).

While this body of knowledge is clearly relevant and important, it is limited on several fronts. First, most studies on supported decision-making concern adults with an intellectual disability, people with dementia are often excluded due to the severity of impairment (Davidson et al. 2015). Second, the focus tends to be on major life decisions (such as treatment decisions or accommodation) rather than everyday choices such as whether to go out; indeed, many of the studies in the international review by Davidson et al. (2015) concern advance planning directives. Further, the focus with supported decision-making is, essentially, a technical or administrative one. It is about enabling a person to make decisions.

Supported everyday citizenship widens the discourse by concentrating on what some might seem insignificant human matters (such as growing a beard) as opposed to the legal or instrumental dimensions evident in debates about supported decision-making. In addition, supported everyday citizenship places an emphasis on relationality (rather than technicalities) and thus positions a person with an intellectual disability or dementia as an emotional being. Thus, we argue that supported citizenship can emphasize the human dimension in the cooperation with service providers strengthening participation of persons with severe disabilities in everyday life.

Second, supported everyday citizenship can be traced back to sociological work on everyday life. Scholars in the sociology of the everyday are interested in the seemingly trivial aspects of ordinary life because they are thought to reveal much about wider societal structures (Kalekin-Fishman 2013). Take, for example, classic work by Foucault, on how the body – the way one moves, gestures and behaves – is part of a ‘political field; power relations have an immediate hold on it’ (Foucault Reader, Rabinow: 173). This is evident in relation to people with an intellectual disability living in a group home, as ‘acts of resistance get constructed as challenging behaviour requiring the intervention of professionals’ (Nunkoosing and Haydon-Laurel 2012, 195). It is also apparent for a person with dementia with any behavioural (bodily) difficulty such as hitting out. Behaviours like this are typically seen as symptomatic of the condition (rather than the environment) and controlled with drugs. These situations show ‘how the experience of our bodies is at once both intensely personal and extremely public’ (Nettleton 1998, 1), especially when one has a disability.

In other areas of work within the discipline of everyday sociology, scholars focus on micro-interactions. How people speak to one other and talk about different things is of interest to researchers because it illuminates how people see themselves in relation to wider social conventions and rules (Kalekin-Fishman 2013). For example, the following comments would be of interest to

a scholar in everyday talk. One was made by a woman with dementia admitted to hospital following a fall at home. Without prompting, she told the researcher: ‘*everybody keeps putting me down as ‘Mrs’ . . . it’s not my fault I’ve never had children, I’ve never been married, did you know that?*’ (Collins 2021). Another was made by a person with an intellectual disability living in social housing and taking part in a study about community inclusion. They said: ‘I shouldn’t be living here because I’m a sponger’ (anonymized for peer review). Remarks like this are sociologically significant because they show how one’s relationships within society are tied to citizenship. For this reason, the scholarship of everyday sociology provides another important kernel for the idea of supported everyday citizenship.

Third, supported everyday citizenship can be traced back to the concept of lived citizenship. As previously outlined, lived citizenship is an idea that links mundane activities to everyday citizenship when those actions connect us to the wider public sphere and collective. Take, for example, the real-life case of a middle-aged woman with an intellectual disability not ‘being allowed’ to carry a doll because it is perceived as inappropriate (Heenan 2013). The activity (carrying a doll) takes place in the woman’s own home and is not causing any harm to herself or others. Nonetheless, her agency is thwarted by the authorities, making a relational link with state agencies. As such, it constitutes an example of everyday citizenship.

Unlike sociological work on everyday life, lived citizenship starts from the premise that we must discover what citizenship practically means to those who are living it by asking the question, ‘what are the issues which people notice, care about, attend to and work to change?’ In the earlier examples, for instance, Jan cared about growing a beard and Jamie was no longer able to express a gender preference, which concerned staff and other residents. Lived citizenship encourages an even deeper analysis by providing four dimensions of probing – these are as follows: spatial, intersubjective, performed and affective (Kallio, Wood, and Häkli 2020). The spatial dimension draws attention to *where* a person experiences agency (e.g. at home, a care home); intersubjectivity to *who* is significant in or for the agentic relationship (e.g. a family member or health professional); performed to *how* agency is practiced (e.g. asserting one’s wants, by taking off wardrobe doors), and affective to *what* it feels like to experience agency (e.g. empowering). As such, lived citizenship clearly underpins the idea of supported everyday citizenship.

