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LIVED CITIZENSHIP FOR PERSONS IN VULNERABLE LIFE SITUATIONS

Theories and practices

Scandinavian University Press

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Preface

Kirsten Jæger Fjetland, Anita Gjermestad and Inger Marie Lid

This edited book is the result of contributions from the interdisciplinary research group "Citizenship", hosted at the Faculty of Health Studies at VID Specialized University. The research group has its focus on exploring and enhancing citizenship through theoretical as well as empirical studies. Both professional practices and everyday life experiences are dimensions explored from the professional point of view of public health, participation and community planning; rehabilitation, everyday life and citizens' influence. Citizens' rights and a relational perspective on disability are fundamental to the studies and projects by the research group. The editors and two of the authors are also engaged in the excellence research project CitPro; Citizenship for persons in vulnerable life situations. Both the research group and CitPro have been significant for developing ideas in this project and as critical readers for each other's chapters.

The 13 chapters are based on the researchers' empirical and theoretical studies exploring lived citizenship in different contexts within health and welfare practices and the everyday lives of citizens in vulnerable life situations. This implies intellectual disability and citizenship in residential housing/assisted living facilities; sheltered workshops; professional practices together with persons with dementia. Further, the book examines citizenship in digital healthcare and chronic conditions, civil society and older citizens, as well as citizenship in the voluntary sector.

This work has been developed over a long period of time; we are grateful for the support from VID Specialized University, Institute of Health, Sandnes campus, for giving us the possibility and resources to develop the research and finance this edited book. Furthermore, we want to thank all the researchers and authors who have contributed to the chapters. We also wish to thank those who have been part of the empirical studies included in this volume as interviewees and those who have opened their everyday lives for us as researchers.

Finally, we are grateful towards our editors at Scandinavian University Press, first Helge Årsheim and thereafter Pål Csaszni Halvorsen, both of whom have followed up and supported the – at times complicated – process of writing and edit-

ing the volume, since we began in early 2019. We also wish to thank the anonymous reviewers for insightful comments.

We hope that the book will find its readers among graduate students, scholars and researchers in the broad field of interdisciplinary disability and citizenship studies.

Sandnes and Oslo, March 2022

Kirsten Jæger Fjetland, *Anita Gjermestad* and *Inger Marie Lid*

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1. Lived citizenship for persons in vulnerable life situations – theories and practices. Introduction

Kirsten Jæger Fjetland, Anita Gjermestad and Inger Marie Lid

The need for care and welfare services has put older people, citizens with chronic conditions and dementia as well as persons with intellectual disabilities in vulnerable situations regarding recognition as citizens with rights and duties. As documented in both national and international white papers (Ministry of Children and Equality, 2016; WHO, 2017a; WHO 2017b), the human rights status for persons with disabilities is under threat and needs to be strengthened. In Norwegian and most western societies, persons with disabilities have experienced discrimination and exclusion throughout history and has been seen as patients and a burden for society and the nation state rather than as citizens of equal status. As Fraser (2009) emphasizes, the social contribution of citizens in vulnerable life situations has not been represented or acknowledged, thus making an incomplete and deficient background for justice and the redistribution of welfare resources.

This edited book will therefore address a need in research as well as professional practice to make visible both the challenges and resources relating to citizenship for people in vulnerable life situations. The book is based on a dialogical perspective of citizenship, including both a relational as well as a rights-based dimension of lived citizenship. The concept of *citizenship* includes the civil, political and social rights and duties of citizens as members of a nation state (Marshall, 1950; Boje, 2017). However, in contemporary scholarship, citizenship concerns not only one's formal status as a citizen but also the lived experiences of everyday life (Lister, 1997). Consequently, distinguishing analytically between formal citizenship on the one hand and realized citizenship on the other emphasizes citizenship as a relational phenomenon practised in social relations (Isin & Turner, 2002).

The lived citizenship of persons, according to Kallio et al. (2020), entails four dimensions: the *spatial*, *intersubjective*, *performed* and *affective*. Kallio et al. (2020) emphasize a focus on the meaning of citizenship in peoples' lives, how it is enacted and experienced, and how living includes the social, cultural and material circumstances of citizens. In the different chapters of this edited book, lived citizenship will be explored in relation to the everyday lives of older people, persons with dementia, intellectual disabilities, chronic conditions as well as with a focus on professional practice as a condition for citizenship for persons in need of care on a daily basis.

Fraser's (2009) terms of recognition, representation and redistribution exemplify citizenship as a phenomenon of both rights and social relations being redefined and fought for, as well as Isin and Turner's (2002) theories that focused on citizenship as value-based *practices*. The different chapters elaborate on a variety of professional contexts and practices in the lives of persons with disabilities, mainly intellectual disability and dementia, and their significantly vulnerable life situations. Within this relational perspective, each chapter has its own angle – whether philosophical, sociological or human rights and justice. In addition, citizenship is also presented as lived, experienced and expressed as relational in value-based social practices and theories.

Against this background, this book highlights lived citizenship with a relational and rights-based perspective within citizenship studies, acknowledging the complexity in facilitating the experience of citizenship of persons in vulnerable life situations (Skarstad, 2019; Halvorsen et al., 2017; Kallio et al., 2020).

The aim of this book is to contribute new insights into lived citizenship related to persons with disabilities, such as dementia, intellectual disability and chronic conditions. Further, the book aims to promote reflection on qualities of citizenship in professional practices. We do so by presenting perspectives that may serve as a point of departure for analysing and discussing qualities and values in professional practice, identifying characteristics of practices that either enhance and realize citizenship practices or hamper and mis-acknowledge the citizenship of persons with disabilities.

The various studies presented represent different methodological approaches, including ethnographic studies with fieldwork and participant observations, action/practice research, research with participatory designs, documentary analysis, reviews, qualitative interviews and theoretical and philosophical studies. In general, the empirical studies are inspired by participatory (Schubotz, 2019) and dialogical research methods (Hauger & Arntzen, 2003), involving different stakeholders as participants or subjects of knowledge (persons with intellectual disabilities, service users), and adapting various degrees of participation and dialogue (Nind, 2014). The plurality of these methodological approaches constitutes a

resource for empirical studies and theoretical investigations of lived citizenship. Due to the plurality of methodological choices, the focus on theoretical versus empirical perspectives as well as the context of the studies, the explicit voice of the citizens in question is present in different ways throughout the book. The second part, "Lived citizenship in the context of intellectual disability", represents the citizens' voice most explicitly; these include the chapters by Duffy, Fjetland, Glørstad, and Gjermestad & Skarsaune (Chapters 7–11).

Based on this variety of perspectives and methodological approaches, the book establishes a dialogical perspective on citizenship in two ways: the first is by creating a dialogue between empirical and theoretical studies; the other is the dialogue established through exploring the complex aspects of lived citizenship as relational *as well as* rights-based practices. This perspective of citizenship studies contributes towards the exploration of both the understanding and meaning of lived citizenship for people with disabilities as well as practices and tools for enhancing citizenship through relational practices.

As citizenship and disability studies represent international discourses and practices, we do this in English, aiming to invite scholars, academics and students to analyse and discuss qualities and values in professional practice, identifying characteristics of practices that either enhance and realise citizenship practices or hamper and mis-acknowledge the citizenship of persons with disabilities or both.

With this background, the book presents contextualized answers to the following question: *What characterizes lived citizenship of persons in vulnerable life situations?*

This edited book is presented in two main sections: *Lived citizenship in the context of older citizens, citizens with chronic conditions and dementia* and *Lived citizenship in the context of intellectual disability*. In both sections, the reader will find chapters taking a theoretical as well as an empirical point of departure, and professional practice as well as the everyday life of the citizen will be addressed. However, before we present the two main sections and the chapters included in the book in more detail, we provide a brief outline of the understanding of vulnerable life situations in this book as well as lived citizenship in the context of equal rights and relations.

LIVED CITIZENSHIP AND VULNERABLE LIFE SITUATIONS

The specific topics and perspectives of this book are concerned with citizenship in situations of multiple vulnerabilities. In this edited book, vulnerability is addressed in three ways: vulnerability as a universal condition of all human beings, vulnera-

bility as a context of disability in everyday life, and vulnerability related to service providers roles, in professional practices. Based on a relational understanding of disability, the vulnerability in the context of disability and service providers and professional practice will mainly be addressed together (UN, 2006).

Vulnerability as a common human condition and experience is addressed in the human rights treaties (UN, 1948; UN, 2006). Vulnerability as a universal condition highlights the fact that the human being is fragile and vulnerable towards changes and variations in health and functions during their lifetime (Fineman, 2008). A common human vulnerability further refers to the relational dependency of the human being related to social and psychological development, living and belonging (Garland-Thompson, 2012; Mackenzie, 2019). As human beings we have a shared human condition of vulnerability by being dependent on others throughout our lifespan.

Universal vulnerability presupposes the recognition of human diversity, as stated in the human rights treaty (UN, 1948), assuming participation and influence for all citizens. As stated in human rights conventions, CRPD (UN, 2006) citizenship for persons in vulnerable life situations like the disabled has been particularly contested (Nussbaum, 2007; Lid, 2017; Fjetland & Gjermestad, 2018). Hence, throughout history, only selected groups of persons have had equal access to citizenship (Lister, 1997). One of the most prominent western theories of justice conceptualizes the envisioned subject of justice as cooperating and contributing to society across the lifetime of all citizens (Rawls & Kelly, 2001). As Fraser (2009) emphasizes, the social contribution of citizens in vulnerable life situations has not been represented or acknowledged, thus making an incomplete and flawed background for justice and the redistribution of welfare resources. This is also described as a citizenship struggle (Sépulchre, 2020) for marginalized groups.

The status as patients given to persons with disabilities has increased the vulnerability they experience in different contexts. Thus, citizenship for persons with disabilities is not about global citizenship, but rather about citizenship status at home, within nations. For persons with disabilities in need of health and care services, the process of making distant strangers into objects of concern and subjects of rights (Flynn, 2012) is a matter of imagining equality; this, according to Flynn (2012), has laid the psychological foundations of contemporary human rights.

Especially persons with intellectual disabilities and dementia experience exclusion from the public sphere and the devaluation of their personal status as citizens (Hydén & Antelius, 2017; Fjetland & Gjermestad, 2018). For persons with intellectual disabilities and dementia, the communicative and cognitive challenges represent a significant vulnerability. Such challenges have overshadowed the subjectiv-

ity of the citizen, and their personhood has been questioned. Indeed, the bodies of persons with severe communicative disabilities have been presented as an empty shell (Hydén & Antelius, 2017). Moreover, the need for a high level of support over the lifetime is used to question the agency and personhood of persons with intellectual disabilities and dementia (Bartlett & O'Connor, 2007; Kittay, 2010; Nussbaum, 2004, 2009; Fjetland & Gjermestad, 2018), emphasizing vulnerability as a challenge and not as a common human condition.

Institutional practices enlighten the importance of material and spatial dimensions that influence the everyday lives of citizens receiving professional care (Kallio et al., 2020). The needs for a high level of support demand institutional care that mediates institutionalized lives, which brings forward a special kind of life involving vulnerability towards group-thinking rather than personalized care (Gjermestad, Luteberget, Midjo, & Witsø, 2017). A professional vulnerability also involves the organizational and structural frames, conditions and resources of welfare policy and services. Such social, economic, organizational and structural circumstances also form and affect the lives and lived citizenship of the citizens receiving care and support. As Kallio et al. (2020) emphasize, both intersubjective as well as material and spatial circumstances/qualities in welfare practices mediate different opportunities for professionals to facilitate citizenship in everyday life. The high turnover of staff as well as a large number of service providers involved in the lives and care of persons with intellectual disabilities amplify the vulnerability of the citizen and complicate the citizens' need for stability and continuity in care. Being surrounded by staff who know you well is a fundamental aspect of affective, intersubjective and embodied dimensions of citizenship (Kallio et al., 2020).

LIVED CITIZENSHIP – EQUAL RIGHTS AND RELATIONS

Political changes in society have led to new struggles for citizenship in contemporary societies. For persons with disabilities, this has been especially challenging, as they often experience that formal citizenship does not necessarily mean equal possibilities. Disabilities – alongside other dimensions such as race or gender – represent a vulnerability towards structural inequality which hampers the development of citizenship.

Over the last 20 years, we can identify a human right turn in disability policy and research. Disability was first included in the human rights context in 1981, when the United Nations launched the first Year for the Disabled; this was followed by the Decade for the Disabled, from 1983–1992. The Convention on the Rights of Persons with Disabilities (CRPD) was ready for signing in 2006 and entered into

force in 2008. The convention has strengthened the citizenship of persons with disabilities, as it raises awareness around disability as a human condition and human rights issue.

Persons with disabilities are recognized as equal citizens regardless of health status, at least in policy documents; moreover, instead of reducing persons to their needs, their rights and duties as citizens and fellow citizens have been highlighted (Bickenbach, 2012; Shakespeare, 2014). According to Article 1 of the CRPD, disability is best understood as the product of an interaction between individuals and the environment (UN, 2006; see also Bickenbach, 2012; Shakespeare, 2018). This theoretical framing merges the individual (medical) and contextual and social dimension, and the interaction between these factors in seeking to understand disability as a complex concept and phenomenon.

In health and welfare services research, the human rights turn can be identified as a shift from person-centred services towards equal citizenship as a goal for service provision (Bartlett & O'Connor, 2007). Consequently, the aim of providing individualized welfare services is that the person in need of such services should not be "kept in their place", but rather be enabled to act as a citizen; such services should also aim to support that citizenship. In addition, this shift underscores the importance of plurality as a fundamental aspect of humanity.

Here, Arendt's (1998) point that we are all born and come to the world as different human beings is salient: abilities may not be of importance in and of themselves, but impairment – whether physical, sensory, intellectual or mental – may, in its interaction with the environment, lead to disabling processes and disabilities that hinder the individual from participating in society on an equal basis with others (UN CRPD, 2006; Shakespeare, 2014). This is the political understanding of disability in Article 1 of the CRPD, which has found its way into research and politics. The consequences of disability are exclusion from equal status and equal rights in concrete situations and contexts, and thus exclusion from citizenship.

The American philosopher Catriona Mackenzie (2019) argues that even relational approaches to citizenship and theories of justice must include an understanding of the rights of the individual person. Thus, a relational approach entails the individual subject.

The authors of this edited book are situated within the Norwegian context, which is part of the Scandinavian welfare model characterized by strong welfare states using welfare reforms to obtain equality (Esping-Andersen, 2015). This entails that welfare services are used as a means to achieve equal opportunities for citizens living under unequal conditions. The dominant model of disability in Norwegian contexts is the relational model (Shakespeare, 2014; Tøssebro, 2010).

Persons with disabilities – intellectual disability, elderly, chronic conditions and dementia – have equal opportunities on par with their fellow citizens. However, Norway has ratified the CRPD and was criticized by the Committee on the Rights of Persons with Disabilities for treating persons with disabilities as patients rather than recognizing them as citizens (UN, 2019). This may reflect a bias in the Scandinavian welfare model regarding disability and service users. While the welfare state may be seen as robust and generous, it may also have mechanisms that keep people "in their place" and thus not fully recognized as equal citizens. Persons with intellectual disabilities as well as chronic conditions in need of care and welfare services are especially vulnerable towards this kind of exclusion from citizenship in a lifetime perspective. This bias has sparked the call for research on conditions for equal citizenship in Scandinavian contexts.

Both NGOs and disability rights organizations in Norway have been arguing for access to services and patients' rights and access to social participation (Grue, 2009). However, citizenship/human rights are perhaps given less priority than welfare rights, and the NGOs thus find themselves in a gap between two different but equally important political issues. This double agenda sometimes leads to weaker arguments for the citizenship agenda. Nevertheless, over the last year, the citizenship agenda appears to have been strengthened – likely because of rising awareness related to the Norwegian ratification of the CRPD.

LIVED CITIZENSHIP IN THE CONTEXT OF OLDER CITIZENS, CITIZENS WITH CHRONIC CONDITIONS AND DEMENTIA

Citizenship as social participation and influence is addressed in international as well as Norwegian white papers concerning older citizens (WHO, 2007; 2017a; Ministry of Health and Care Services, 2016; 2018). Dementia is given particular attention as a condition with increasing prevalence, and therefore attention regarding planning for quality in everyday life as well as welfare (WHO, 2017b; Ministry of Health and Care Services, 2020). Although references are made to human rights and human rights conventions such as CRPD (UN, 2006) and the importance of social participation and belonging for quality of life across a lifetime, justifications refer to demographic changes that cause economic challenges in welfare. Technological and social innovations like digital health care and citizen involvement in local communities are presented as ways to improve both quality of life as well as economic pressure on the welfare system (Førde, 2019; Helgesen & Herlofson, 2017; European Commission, 2019). The challenges faced and resources

required for lived citizenship are discussed in Chapter 4, "Participation, civil society and citizenship in later life" (Haarr & Groven) and Chapter 5, "How may digital healthcare influence citizenship for people with chronic conditions" (Lie, Fjetland, & Tokovska).

There is a comprehensive literature focusing on citizenship and dementia or intellectual disabilities (Halvorsen et al., 2017; Halvorsen et al., 2018; Hydén & Antelius, 2017; Nedlund, Bartlett, & Clarke, 2019). Living with dementia, in particular, has been critically explored in the context of citizenship as practice and perspective. Medical perspectives in dementia have strengthened the understanding of dementia as a tragedy and a loss of function (Kontos, Miller, & Kontos, 2017). Moreover, responding to the lack of subject positions in professional welfare, person-centred perspectives have emphasized the importance of listening to the needs and wishes of each person (Bartlett & O'Connor, 2007).

However, citizenship perspectives highlight the importance of the connection between capabilities, abilities and social belonging and community participation. A critique of medical as well as person-centred care paradigms has been broadening the debate, acknowledging the embodied knowledge as well as the importance of intuitive communication and relational attachment and bonding (Bartlett & O'Connor, 2007; Nedlund & Nordh, 2018). Citizenship studies emphasize the rights of citizens to choose to live at home with dementia (Bartlett & Brannally, 2019). Research focusing on living at home with dementia provide evidence for the importance of family perspectives as a quality in professional welfare, as well as the influence of national and global white papers on and structures for maintaining citizenship for every citizen (Bartlett & Brannally, 2019).

Exploring citizenship while living with dementia has inspired and enhanced humanistic perspectives of existence, giving the importance of basic human dignity and respect – as well as creativity, playfulness and meaning – a more prominent position in citizenship research (Bartlett, O'Connor, & Mann, 2010; Kontos & Grigorovich, 2018; Canning & Blakeborough, 2019). Lived citizenship as performed and experienced emotionally in both intersubjective relations and material and spatial contexts has also been explored (Kallio et al., 2020). The chapters in this section particularly highlight the influence of different understandings and theoretical perspectives in academic literature for the practical performance of lived citizenship in professional practices. Citizenship as a value-based, ethical phenomenon including social participation across a lifetime is the main issue at stake in these chapters.

In this part of the book, the following chapters highlight lived citizenship in the context of older citizens, and citizens with chronic conditions and dementia:

In Chapter 2, Sund, Hanisch & Fjetland present a review of the literature exploring different citizenship conceptualizations and practices for persons with dementia living in nursing homes. Citizenship emerges as a critique against dominant biomedical and health and care-based understandings that hamper the experience of lived citizenship. The authors present arguments that show how citizenship practices highlight opportunities for engagement and participation in nursing homes. Citizenship is facilitated in societal connections and can be found in minor acts of participation, enabled through acknowledging the intentionality of the body or achieved through social networks. The review points to the structural, material, social and relational characteristics of nursing homes, as well as society's perceptions of dementia, which may challenge such practices. The conclusion underscores the benefit of these sometimes conflicting understandings complementing each other in order to enable people with dementia in nursing homes to experience enhanced lived citizenship.

In Chapter 3, Synnes elaborates "an ethics of the unconscious and cultural citizenship in dementia" by arguing for engagement with arts and poetic language as part of a cultural citizenship for persons with dementia. Synnes argues that this might open up a nuanced awareness of agency, contribution and belonging. Involvement with the arts entails an acknowledgement of the affective and emotional dimensions of lived citizenship through unconscious fears and desires we might have towards persons with dementia, both on an individual as well as a societal level. These theoretical perspectives are put in dialogue with the authors' empirical research on the use of visual arts and poetry writing in dementia care, enhancing the experience of lived citizenship.

In Chapter 4, Haarr & Groven explore how Norwegian municipalities are concerned with developing material and social spaces for cooperative relations with families, the private market and civil society, which build and develop future-oriented practices that enhance and support lived citizenship. The methodological approach is a case study of older adults eating dinner while living at home. The authors use an occupational justice perspective that argues for material and relational citizenship rights, which thus supports the need to establish lasting and inclusive meal practices and local community settings to ensure lived citizenship in later life.