Fourth, supported everyday citizenship can be traced back to the notion of inclusive citizenship, advocated by Lister (2007). For Lister, inclusive citizenship is a ‘multi-tiered concept and practice’ with a strong conceptual heritage (58). Drawing directly on original work by feminist scholar Naila Kabeer, Lister outlines the four values of inclusion citizenship in terms of (1) justice – ‘when it is fair to be treated the same, and when it is fair to be treated differently’ (2) recognition – ‘the intrinsic worth of all human beings, but also recognition of and respect for their differences’ (3) self-determination – ‘people’s ability to exercise some degree of control over their lives’ and (4) solidarity – ‘the capacity to identify with others and to act in unity with them in their claims for justice and recognition’. These values, argues Lister, help to ‘fill in the lacunae in citizenship studies’ regarding adults with disabilities (and children) (53).

As one of the foundational roots for supported everyday citizenship, it is important to highlight a potential flaw with inclusive citizenship, which is the assumption that every citizen is capable of self-determination. Several scholars have challenged the idea of the ‘autonomous citizen capable of independent decision-making and rational choice’ that tends to underpin debates about inclusive citizenship (Curtise 2010, 266). For us, it raises a fundamental question about how we are to understand the ‘self’ in the context of self-determination when a person has an intellectual disability or dementia. Indeed, as Curtise rightly points out, ‘(a) fully inclusive basis for inclusion, therefore, entails accepting shared identities as *supported*, incompetent subjects (ibid)’ (our emphasis). Hence, the value of using and expanding upon this idea to inform supported everyday citizenship.

Fifth, and finally, supported everyday citizenship can be traced back to the human rights literature, which concerns everyday life and focuses on equal status, equal access to citizenship and belonging (Hirschmann and Linker 2015; Nind and Strnadová 2020). As several scholars have

pointed out, there is a tension with the universalism of citizenship and recognition of difference as represented by disability (see, for example, Lister 2007; Waldschmidt and Sépulchre 2019). Persons with intellectual disability in need of support in everyday life rely upon a beneficial nation state to guarantee these rights. Persons with impairment and disability who are unable to make a long-term sustained contribution to society fall outside the Marshallian model of citizenship (Turner, 2009, 71). For this reason, scholars have argued for citizenship to be combined with human rights (Waldschmidt & Sepulcher, 2019). The CRPD strengthens the human rights for persons with disability, in theory at least. However, the link between vulnerability and human rights is more complex. Vulnerability is a human condition shared by all humans and is as such a common basis for human rights (Mackenzie 2019; Turner 2005). It is an ontological fact that human beings are embodied and vulnerable. But there are significant differences in how this common vulnerability is experienced and responded to within communities and by nation states. Everyday citizenship is a human rights issue, and as such, universal. As persons experience vulnerability different, it is a responsibility of the nation state to support everyday citizenship in everyday social practice. Therefore, the recognition of citizenship and individual rights is crucial for providing the support needed (Mackenzie 2019).

Discussion

This article contributes to professional practice and social work studies by discussing supported everyday citizenship in relation to persons living with intellectual disability or dementia. Recognition is an integral part of inclusive citizenship, especially for a person with a disability (Lister 2007). Moreover, recognition by the nation state, as well as human society at large is a prerequisite for a person to be considered a 'bona fide member of a political community' (Turner 2007, 7). Supported everyday citizenship takes a dynamic and relational approach to understanding what it means, and what it takes, to be human and to be a person.

As previously stated, there are similarities and differences in the situations of people with intellectual disabilities or dementia. One parallel we have noted is that subjectivity is often denied for both groups. In the examples we presented, the person's thoughts and feelings were disregarded by others. This is significant as it shows how elementary the agenda is for enhancing the social and political participation of persons with disabilities in need of welfare services. A divergence is that for a person with dementia, who has had a life before, denial of subjectivity is likely to be a new and uncomfortable experience. Whereas for Jan and others like him, intellectual disability is integral to one's identity, and so denial of subjectivity is likely to be a lifelong experience. Irrespective of the similarities and differences, the mechanisms of supported everyday citizenship are applicable to both groups, as these are forms of disability which comprise autonomy and cognition, and so people are likely to need support to fulfil the various freedoms and obligations of citizenship.

Supported

The 'supported' element of supported everyday citizenship refers to the fundamental mechanisms for ensuring the participation of persons with an intellectual disability or dementia in everyday life. In our view, when welfare providers deploy these support mechanisms, enabling, unforceful and ethical care practices are more likely to ensue. A primary mechanism for supported everyday citizenship is knowledge of disability rights. Knowing about the Convention and realizing that it applies to a person with an intellectual disability or dementia is a supportive mechanism. This is because the medical paradigm tends to prevail in a welfare context, meaning that people with an intellectual disability or dementia are positioned as 'service users' or 'clients' rather than citizens with disability rights. The Convention 'clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and

where protection of rights must be' (United Nations 2006). Therefore, it is important that everyone is informed of this area of policy.