In Chapter 5, Lie, Fjetland & Tokovska undertake a narrative review that aims to clarify the current knowledge around how digital healthcare may influence the lived citizenship of adults with chronic conditions. The discussion suggests that, for some people, digital healthcare may positively support lived citizenship. However, digital health technologies may also exacerbate inequalities between patients,

leading to a greater need for differentiation in professional practices. The study shows that digital healthcare creates new demands and responsibilities for healthcare personnel to ensure citizens' digital competence to enhance the experience of lived citizenship.

LIVED CITIZENSHIP IN THE CONTEXT OF INTELLECTUAL DISABILITY

There is a history of invisibility and ignorance related to persons with intellectual disabilities, exemplified by institutionalization from the beginning of the 1900s until the 1990s, when the process of deinstitutionalization began in the Nordic countries (Tøssebro et al., 2012). Persons with intellectual disabilities have a long history of being mis-recognized as full citizens (Kittay, 2010; Nussbaum, 2004). Due to the history of institutionalization, combined with needs for a high level of support, persons with intellectual disabilities are more likely to be perceived as subjects of care than full citizens (Kittay, 2010; Nussbaum, 2004). This indicates how people with intellectual disabilities are marginalized and struggle to claim full and equal citizenship.

Following the deinstitutionalization process in Norway, persons with intellectual disabilities experienced increased self-determination (Söderström &Tøssebro, 2011; Kittelsaa & Tøssebro, 2012; Tøssebro, 2019). However, this trend is reversing (Tøssebro, 2019). With higher cost-related pressures, less personalization of services and more group-oriented thinking, professional interests are prioritized at the expense of individualized services for persons with intellectual disabilities (Söderström & Tøssebro, 2011; Tøssebro, 2019). Basic human rights are therefore not fulfilled. This new trend has also been confirmed by the recent official report, "Det gjelder livet!" (Norwegian Board of Health Supervision, 2017). The current situation highlights a contradiction in government politics towards persons with intellectual disabilities: although the government and municipalities are obliged to formally secure the citizenship and fundamental human rights for persons with intellectual disabilities, they are simultaneously reducing welfare budgets. Despite the deinstitutionalization process and the strengthening of fundamental rights of persons with intellectual disabilities, the policies towards this group indicate a transformation – rather than a disappearance – of power (Altermark, 2017). Persons with intellectual disabilities who receive support from health and welfare services still suffer from constraints and paternalistic care. This edited book addresses these challenges by exploring lived citizenship in a dialogic perspective as both rights and social relations, through investigating both theories and practices.

Studies exploring welfare services post-institutionalization emphasize the possibility that the rights perspectives overshadow the importance of intersubjective relationships in the everyday lives of people receiving professional care (Altermark, 2017). Tøssebro (2019), referring to Habermas, points to the dominance of structural perspectives – for instance, the rights and needs of staff, rotation plans and resources in housing facilities – overrunning the focus on lived experiences and lifeworld of citizens who receive professional care. These studies bring knowledge to the importance of different and interrelated dimensions that mediate the performance and enactment of lived citizenship, including the spatial, intersubjective and affective (Kallio et al., 2020). In this book, the lifeworlds and lived experiences of people with intellectual disabilities are put forward by Simon Duffy in Chapter 7; he presents the seven keys model of citizenship developed together with persons with intellectual disabilities. Both the structural and relational foundations of lived citizenship are addressed. Also, performed citizenship is examined by Fjetland in Chapter 8; she shows how it is communicated by the voice and narrative resistance of citizens with intellectual disabilities in a sheltered workplace. Furthermore, Glørstad, in Chapter 9, highlights the performed dimension of lived citizenship within a cultural context, giving voice to an actress with intellectual disability.

A majority of persons with intellectual disabilities are in need of care on a daily basis, making professional relationships a crucial condition for the enactment of lived citizenship. The importance of professional competence in promoting lived citizenship are put forward by Fjetland & Paluga in Chapter 13, in which they explore social education students' knowledge and understanding of self-determination and citizenship. In line with Kallio et al. (2020) and the spatiality of lived citizenship, people with intellectual disabilities and their lived citizenship cannot be separated from their context, meaning their need for support from health and welfare services, their living arrangements and their social and economic situation. Here, the material context concerning lived citizenship is particularly investigated by Hoydal & Thygesen, Chapter 10, in the context of meal practices in group homes. A relational as well as rights-based perspective on lived citizenship is further at stake in Chapters 11 (Gjermestad & Skarsaune) and 12 (Wærness, Teigland, & Gjermestad) where the authors discuss the importance of theoretical understanding for the development of reflective professional practices that contributes to the experience of lived citizenship.

In different ways, the chapters in this section pinpoint how the relational and material context in the lives of people with intellectual disabilities may affect lived citizenship in everyday life, focusing on self-determination, assisted living facilities, work and culture.

As an analytical starting point to Chapter 6, Lid takes the fact that persons with cognitive disabilities have been excluded from equal status and citizenship, with reference to dependency and an assumed lack of capacity for individual autonomy. Drawing on theoretical perspectives from political philosophy and feminist ethics, the chapter discusses the normative foundation of freedom, autonomy and dignity. The chapter explores the extent to which the human rights subject must be an autonomous and independent person, and how these concepts should be reformulated as relational.

As elaborated by Duffy in Chapter 7, the seven keys model of citizenship was developed together with a woman with an intellectual disability. The model concretizes and operationalizes the significant aspects of the interrelated structural and relational dimensions of the lived citizenship. It offers an emancipatory conception of citizenship based on the lived experience and advocacy of persons with intellectual disabilities. Duffy challenges the idea that citizenship should be defined by the powerful, and emphasizes the importance of the perspective of the excluded citizens. People who are pushed to the margins best understand what is important to them. The chapter explores the Keys to Citizenship model as one such emancipatory framework supplementing the idea of human rights. While human rights assert the resources and freedom we should all have, citizenship is the way we should all live.

In Chapter 8, Fjetland takes as a point of departure the context of the lunch break at sheltered work; this enables the exploration of dimensions of lived citizenship through the narrative possibilities. The study explores the narrative co-authorship from a perspective of agency and citizenship. The material and spatial resources at work mediate narratives of resistance between colleagues, and represent performed citizenship through intersubjective relations. The empirical text is placed in the context of theories of narrative philosophy and understanding and relational and rights-based theories of citizenship. The narrative highlights basic ethical and moral dilemmas connected to the organization of living and everyday life for persons with intellectual disabilities. As opposed to professional practices that disempower the everyday life of persons with intellectual disabilities, the results point to the workers' relational competences in enhancing agency and a citizenship of resistance through co-authorship and narrative care.

In Chapter 9, Glørstad discusses how lived citizenship is enacted and performed within a cultural context. The theatre represents a spatial and cultural context for constituting citizenship, developing relationships, and exploring identities. From a perspective of sociology of culture, Glørstad asks what the drama "I answered a dream" by Marthe Wexelsen Goksøyr and Siv Svendsen tells us through its rep-

resentations about living as a woman with a learning disability. The manuscript is read through the lens of a performative approach to citizenship and "acts of citizenship" as a methodological approach.

In Chapter 10, Hoydal & Thygesen explore the relationship between materiality and citizenship. Building on empirical data from fieldwork and interviews, they mobilize the notion of "arrangements" to show how different forms of citizenship are constituted through everyday meal practices – highlighting the role of materiality and technology in the process. The authors argue that materialities are key actors in all meal arrangements and play different roles in these arrangements related to their size and scope. The authors further emphasize the need to include materialities in the understanding of relational and lived citizenship and conclude that the values at stake in understanding citizenship for persons living in assisted living facilities need to be understood in context.

In Chapter 11, the spotlight is placed on persons who communicate via means other than verbalizing words. This lack of verbal language might threaten autonomy as well as citizenship. This chapter applies the lens of lived citizenship to discuss the reported conditions for participation. Gjermestad & Skarsaune conclude that citizenship must be facilitated through caring practices in everyday life, where the person with profound disability is acknowledged as an agent. These relational conditions can only be realized if the structural conditions amplify them. They also highlight how relations and structural conditions within residential housing are intertwined in the performed and enacted citizenship of people with needs for a high level of support living in institutional settings within the welfare system.

In Chapter 12, Wærness, Teigland & Gjermestad describe trauma-conscious understanding as a promising model for use in caring encounters with persons with intellectual disabilities. The results from a research project presented here indicate that the staff changed their professional understanding from focusing solely on rules towards an increased focus on the quality of their relationships with service users; this also highlighted and enriched their understanding of crucial affective, emotional and intersubjective dimensions and conditions around the lived citizenship of persons with intellectual disabilities within the context of professional practices in residential housing. A trauma-conscious understanding of the service users among the staff also seemed to enhance their ability to recognize their emotional and physical expression and communication. This shows the importance of practical and communicative competence to promote lived citizenship.

In Chapter 13, "Self-determination and citizenship", Fjetland & Paluga explore how citizenship involves self-determination. The chapter explores social education students' understanding of self-determination as they present it in their bachelor

theses. The authors discuss what understandings of citizenship can be interpreted from students' descriptions and interpretations of self-determination. The authors conclude that students refer to both a conditional and an unconditional, universal understanding of citizenship. This lends support to the argument that lived citizenship as a theory and a practice can shed light on the challenges that students experience in self-determination practices.

The aim of this book is to contribute to new insights into lived citizenship in a rights and relational-based perspective concerning citizens in vulnerable life situations. Citizenship representing a contextual, social as well as a relational phenomenon, implies that the chapters are invitations to reflect together with the authors on the qualities of citizenship in everyday life as well as in professional practices. By offering this edited book from the Scandinavian context for international readers, our aim is to engage with the international discourse on equal and lived citizenship for persons in vulnerable life situations.

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2. Citizenship for persons with dementia in nursing homes: A literature review

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Abstract This literature review explores citizenship conceptualizations and practices for persons with dementia living in nursing homes. Citizenship emerges as a critique of dominant medical and care-based understandings, and seeks to combat discriminatory practices through engagement, participation and upholding societal connections in residents' lives. By viewing these understandings as complementary, we may begin to bridge the gap between residents' apparent needs and their capabilities as citizens.

Keywords citizenship | dementia | nursing homes | Goffman | review

INTRODUCTION

O'Connor & Nedlund (2016) describe a historical trajectory in dementia research. Initially considered a natural part of ageing, dementia was increasingly framed as a medical condition towards the end of the twentieth century. While twenty-first-century research continues to engage medical knowledge, analytically and empirically the analytical scope continues to expand. That trajectory, in particular the expansion to include understandings that go beyond the medical, provides the analytical backdrop for this review.

Arguably, new perspectives emerged in response to an inherent reductionism in the biomedical view. According to Bartlett & O'Connor (2007), a sole medical perspective primarily focuses on cognitive function and medical treatment, thereby reducing the understanding of dementia to loss. Although there are several responses to this understanding, the emergence of person-centred care is one of the most influential. According to Bartlett, O'Connor & Mann (2010), it provided a framework for recognizing the person as intrinsically worthy of respect and helped shift understanding of dementia from a medical to a humanistic perspective.

While person-centred care helped shift the primary interest from clinical indicators to the person in question, it too has been criticized for entailing reductionism. Bartlett & O'Connor (2007) argue that person-centred care does not recognize people with dementia as social actors, capable of asserting power and influence in their lifeworld and social communities. To avoid this reduction – where people with dementia is seen as passive "objects" for person-centred practices – another expansion took place: the emergence of dementia research within a citizenship framework. This framework argues for dementia services that are rights-based rather than needs-based, and that people with dementia should be fully recognized as active subjects in their own life as well as in research.

According to Bartlett & O'Connor (2007), citizenship was traditionally seen as a status given to a person as a full member of society, with given rights and duties (cf. Marshall 1949/92). In recent years, citizenship has been redefined, from an exclusive status to an aspect all humans realize through everyday situations, relationships, and actions. The exact explications of this turn remains open to interpretation. Through their review of citizenship and human rights principles for people with dementia, Kelly & Innes (2013) argue that these concepts are applied less frequently and rigorously in dementia care than other health and social care literature. Baldwin & Greason (2016) similarly warn that citizenship can become a plastic word, void of meaning, if its practice is not made specific.

To shed light on these practices, we must also take the context into account. Dementia causes cognitive decline that might challenge opportunities for active citizenship, and in moderate to severe stages many consequently reside in nursing homes with 24-hour support. Such institutions are, according to Stafford (2003), "caught in the middle": "In the cultural order, the hospital exists as a clear domain. The home exists as a clear domain. The nursing home, caught in the middle, dwells in an unending no-man's land, a grey area in our society" (p. 18). The "grey" character of the nursing home – trying to be both home and hospital – makes it a site of many different orientations and forms of meaning making. Relying on Erving Goffman's (1961) well-known concept of "total institutions", we combine an emphasis on citizenship with an investigation of how institutional life may thus in itself put citizenship under pressure. Hence, it is clear there is a need for more precise knowledge on how citizenship takes place in this context. For that purpose, this review responds to a seemingly simple question: *How is citizenship for persons with dementia living in nursing homes conceptualized and described in the research literature?*

METHODOLOGY

As part of the main author's Ph.D. project, a literature review of published peer-reviewed articles was conducted. Grant & Booth (2009) present 14 types of review, with different levels of ambition related to a stringent and documented search process, analysis and quality assessment. A literature review was chosen because it enables examination of published research, while analysis can be thematic and descriptive, suiting the purpose of the study. A search protocol was formulated to guide the review process. The review procedure and arguments for choices made are presented below.

Review procedure

Guided by the 12 steps recommended by Kable, Pich & Maslin-Prothero (2012), Table 2.1 documents our review process.

Table 2.1: Procedure for review

12 STEPS	PROCESS OF OUR REVIEW
1) Purpose statement	Research question: How is citizenship for persons with dementia living in nursing homes conceptualized and described in the research literature?
2) Databases	Searches were conducted in November 2018–January 2019 (repeated August 2019): Cinahl, Medline, OT-seeker, Helsebiblioteket, SweMed, NORART, DOAJ, Academic Search Elite, Science Direct, and the Norwegian journal Nursing Science (Sykepleien forskning).
3) Limits applied to search	2000–2019. Knowledge and practice have developed immensely during recent decades. The scope is therefore limited to research published after the year 2000.
4) Inclusion/exclusion	Articles must: 1) Use/define the term citizenship; 2) Focus on/include people with dementia; 3) Focus on the nursing home context; 4) Be peer-reviewed published articles written in English, Norwegian, Swedish or Danish; 5) Be empirical primary research or theoretical articles.
5) Search terms	Citizenship AND dementia
6) Document the research process	Databases, search terms, results and inclusion process were thoroughly documented.
7) Assess retrieved articles	Blinded inclusion/exclusion. Reference lists were searched for additional articles.
8) Summary table of included articles	Figure 2.1; Flowchart of the inclusion/exclusion process
9) Number of retrieved articles	15
10) Quality assessment	No quality assessment was performed. Articles have gone through a peer-review process before publication.
11) Critical review	Descriptive review
12) Check reference list for accuracy	Conducted

Inclusion criteria

The criteria for inclusion are defined as follows:

Criteria 1) Must use/define the term citizenship: Authors discussed whether to operationalize citizenship, searching for concepts such as autonomy, self-determination or participation. Our understanding of citizenship goes beyond these concepts individually. To enable exploration of citizenship as a concept or practice, only articles using the term were included.

Criteria 2) Must focus on/include people with dementia: Research suggests citizenship may be particularly challenging for people with dementia. It was therefore considered important that articles specifically discuss citizenship in relation to dementia.

Criteria 3) Must focus on the nursing home context: Nursing home life may hold specific challenges related to citizenship. Broadening the scope to explore citizenship in general could produce knowledge with less relevance for this institutional context.

Criteria 4) Must be peer-reviewed published articles written in English, Norwegian, Swedish or Danish: Inclusion is limited to published articles exposed to a process of quality assessment. For practical reasons, the scope is limited to languages understood by the authors.

Criteria 5) Can be empirical primary research or theoretical articles: Both conceptualizations and practices of citizenship are explored. Both theoretical arguments and empirical explorations are therefore considered relevant.

Search process

Searches were conducted through international and Scandinavian sources, enabling inclusion of articles written in English and the Scandinavian languages (for an overview of the databases, see Table 2.1). Searches were performed by the first author using the search combination Citizenship AND Dementia. Context terms were not added during searches (e.g. “nursing home”, “care home”). Trial searches showed that adding context increased the risk of missing relevant articles, since a variety of names are used for such institutions. The result size was considered manageable, therefore contextual relevance were assessed manually.

Primary search resulted in 366 titles. The first author performed initial inclusion/exclusion based on the inclusion criteria, assessing titles, keywords and abstracts. Eighty articles were included for further consideration; after the removal of duplicates, 42 articles remained. All 42 articles were manual searched by the first author for further references, resulting in four articles being included for further considerations. The remaining 46 articles were read in full by the first and last author. A blinded inclusion/exclusion was performed, and the authors met to agree on the final inclusion. The process resulted in 12 articles meeting all criteria for inclusion. A repeated search was conducted in August 2019 to ensure identification of new publications from the last year. The same procedure was performed, resulting in the inclusion of three new articles (Figure 2.1).

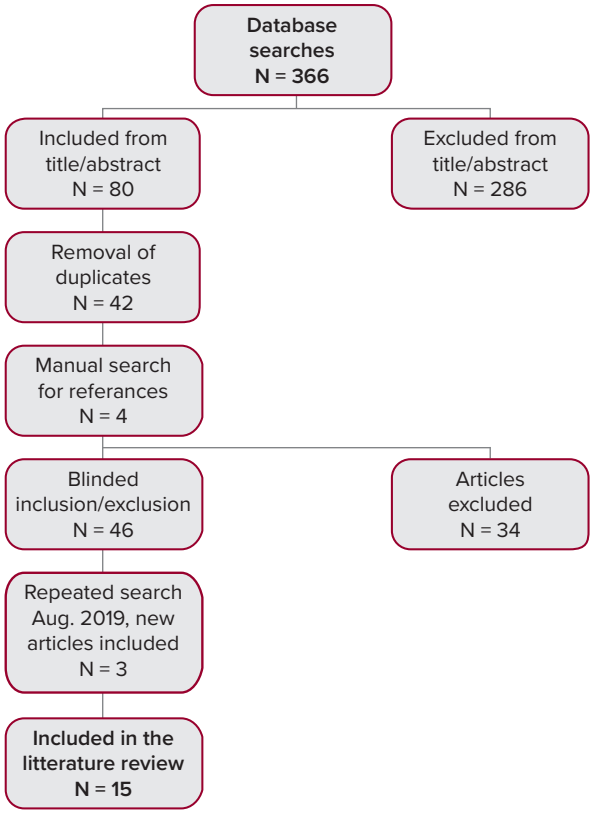

Figure 2.1: Flow chart of the inclusion/exclusion process.

Characteristics of included articles

15 articles were included (Table 2.2). Several were theoretical, others explored citizenship through empirical studies.

Table 2.2: Typology of articles

Authors	Year	Title	Methods	Citizenship	Country
Morgan-Brown, Brangan, McMahon & Murphy	2019	Engagement and social interaction in dementia care settings: A call for occupational and social justice	Observational study using ATOSE to document degree of engagement and social interaction	Citizenship through engagement and social interaction	Ireland
Canning & Blakeborough	2019	Intergenerational dance in long-term dementia care: Social citizenship in dementia care	Interviews. Participant observations	Social citizenship through dance	Canada
Grigorovich, Kontos & Kontos	2019	The "Violent Resident": A critical exploration of the ethics of resident-to-resident aggression	Theoretical	Relational citizenship and resident-to-resident aggression	Canada
Grigorovich & Kontos	2018	Advancing an ethic of embodied relational sexuality to guide decision-making in dementia care	Theoretical	Relational citizenship and sexuality	Canada
Ursin & Lotherington	2018	Citizenship as distributed achievement: Shaping new conditions for an everyday life with dementia	Qualitative ethnographic interviews	Collectivist and distributed understanding of citizenship in everyday life	Norway
Kontos & Grigorovich	2018	Integrating citizenship, embodiment, and relationality: Towards a reconceptualization of dance and dementia in long-term care	Theoretical	Relational citizenship and dance	Canada
Kontos & Grigorovich	2018	Rethinking musicality in dementia as embodied and relational	Theoretical (used qualitative data)	Relational citizenship and musicality	Canada
Marsh, Courtney-Pratt & Campbell	2018	The landscape of dementia inclusivity	Qualitative participatory	Cosmopolitan citizenship and community gardening	Australia
Simpson, Wilson, Brown, Dickinson & Horne	2018	"We've had our sex life way back": Older care home residents, sexuality and intimacy	Qualitative interviews	Sexual citizenship and sexuality	UK
Gjødsbøl, Koch & Svendsen	2017	Resisting decay: On disposal, valuation, and care in a dementia nursing home in Denmark	Qualitative ethnographic	Citizenship through substitution processes in everyday care	Denmark
Ursin	2017	Practicing citizenship: Analysing everyday life among families living with dementia	Qualitative ethnographic interviews	Relational citizenship through everyday practices	Norway
Kontos, Miller & Kontos	2017	Relational citizenship: Supporting embodied selfhood and relationality in dementia care	Qualitative analysis (data from mixed methods intervention)	Relational citizenship and creativity and sexuality	Canada
Kontos, Grigorovich, Kontos & Miller	2016	Citizenship, human rights, and dementia: Towards a new embodied relational ethic of sexuality	Theoretical	Relational citizenship and sexuality	Canada

Authors	Year	Title	Methods	Citizenship	Country
Ward, Campbell & Keady	2016	"Gonna make yer gorgeous": Everyday transformation, resistance and belonging in the care-based hair salon	Qualitative ethnographic	Emplaced, embodied and performative citizenship and the care-based hair salon	UK
Baldwin & Greason	2016	Micro-citizenship, dementia and long-term care	Theoretical (used qualitative material)	Micro-citizenship in nursing home everyday life	Canada

RESULTS

Since the 15 articles differ in many ways, we began our analysis by conducting a narrative summary, providing a general descriptive discussion of the research findings (Evans, 2002). These summaries respond to three decisive questions: How is citizenship in nursing homes a) conceptualized and (b) described as practice, and (c) have these understandings changed over time?