Another mechanism for supported everyday citizenship is allowing time. A person with an intellectual disability or dementia often needs more time than is typically required to participate in everyday life. Indeed, research shows that people with dementia are likely to feel rushed and to experience time very differently to those who provide the care service (Eriksen et al. 2021). Hence, in quality care facilities, people with advanced dementia are afforded the extra time they need to complete everyday self-care tasks by themselves, such as, brushing teeth, eating and drinking (Hitzig and Sheppard, 2017). Similarly, college students with a learning disability often request and are given extended time for tests and assessments (Lewandowski, Cohen, and Lovett 2013). Conversely, in some situations, 'allowing time' can hinder a person with an intellectual disability or dementia; if they are in urgent need of welfare or advocacy, for example, or if time is running out, as was the case with Jamie. Thus, allowing time is only a support mechanism when it works in favour of the person with an intellectual disability or dementia.

Everyday

The 'everyday' element refers to the routinized nature of dis/enabling, (un)forceful and (un)ethical practices. It includes everyday objects, practices, emotions and all the sensations that make up a person's average day, from hunger pangs and pain to feeling overlooked and excluded. Recall, for example, how one day, Jan said he wanted to grow a beard but was not allowed to because he had previously made an agreement to shave. In effect, the everyday brings the humanity into the quest for citizenship. It is the part of supported everyday citizenship that seeks to 'honour the humanness inherent in dis/ability', without it one has the behaviourist (technical) paradigm (Goodley and Runswick-Cole 2014).

Unlike supported decision-making, there is a routineness to supported *everyday* citizenship. Whatever changes or decisions a person with an intellectual disability or dementia wishes to make (however slight, such as growing a beard) are dependent upon the endorsement of other people. There is a value, then, in considering the practical application of supported *everyday* citizenship. The notion of 'everyday ethics work' is useful here – this is a view of 'ethics as embedded and embodied in everyday practice', as opposed to the normative ethical principles found in textbooks on ethics (Banks, 2016, 36). Banks uses the term 'ethics work' to refer to the:

effort care professionals put into seeing ethically salient aspects of situations, developing themselves as good practitioners, working out the right course of action and justifying who they are and what they have done. Broadly speaking, 'ethics' relates to matters of harm and benefit, rights and responsibilities and good and bad qualities of character. The term 'work' is used in this context 'to cover the psychological and bodily processes of noticing, attending, thinking, interacting and performing' (36).

The continuous daily nature of ethics work has links to citizenship because it effects how much control a person with an intellectual disability, or dementia exerts over their own life.

Citizenship

The 'citizenship' element of supported everyday citizenship is about a person with an intellectual disability or dementia being in control of their life. In welfare settings, there is a pretence that person-centred care is provided, and people are treated as individuals. However, as we have seen in our examples, the reality for many adults with an intellectual disability or dementia is that individuals have very little choice or control over where they live, who they live with, or how they look. This is because, as previously mentioned, relationships in a care context are typically object-subject even if they are called person-centred care.

Debates about inclusion and choice have been criticized for being ideological (see for example (Jackson and Irvine 2013). However, as our situational examples have shown, choice and wanting does come from within; these are human desires, not only political ideology. Hence, it has been suggested that to find citizenship on an empirical level, we need to: ‘map how [service] users can control and influence their lives when using public services’ (Trætteberg 2017, 212). In addition, understanding choice and control, as experienced by adults with an intellectual disability is an increasingly important field of research (Curryer et al. 2018). For us, this is an essential element of supported everyday citizenship, which warrants closer attention.

Conclusion

When considered together, the situation for persons living with intellectual disability or dementia is remarkably similar. Both groups are subject to the powerful influence of others and are likely to find themselves in a care setting, where the use of force is of a special nature because it happens routinely and in everyday situations. This is significant from a human rights and citizenship perspective, as it shows how persons living with intellectual disability or dementia are still effectively regarded as objects of care rather than equal citizens with rights, duties and freedoms. By focusing on supported everyday citizenship, this article seeks to integrate discourse in professional practice and social work studies to include persons living with intellectual disability or dementia. In so doing, relationality becomes a more critical component in conceptualizations of citizenship. Further, it is hoped that individual factors such as cognition and self-determination are given more priority in practice and empirical research and the professional ethics required for lived citizenship are recognized and investigated. Finally, the discussion has reworked and strengthened the idea of relational citizenship (Pols 2016; Lid, 2022). As such, the article adds to the current debate within social work, professional practice and social work studies about the value of the concept by suggesting how to rethink and expand it.

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