Concepts of citizenship

Several of the reviewed articles, e.g. Canning and Blakeborough (2019), employ the notion of social citizenship. In the context of dementia, Bartlett et al. (2010, p. 37) have defined social citizenship thus:

> Social citizenship can be defined as a relationship, practice or status, in which a 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. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level.

Six articles originating from a Canadian research environment explored a model of relational citizenship. This body of research extends social citizenship by incorporating central tenets of relationship-centred care and embodied selfhood theory. They argue that embodied selfhood challenges assumptions of loss of agency with dementia by treating the body as itself having creative and intentional capacity. It is emphasized that relational citizenship calls for the development of institutional policies that reduce oppressive organizational practices, and enhances the provision of leisure and social activities (Grigorovich & Kontos, 2018; Grigorovich, Kontos, & Kontos, 2019; Kontos & Grigorovich, 2018a, 2018b; Kontos, Grigorovich, Kontos, & Miller, 2016; Kontos et al., 2017).

Ursin (2017) also employs a notion of relational citizenship, exploring interactions between the social and material for people living with dementia. Ursin & Lotherington (2018) promote a collectivist and distributed understanding, critiquing that previous studies often perceive citizenship as allocated statically to individuals.

Morgan-Brown, Brangan, McMahon & Murphy (2019) point to the notion of equity, particularly in social and occupational engagement, as the defining aspect of true citizenship. Baldwin & Greason (2016) introduce micro-citizenship for persons with dementia in long-term care, while Gjødsbøl, Koch & Svendsen (2017) discussed citizenship in relation to how staff – through everyday care – upheld meaning and value in life for residents in the nursing home. Ward, Campbell & Keady (2016) highlight emplaced, embodied and performative citizenship; they focused on women's everyday experiences and the care-based hair salon. Simpson, Wilson, Brown, Dickinson & Horne (2018) and Marsh, Courtney-Pratt & Campbell (2018), finally, employ the notions of sexual citizenship and cosmopolitan citizenship, respectively.

Practices of citizenship

Grigorovich et al. (2019) critiques the resident-to-resident aggression discourse and its focus on individual characteristics and triggers related to the diagnosis of dementia. Grigorovich & Kontos (2018) and Kontos et al. (2016) highlight the need for better support of resident's sexual rights in long-term care, recognizing sexuality as a universal human need and fundamental to embodied self-expression. Kontos et al. (2017) explored how embodied selfhood and relationality might be supported or undermined at the micro level, focusing on creativity and sexuality. They argue that the arts draw on the potentiality of the body for innovation and creative action and support non-verbal communication and affect, therefore as an important means to sustain citizenship. Within a relational model of citizenship, creative engagement, e.g. dance (Kontos & Grigorovich, 2018a) or music (Kontos & Grigorovich, 2018b), are not understood as consciously learned principles and rules, but acknowledges the taken for granted and latent knowledge our bodies possesses. As such creativity is not an intellectual operation but arises from practical involvement.

Baldwin & Greason (2016) argue that micro-citizenship creates a link between the personal and political, incorporating individualistic aspects of person-centred care, and political and rights-based aspects of citizenship. In the micro-arena, people seek to realize citizenship in interactions with others, through ordinary everyday activities. Micro-citizenship is described as precarious if left to individuals to realize, since it is dependent upon the attitudes and behaviour of individual staff

members. It must therefore be supported by institutional policies and made specific for practice.

Ursin & Lotherington (2018) explored links between multiple care relations, citizenship and knowledge, demonstrating how different care collectives act and produce citizenship differently, and how agency emerges as an effect of care in practice. Ursin's article on the organization of services (2017) explores how social actors (e.g. family, staff) and material actors (e.g. food lists, journals, taxi cards) are entangled into seamless networks that may – or may not – enable people with dementia to act as citizens.

Gjødsbøl et al. (2017) suggest that life's meaning and worth were established when residents gained qualities of personhood and agency through substitution processes. Because of the residents' dependence on others, the caregivers became vehicles through which they were interpreted, emerging as persons through the activities of others. Bringing forth the person was considered a core achievement in care, substituting lost functions and re-establishing people with dementia by helping them exist in time, space and social relations.

Morgan-Brown et al. (2019) call for occupational and social justice, using an observational tool (ATOSE) to measure the degree of engagement in long-term care. They argue that by clearly identifying engagement in long-term care as good practice, poor practice and proposals for change can be recognized.

Canning and Blakeborough (2019) explore intergenerational dance in a nursing home. They argue that arts-based interventions promote positive engagement and provide opportunities for creative expression and social inclusion.

Ward et al. (2016) argue citizenship can be shored up or undermined in day-to-day encounters and relationships, and that such encounters must be perceived as reinforcing and upholding inequalities. Everyday discrimination is described as often passed unseen, repetitive and cumulative, and that citizenship is expressed through actions and activities of everyday life.

Marsh et al. (2018) explored how community gardens can promote insights into dementia inclusivity and cosmopolitan citizenship. Cosmopolitan citizenship involves more than care and compassion but is about ensuring inclusion and agency even when agency is considered reduced due to cognitive impairments. They argue against growing movements to create tailored gardens for people with dementia, which creates separation from the community, arguing that community gardens can represent a space to practice citizenship.

Simpson et al. (2018) explored sexuality in care homes, where dominant narratives among participants positioned residents outside sexual citizenship, as post-sexual or post-intimate. The authors argue that this can reflect an ageist erotopho-

bia occurring within conditions of panoptical control which construct residents as post-sexual. The term ageist erotophobia describes anxieties concerning older people as sexual beings. Panoptical control means that such thinking can be internalized by residents themselves. Through this, residents can be denied sexual citizenship.

Changing understandings

Most articles describe how biomedical understandings historically has dominated the dementia field, viewing people through pathology. Through this lens, Kontos et al. (2017) argue that capacities for communication and intellect are linked to the practice and status of personhood and citizenship, through a focus on cognitive deficits and decline. Canning & Blakeborough (2019) argue that such a reductionist lens calls the person's identity and personhood into question. According to Kontos & Grigorovich (2018a), this leads to a belief that people with dementia are unable to make meaningful contributions to their own lives or those of others, denying agency and citizenship. Kontos et al. (2017) write that concerns about inhumane consequences caused by the pathologization of dementia led to other paradigms, e.g. person-centred care contributed to a shift in focus from pathologizing behaviour to understanding the meaningfulness of actions. Relationship and person-centred care sought to strengthen the focus of care to interdependence and relationality. Nonetheless, person-centred care is criticized for decontextualizing the individual from relationships and social participation. The focus remains on care relationships, overlooking other relationships the person might have, such as with the public and political sphere. As such, people with dementia are still conceptualized solely as "in-need-of-care".

According to Kontos & Grigorovich (2018a) and Kontos et al. (2017), the turn to citizenship intends to redress the way people with dementia are socially and structurally disadvantaged because of assumptions that agency is eroded by dementia. The interest in citizenship in the dementia field has increased in recent years; however, several authors argue that citizenship in this area is under-theorized, both in practice and research (Baldwin & Greason, 2016; Kontos et al., 2017; Ursin, 2017; Ursin & Lotherington, 2018).

DISCUSSION

This article seeks to answer the research question: How is citizenship for persons with dementia living in nursing homes conceptualized and described in the

research literature? We have sought to describe the concepts and practices of citizenship presented in the included articles, as well as their critiques of medical and care-based paradigms. In the following section, citizenship is discussed in relation to three arguments. For one, basic characteristics of nursing homes, and secondly, our understandings of dementia, influence how residents can enact their citizenship. Third, we need to view different knowledge paradigms as complementary in order to bridge the gap between residents' needs and capabilities as citizens.

Nursing home characteristics

Nursing homes are not one homogenic entity. They can have different physical structures, recourses, ideologies or admission criteria. Some common characteristics may be people living close together, not choosing who they live with, to varying degrees being allowed to leave by themselves, and where institutional routines may set the stage for everyday life. Hence, it is perhaps useful to discuss the results in light of Goffman's (1961) concept of the total institution, defined as: "... a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman, 1961, p. xiii).

The depiction of "a formally administered round of life" (Goffman, 1961) may relate to strict procedures and inflexible institutional regimes. Baumbusch (2008) describes a systematic decommissioning of citizenship for both residents and staff through her critical ethnography of Canadian long-term care, arguing that being part of an institution where rules and regulations dictate most aspects of life can contribute to progressive loss of identity. In Heggestad, Nordtvedt & Slettebø's (2013) article "Like a prison without bars", residents felt their freedom was restricted. One participant expressed that she did not experience the nursing home as home. Home for her was a place where you could walk around and do what you like. Findings revealed that feelings of a lack of freedom may be related to institutional frames, like routines and locked doors, as well as living with strangers. Eyers, Arber, Luff, Young, and Ellmers (2012) described a care home day that resembled the clinical model of a hospital rather than a personal home environment. The policy rhetoric of individual choice, autonomy and dignity was confronted by the reality of institutional care. This exemplifies Stafford's (2003) depiction of the nursing home as "caught in the middle", being both hospital and home, though favouring the hospital and biomedical mode of thought.

Another aspect of Goffman's (1961) total institution relates to "being cut off from the wider society". Baumbusch (2008) writes that staff and residents may

experience that by entering the nursing home they cross a border and become invisible to others in society. This may create a divide between those within and those outside. While those within lose contact with the outside world, society in general may not be privy to insight into nursing home everyday life. Such a divide may contribute to a societal fear of nursing homes, as depicted by Stafford (2003):

> Death itself is feared less than a long, lingering stay in the nursing home. […] Those who work within have low status in our society. Those who live within endure a social death, cut of in many ways from the outside world… (Stafford, 2003, p. 17).

Citizenship scholars argues for practices that combat exclusion from society and inflexible institutional regimes that limit opportunities for engagement. In the study by Canning & Blakeborough (2019), connections with society were preserved by inviting children into the nursing home through a shared goal of dance, and as such dementia slipped into the background. Features of public places, e.g. community gardens (Marsh et al., 2018), may also enable inclusion in society, contrary to beliefs that such environments are too risky for people with dementia. Certain places, e.g. the care-based hair salon (Ward et al., 2016), may also offer opportunities for the expression of citizenship, through creating a shared temporal frame and a place for resisting everyday discrimination.

Morgan-Brown et al. (2019) argue citizenship places an obligation to identify and address occupational injustice, documenting that residents spent an average 62.4 % of their time not engaged while in communal rooms. Baldwin & Greason (2016) promote micro-citizenship through normal everyday activities, exemplified by a woman who kept running away with the tea-trolley. Her actually serving tea to other residents was a form of participation linked with meaning and identity; still, staff would express concerns regarding residents' capabilities, or risks associated with it. In the garden, people with dementia were assumed to be able (Marsh et al., 2018), participating in unexpected ways compared to life inside the residential home, where some staff hesitated to allow low risks because of safety concerns. Being denied such opportunities can be understood through the everyday discrimination highlighted by Ward et al. (2016), arguing that the struggle for self-determination, belonging and social participation happens through mundane encounters that are hard to identity. If safety takes precedence (Marsh et al., 2018), residents might be prevented from doing "risky" activities, such as pouring a hot drink themselves. This can lead to an everyday life where opportunities for engagement are scarce, and where, as shown by Eyers et al. (2012), residents changed everyday habits to try to adapt to care home routines.

Perceptions of dementia

Institutional regimes are likely influenced by society's perception of dementia and the stories told. A biomedical understanding frames such stories as loss of identity, agency and autonomy, and highlights safety and control. Kontos & Grigorovich (2018a, 2018b) argue that the bio-medicalization of behavioural and psychological symptoms can lead to care focusing on bodily needs and managing challenging behaviours. Then normal human behaviour is seen as a set of problems to be managed, and actions of people with dementia as expressions of disease (Ursin & Lotherington, 2018), not as meaningful or intentional as one would perceive other citizens. Baldwin & Greason (2016) problematize how citizenship may be straightforward when a person is deemed capable, but less clear if staff view dementia as undermining possibilities of engagement and participation. In Dupuis, Wiersma & Loiselle's (2012) study, the behaviour of residents without dementia was almost always viewed as intentional, whereas only selected behaviour of residents with dementia was viewed the same. Perceptions of independence (Boyle, 2008) or stereotypes of the elderly as post-sexual (Simpson et al., 2018) can be internalized by residents, leading them to adapt to the expectations of the nursing home. This demonstrates that a diagnosis of dementia, and perceptions of ability, in themselves, can reduce citizenship. The person is "sick", leaving the responsibility with healthcare professionals to provide treatment and care.

Solutions introduced to combat the biomedical legacy, such as person-centred care, placed "the person" centre stage, highlighting psychological needs and identity in preserving dignity and personhood (Kitwood, 1997). Currently, according to Harnett & Jonson (2017), we still tend to define normality by comparing residents, whilst comparisons to others in society are used to a lesser extent. This may lead to acceptance of everyday limitations because it is considered normal within this framework. Citizenship represents an expansion, towards being a "citizen", with the right to expect the same from life as others.

Complementary knowledge-paradigms

A "battle" of paradigms seems to emerge from the included articles, represented by understandings and practices, framing the lives of people with dementia. Citizenship emerges as a critique of the dominant biomedical and health and care-based understandings. Still, cognitive decline associated with dementia might challenge abilities for active participation. Gjødsbøl et al. (2017) describe a profound dependency: some residents were unable to communicate or move, whilst others to varying degrees were able to establish themselves in the world. Approximately

75% of people with dementia may have neuropsychiatric symptoms (Bergh, Holmen, Saltvedt, Tambs, & Selbæk, 2012), and staff may be faced with complex ethical dilemmas (Rognstad & Nåden, 2011), including balancing autonomy and force when residents exhibit challenging behaviours. This underscores the need for medical and care-based knowledge, and nursing homes provide a place that ensures residents' health and safety. But if nursing homes, as Cahill (2018) argues, are often dominated by excessive focus on clinical management, drug treatment and control, this "formally administered round of life" (Goffman, 1961) may put residents' freedom and citizenship under pressure.

Citizenship does not translate into complete autonomy or an all-or-nothing competence. Gjødsbøl et al. (2017) describe that staff recognized that even small contributions, such as sticking up a big toe during dressing, were significant. Kontos & colleagues promote an embodied knowhow that enables residents to emerge as citizens (Grigorovich & Kontos, 2018; Grigorovich et al., 2019; Kontos & Grigorovich, 2018a, 2018b; Kontos et al., 2016; Kontos et al., 2017). Creativity is not seen as purely intellectual, but arises from practical involvement requiring the person to be tactically involved (Kontos et al., 2017). Collective citizenship (Ursin & Lotherington, 2018) acknowledges that lived citizenship is not something we achieve by ourselves but as part of social networks that supports residents' abilities for participation.

Bartlett et al. (2010) write that personhood and citizenship are intertwined: both are important, but they bring different aspects to the debate. While citizenship implies discussions about power and is focused on rights, personhood emphasizes the uniqueness of the human experience and is focused on needs. Ursin & Lotherington (2018) argue that to enable citizenship the ability to shift between knowledge regimes is critical, and that we must be able to detect the timeliness and appropriateness of different knowledge regimes. As such, it seems vital that these sometimes conflicting understandings complement each other to ensure that people living with dementia in nursing homes experience life to the fullest extent possible.

Limitations

The scope was limited to research specifically utilizing the term citizenship and focused on the nursing home context. We recognize that citizenship isn't solely researched in articles that mention citizenship, and that knowledge from other contexts might be relevant. Still, this was designed to explore the concept and practice of citizenship in this specific institutional context. Another challenge relates to

different levels of theorization in the articles included, from theoretical arguments, qualitative empirical studies as well as one utilizing quantitative data. This challenged a transparent process of analysis, as a result the risk of bias is heightened. Our interpretations may, as such, be influenced by our own preconceptions, something we have sought to limit by close collaboration between all three authors throughout the process. A limited number of countries and research environments are represented, e.g. only research from western countries was included, and we recognize that nursing homes may be organized differently between nations. The oldest articles included were published in 2016. This may be indicative of a growing interest in citizenship, showing it may be in its early years when it comes to research.

CONCLUSION

This literature review sought to gather knowledge of the conceptualizations and practices of citizenship for people living with dementia in nursing homes. A range of citizenship concepts were utilized by the authors, seeking to combat discriminatory practices and to promote opportunities for engagement and participation. Citizenship practices may be under pressure by certain nursing home characteristics, such as inflexible institutional regimes, or limited according to the perceptions of abilities. They promote opportunities for participation in activities and everyday chores, enabled through supporting social networks, where even minor acts can hold significance. It promotes acceptance of risks, acknowledgement of the body's intentionality and upholding societal connections. Citizenship emerges as a critique of dominant biomedical and health and care-based understandings. Through viewing these understanding as complementary, we may begin to bridge the gap between residents' apparent needs and their capabilities as citizens.

Implications for future research

The challenges and limitations of a citizenship perspective that emerge when we use a multiple knowledge perspective to understand everyday life with dementia ought to be studied. We need further empirical exploration of citizenship practices in nursing homes, in a way that encompasses both apparent needs and disabilities of people with dementia and their abilities as citizens.

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3. "A tune beyond us, yet ourselves": An ethics of the unconscious and cultural citizenship in dementia

Oddgeir Synnes

Abstract The chapter argues for engagement with the arts as part of a *cultural citizenship* for persons living with dementia as it might enable a nuanced awareness of agency, contribution and belonging. Furthermore, this argument is linked to an *ethics of the unconscious* – on an individual as well as a societal level. These perspectives are brought into dialogue with the author's empirical research on the use of visual arts and poetry writing in dementia care.

Keywords cultural citizenship | ethics of the unconscious | dementia | poetic language | arts

INTRODUCTION

How do we include persons living with dementia in our society and in our lives? How do we respond to their needs and their wishes? And how do we acknowledge and support the capacities and capabilities of persons with dementia as citizens? The evolving field of citizenship in dementia studies has underscored how persons with dementia should be empowered and given opportunities to participate in and contribute to society, raising our understanding of the needs and capabilities of persons with dementia to the societal level (see Bartlett & O'Connor, 2010; Nedlund, Bartlett, & Clarke, 2019).

In this chapter, I will argue that one productive way towards participation and citizenship for persons with dementia is through engagement with the arts and poetic language that might enable a nuanced awareness of agency, contribution and belonging. The argument will be grounded in examples from my own experi-

ences working as an assistant in dementia care as well as from two practical and academic projects in which I have been involved. The first involved the writing of poetry with persons with dementia (Synnes, Råheim, Lykkeslet, & Gjengedal, 2021) and the second investigated encounters of persons with dementia with visual art in an art museum (Lea & Synnes, 2020).[1]

The examples will be brought into dialogue with perspectives that highlight aesthetic aspects of citizenship: *a narrative citizenship* that underscores the need for a multitude of possibilities of expression and voice (Baldwin, 2008) and a *cultural citizenship* that argues that citizens need to be given opportunities to partake in culture's meaning – producing processes in society (Van Hensbroek, 2010).

Furthermore, my argument of bringing practices of art and poetic language to the attention in dementia is intrinsically linked to an ethics of how we respond as individuals and as a society to other persons. Here I am indebted to philosopher Kelly Oliver and her understanding of *an ethics of the unconscious* (2004), which raises the need for an ethics to acknowledge also the unconscious fears and desires toward other people and how the arts and our imaginative abilities are crucial for achieving this.

THEORETICAL PERSPECTIVES

Oliver's ethics of the unconscious (2004) is influenced by the psychoanalysis of Freud, where the unconscious consists of repressed feelings, automatic skills, subliminal thoughts, habits and automatic reactions, and even hidden desires and phobias. But Oliver differs from traditional psychoanalytic theory in how she applies the concept of the unconscious to address social problems like oppression, and in how this influences us both on a subjective and a societal level. Hence, her understanding of an ethics of the unconscious opens for a societal perspective and thus, I will argue, also for the possibility or hindrance of citizenship. This is a radical ethics that acknowledges that our unconscious fears and drives might influence how we respond to people and how people are able to respond to us, something that might be of particular relevance when it comes to how we as individuals and a society relate to dementia. Recent research has claimed that dementia has replaced cancer as the most feared disease in many Western societies, and the most feared disease among older people (Bystad, Grønli, Lilleeggen, & Aslaksen, 2016; Alzheimer's Association, 2014). Furthermore, research has also shown how media

1 For a more in-depth exploration of methodology, ethics and findings, see the articles referenced.

portrays dementia in predominantly negative ways (Peel, 2014) which might include a loss of identity and self (Van Gorp & Vercruysse, 2012). This *tragedy narrative* influences negative attitudes towards persons living with dementia (Dupuis, Kontos, Mitchell, Jonas-Simpson, & Gray, 2016). It has been suggested that one way of opposing this hegemonic narrative is through engagement with the arts which can open "transformative spaces in which to challenge dominant assumptions […] and envision new possibilities…" (Dupuis et al., 2016, p. 358).

A central point in Oliver's theory is precisely the need for imagination through engagement with the arts. For Oliver, oppression influences the imaginative ability of the oppressed, and we thus need the arts to be able to imagine differently.

Oliver's perspectives on imagination's role in ethics can furthermore be seen in relation to a narrative understanding of citizenship in dementia, in how forms of storytelling might open ways of meaning making, potential contributions and agency of persons with dementia. Baldwin (2008) argues for an understanding of personhood in dementia as a performative activity that requires narrativity. At the same time, narrative traverses the subjective, the inter-personal and the societal – stories are linked to relational practices and are performed through the participation in various arenas in society and hence narrative calls for an intertwinement with citizenship, linking the personal and the political. In his outline of a narrative citizenship, Baldwin argues for the necessity of a *narrative agency* that involves two crucial aspects. Firstly, persons with dementia must be able to express themselves despite limited linguistic abilities. This calls for a broad understanding of narrative, where stories can also be articulated in dance, movements and other non-linguistic expressions. Secondly, persons with dementia must be given opportunities for narrative expression (Baldwin, 2008, p. 225).

Calling upon my own experiences from dementia care as well as my research on poetry writing and dementia (Synnes et al., 2021) and visual arts and dementia (Lea & Synnes, 2020), I will argue for an elaboration of a narrative citizenship that involves *poetic language* and what philosopher Gaston Bachelard terms *poetic instants* (1939/2013). While Baldwin calls for an expansion of narrative that is non-linguistic, I will argue for an expansion of narrative citizenship through the addition of a different genre that offers another perspective of linguistic capabilities and agency. One challenge with narrative and dementia is the struggles for coherence and the implicit narrative norms that are often required of storytellers (Hydén, 2018). As poetic language to a large degree differs from narrative's emphasis on coherence and horizontal time, poetry can offer an alternative linguistic potential for agency in dementia. Bachelard's emphasis on the poetic instant is an acknowledgement of what happens in the moment; it does not require to be part

of a linear narrative. For Bachelard, this recognition of poetic moments is closely related to existential and ethical issues as much as linguistic ones, and involves a deep moment of listening (Kearney, 2008, p. 40). Furthermore, it involves an emancipatory moment, an emancipation of the person "imprisoned in horizontal time" (Bachelard, 1939/2013, p. 175). Thus, for Bachelard, poetic instants involve an ethics of *attention* to the moment, of what happens there and then which is not dependent on what has gone before. I will apply Bachelard's perspective through a reading of several encounters from my own practice in dementia care where I will argue that poetic instants may offer an interpretational frame of possibilities and recognition.

By applying the theoretical perspectives above, I will in the following argue that including persons living with dementia in society requires *an ethics of the unconscious*; challenging our assumptions and understandings, both on an individual and societal level. Furthermore, this challenge requires the imaginative abilities we can find in the arts and in a poetic language. My investigation will thus look into how *narrative*, *poetic instants* and participation in the arts can enable a nuanced awareness of potentiality and possibility that must be seen as part of a *cultural citizenship* for persons living with dementia.

AN ENCOUNTER

I will start with a personal anecdote that has followed me ever since the summer I was 20 years old when I worked as an assistant at the nursing home in the small village where I grew up in the northern part of Western Norway. I didn't really know what to expect, apart from the jokes from the rest of the boys that I was about to enjoy a summer of changing nappies on old people who had forgotten who they were. But something happened in the encounters between me and the residents at the nursing home; something that led me to work for eight years in different nursing homes, as well as changing my career path, where I switched my plans from becoming a high school teacher to working in the field of narrative gerontology. From this first summer, many of the encounters have remained, in particular the following one.

> It was a hot June afternoon when an older woman living at the dementia unit called out to me from her room: she needed a glass of water. When I approached her, she instructed me that it had to be from the lake Grytalivatnet, which is situated beneath the mountains of Lauparen at 1434 meters above sea level, and Grytavasstinden (1328 meters above sea level) where the peaks are

covered in snow the whole year. I sat down with her and explained that this water was not from Grytalivatnet. At first, she didn't want the water, but after hearing that I very much knew the lake and where it was and that I might be going up there the next weekend, she reluctantly accepted the glass of water and I got some narrative fragments about her time being a milkmaid there in her youth. It was difficult to get a sense of the details she was muttering, but there was a mention of the joy of being with the animals there and a remark about some young boys coming up for what I believe was a Saturday evening.

THE ENCOUNTER READ AS PART OF A NUANCED NARRATIVE CITIZENSHIP

Why has this particular encounter stuck with me ever since? I think there are several reasons – maybe reasons still unknown to me – but I experienced this woman's calling out for the glass of water, her request when she demanded it be from Grytalivatnet, to be an existential request that opened up something in me and made me responsible for how I approached her and how I responded. I was forced to look at myself and the woman from another perspective. Of course, I knew that the residents in the nursing home all had a unique life history, but it was as if this little fragment made me realize it in a different way; her calling out to me was something to which I was morally obliged to respond. Additionally, I learned something about myself and my situatedness in a culture. Baldwin (2008, p. 225) underlines how one way of maintaining a narrative agency for persons with dementia might be by their possible contribution to the stories of others. This is also in line with a long-standing view I have held when interpreting this encounter. According to the moral philosopher Alasdair MacIntyre (2007), the stories we are told define the persons we become; it is through the stories of our culture that we learn to find a place in that culture. For me, the encounters with the stories of the older residents, including narrative fragments at the dementia unit, led to an awareness of my belonging to the place where I was living. I experienced a connectedness and a gratitude towards the residents who let me take part in some of the episodes and memories that had been and still were an important part of their lives, and which now became fragments of my own history. The places and the nature of my hometown changed after that summer. Whenever I go up to the Grytalivatnet lake, I always see the older woman demanding a glass of water from this particular place, looking at different places where she might have walked as a milkmaid.

THE ENCOUNTER READ AS A POETIC INSTANT

However, my ongoing reflections on this particular encounter have also made me rethink it in light of Bachelard's notion of the poetic instant. Clearly there is not much of a story going on in this encounter. Narrative fragments, yes, but how much of the story of this woman can I claim to have met? A common way of understanding a narrative or story is a telling of something that happens as a consequence of some previous episode(s) (see e.g. Bruner, 2004; Ricoeur, 1991). Hence, a narrative is the synthesis of heterogenous elements over time that are made into a meaningful whole through the plot. (As such, my re-telling of the encounter is more of a story in which I interpret the encounter and how this has affected me.) By looking at this particular encounter from another angle, might it be interpreted, not as a narrative fragment or a "broken narrative" (Hydén & Brockmeier, 2008) but as a poetic instant? For Bachelard, poetry shatters the continuity of clock time or sequential time and introduces what he calls "vertical time" (Kearney, 2008, p. 38). While narrative time is continuous and horizontal, poetic time for Bachelard is discontinuous and disruptive. It is a single moment that involves an awareness of a dynamic ambivalence that "…compels us to value or devalue" (Bachelard, 1939/2013, p. 59). Thus, for Bachelard the poetic instant implies an ethics of a "morality of the instantaneous" that is not dependent upon a history or continuous time, but is an emancipatory power manifested in the poetic moment. As Lescure (1966/2013) comments on Bachelard: "For never – not for a single moment are we the sum of our past. Each instant discovered is what grants new sense, at every instant to the senseless history we have lived so far" (p. 70).

To look at this encounter as a poetic instant might offer a different interpretation than to see it as an encounter between her life story and mine. True, the narrative fragment from the lake played a significant part, but maybe not as narrative time – as a part of her continuing life story – but as poetic, vertical time. In light of Bachelard, could one not think of this encounter as a freeing of horizontal time, of our situatedness, as an older woman with dementia living in a nursing home and myself as a young immature assistant; an encounter at that specific moment of vertical time. As Bachelard writes: "Time no longer flows. It spouts" (1939/2013, p. 60). As such, the fragment from the lake was vital, but as part of the moment, of the encounter there and then. A genuine meeting between two persons involves a "synthesis of event and eternity" (Bachelard, quoted in Kearney, 2008, p. 41). But for this to happen, it requires attention and receptivity towards the moment and the other.

THE ENCOUNTER READ AS AN ETHICS OF THE UNCONSCIOUS

One lasting impression of this encounter is how it changed my way of thinking, and I believe that this has a lot to do with how I had unconsciously thought of people with dementia. According to Oliver (2004), a true ethics must not just take responsibility for our actions and values but also for our unconscious desires and fears. This is a radical ethics that acknowledges that our unconscious fears and drives might influence how we respond to people and how people are able to respond to us. This last part, how people might respond to us, and what conditions and preconditions underline and influence possible responses, are crucial for Oliver, who sees these at the heart of our subjectivity. Oliver criticizes traditional psychoanalysis for putting too strong an emphasis on the individual psyche; rather she is arguing that subjectivity is formed through *relationality*, meaning relationality comes first. As Oliver stresses: "Subjectivity is constituted through response, responsiveness, or response-ability and not the other way round. We do not respond because we are subjects; rather, it is responsiveness and relationality that make subjectivity and psychic life possible" (2004, p. xviii).

Oliver writes from the perspective of feminism and post-colonialism, but I find this to be significant for dementia too. Under what conditions do persons with dementia have an ability, an arena or another human being to respond to – to have the opportunity of "response-ability". For Oliver, an ethics of the unconscious involves an "endless responsibility" that is indebted to otherness and others, and that we can never fully comprehend but must continually strive to understand. This is a perpetual task of trying to grasp the other and ourselves, while knowing that we can never fully get there. As Oliver argues:

> We do not know or understand ourselves. We do not know or understand others, perhaps most especially those closest to us. Once we fall under the illusion that we do, that we understand ourselves and others, then we lose the possibility of communication […] Acknowledging that we don't understand or know, and moreover that we can never fully understand or know, provides the impulse for interpretation. Because we cannot know, we interpret. Because we cannot know, we mean. Because we cannot know, we are beings who mean. And through endless interpretation, our lives become meaning full (2004, p. xxiv).

Working with and being involved with people with dementia places considerable demands on our interpretations and our responses. It is an ethical demand that always ask us to question our understandings. Returning to my encounter with the

woman and the lake: how can I know what she asked for when she asked for a glass of water? I cannot really know. Her call or response-ability was met by a response from me, and I have interpreted her calling out as an existential need, her subsequent narrative fragments as possible expressions of longing and a need for belonging. Linking this to agency and response-ability, I will underline how this encounter is both part of my narrative and a poetic instant that still remains, both as appreciation, puzzle and ongoing interpretation.

THE ETHICS OF THE UNCONSCIOUS AND THE NEED FOR IMAGINATION

When Oliver is arguing for an endless interpretation, she turns to arts for its imaginative abilities. Through arts and imagination, we can see different possibilities for our being in the world by challenging our pre-understandings. In his novel, *A Death in the Family: My Struggle* (*Min kamp 1*), the Norwegian author Karl Ove Knausgaard ponders how we have forgotten that which could shake us out of our comfort zone or what could hold the potential for new insights: "for the problem is that the intellect has taken over everything […] The limits of that which cannot speak to us – the unfathomable – no longer exist. We understand everything, and we do so because we have turned everything into ourselves" (2012, p. 201).

In another passage, he writes of how his move to Stockholm prompts a fresh outlook on things, but how this newfound lens will slowly fade again into the background:

> The bell had rung. The sounds here were new and unfamiliar to me, the same was true of the rhythm in which they surfaced, but I would soon get used to the rhythm of them, to such an extent that they would fade into the background again. You know too little and it doesn't exist. You know too much and it doesn't exist. Writing is drawing the essence of what we know out of the shadows. That is what writing is about. Not what happens there, not what actions are played out there, but the there itself. There, that is writing's location and aim. But how to get there? (Knausgaard, 2012, p. 17).

How do we recognize the unfathomable, how do we open up for an everlasting interpretation of those others which we cannot actually know as ourselves? And how can we challenge our pre-habitual and often tacit understandings of dementia? "But how to get there?". For Knausgaard, that is the task of writing. In the following, I will turn to some examples, both through experiences from a poetry writing project in dementia care, and from a project on dementia and visual arts.

HOW TO GET THERE? POETIC INSTANTS, DEMENTIA AND CITIZENSHIP

As Knausgaard writes: "You know too little and it doesn't exist. You know too much and it doesn't exist." A challenge in dementia care might indeed be that we know too little and too much. We know too little in that we do not know enough of what it is like to live with dementia, nor do we have adequate understanding of potential and possibilities of persons with dementia. And we might know too much in our (un)conscious thoughts and expectations of people living with dementia. Additionally, our actions and understanding (that is, family, friends, health professionals, researchers – and the society as a whole) might influence people living with dementia in their capacities and their thoughts about themselves. Oliver specifically raises the issue of how our unconscious fears and drives, as subjects and as a society, might involve an abjection of other people, that is, their experiencing of being cut off, of experiencing themselves as different or as other.

When starting my work on poetry and dementia, I was influenced by English poet John Killick, who for many years has worked extensively with poetry in dementia care (1997, 2018). According to Killick, poetry has the potential to capture the language of dementia: "Suddenly talk blooms with metaphor, allusion, the currents of feelings are reflected in rhythm and cadence" (Killick, 1997, p. 7). However, when Killick first started out, he didn't know what to expect. At the first nursing home he went to, the manager said to him on arrival: "It's a great mistake sending you here." And he opened a door and he said: "There's 30 people with dementia in that room... you'll get nothing out of any of them" (Killick, 2005). Sad as this quote is, it is not unusual to hear from people working with persons with dementia similar expressions. As Knausgaard writes: "You know too much, and it doesn't exist".

But Killick experienced right from the start that he became involved in relationships and conversations with the people living there, and he was astounded at many of the poetic expressions that he got through talking to the inhabitants. One example was a woman expressing her thoughts on living with dementia (And Killick stresses that he never adds anything):

> "This is your forehead..." indicating the top part, "... and it's like something hits it, smashes into it really hard, like a collision of planets and the whole goes into pieces, you lose a piece of the whole or you become many separate parts of the whole but not one planet, not one whole anymore." (Killick, 2005)

I read this as an example of a poetic instant, of an emancipatory meeting of the moment. At the same time, this can be read in light of Oliver's ethics: "We have a

responsibility to open up rather than close off the possibilities of response, both from ourselves and from others" (2004, p. xviii). We need an imagination of what is possible in human encounters, and we need to include in the realm of meaning people we regard "as those incapable of making meaning, as those who do not belong…" (Oliver, 2004, p. 195). For Killick, listening made him realize the capabilities and potential of language use in a person with dementia, which Killick sees as an unconscious process towards a more emotional kind of language.

Working in dementia with both narrative and poetry, I subscribe to Killick's argument that the use of poetry can feel liberating. While storytelling can require too much, poetry might open up different possibilities. In a recent project at a day care centre, I led several poetry groups for persons living with dementia (see Synnes et al., 2021 for an in-depth presentation of the project). Inspired by Killick, we made poems based on the participants' words. Sometimes poems were composed in the group and read aloud right after that, but mostly the poems were made after the group sessions had ended. The whole group meetings were tape-recorded, and I immediately transcribed them after the meeting. That same afternoon I sat down with a member of the project team, Arne Ruset, who is both a poet and a psychiatrist of old age and together we edited poems from the transcripts. Many tellings and narrative fragments that did not work as stories could be framed as evocative poems. In the process of editing the poems we stuck to the participants' words, never adding anything but often editing the transcripts by removing sentences or words, dividing sentences into stanzas etc. In this process, we were astonished at how many poems could be found in the transcription of one session (which lasted approximately an hour). The poet and psychiatrist expressed genuine surprise at the qualities of many of the poems that possessed a freshness and a lack of cliché, which are often prevalent when amateurs write poetry. One example was the short poem told by an older woman when the participants were sitting reflecting on a picture of a tree, and where she reminisced about the only tree they had on the small island where she grew up:

The only tree I had
was a little willow
It rose up against the garden fence
and then it bowed to the wind
Could not climb it
One of the sturdiest trees that exists
Nothing else could manage out there
in the sea

What did the poems, their creation and their subsequent readings achieve? I argue that they are examples of a nuanced narrative agency, or what we might term poetic agency. By treating the various transcripts of the conversations as possible poems in the making, it changed our interpretational outlook at what could be found in the language of persons with dementia. In his book on Wallace Stevens' poetry, philosopher Simon Critchley (2005) argues that poetry makes us see things anew by making the ordinary extraordinary. But as Critchley underlines, "the extraordinary is only extraordinary if it refers back to the ordinary" (2005, p. 11). The poetic imagination is tied to our common world, but where the ordinary is transfigured. The participants all expressed enthusiasm at hearing their poems, there was a lot of laughter and some tears as well; and they recognized their own words and expressions, as well as those of the others in the group. At the same time, they also experienced that their words were elevated when they were made into poems; the ordinary was made extraordinary. In Wallace Stevens' poem "The man with the blue guitar" there is a line about art's creative potential that reads "a tune beyond us, yet ourselves" (1967, p. 133). I believe that one of the reasons that the participants were moved by hearing their poems was the heightened attention given to their words. The poems were clearly their own words, but transfigured; they were a tune beyond them, yet themselves.

As we found the poems to possess literary qualities as well as being poignant examples of linguistic capabilities in dementia, we believed that the poems should be brought to a larger audience. In cooperation with the renowned literary festival in the city, the poems and the project were presented. In a full auditorium, a selection of poems was read aloud by a professional actor and was followed by a debate about the qualities of the poems and the possible impact of the project. In the front rows of the audience, most of the participants were present. The poems were also presented in cooperation with the local bus company; during the festival, the participants' poems were printed on the back of the buses and inside.

Good Norwegian
Mother was from Germany
Cannot remember that she spoke
Anything else than Norwegian
She spoke good Norwegian
But when she got angry
She spoke German!

Three years after the presentation at the literary festival, a collection of the poems was published (Synnes & Ruset, 2021) and several of the authors were interviewed in the local newspaper. Presenting the poems at the literary festival, at the back of the buses and through a publication can be seen as one way of supporting a narrative and cultural citizenship for persons with dementia, both by providing opportunities, arenas and access (Lid, 2020; Hensbroek, 2010) as well as an opening to impact others (Baldwin, 2008). According to Oliver (2004), imagination can involve a renewal of agency for creating meaning. At the same time, she stresses that meaning making is always relational and bound up with the culture underli-

ning the need for access and arenas. The need for visibility is highlighted by Critchley, who argues that poetry can teach us "an insight into things that comes from having them in sight" (2005, p. 6). Seeing and hearing words and poems by persons with dementia can have an effect. The leader of the day care centre, who was part of the discussion and reading at the literary festival, told me afterwards how the participants had been touched by the readings, but also how several people whom she had never met had approached her afterwards.

A related example of how art and the access to cultural arenas might challenge our understanding of dementia comes from a project concerning the participation of persons with dementia in designated exhibitions in visual art museums (see Lea and Synnes, 2020; 2021; Lea, Hansen & Synnes, 2020). One notable aspect was how the meeting with the paintings surprised many of the participants. As one man who had never been in an art museum expressed:

> I've never thought I could take part in anything like this. Nobody has told me that I could just look at a painting … and see things … Never even heard about it. It didn't even occur to us that this [the art museum] could be a place for us to be. We were too low … Art, you know, was for the highbrow people and people with money. Previously I was a bit intimidated. If I saw a big painting, I never thought it could have anything to do with me (Lea & Synnes, 2000, p. 9).

Naturally, this did not create an epiphany for all. But for many of the participants, being in a group and having the opportunity to participate in conversations about art created something special. As one woman said: "I felt as if the Alzheimer's wasn't there anymore. It wasn't a thing for me when we were at the art museum. It felt good. I felt it in my body I know that the Alzheimer's will return, but right there, if someone had told me that I had Alzheimer's, I probably would have thought they were joking with me" (Lea & Synnes, 2000, p. 9).

The experiences from the exhibitions took also several of the healthcare personnel and the volunteers who followed the participants by surprise. One volunteer said of an older lady: "she talked more in one hour than she has done for half a year". And though several noticed that this was not suitable for all the participants, they expressed astonishment at how much enthusiasm and involvement the art exhibition elicited.

WE ARE ALL PREJUDICED

We are all guilty of being prejudiced. One episode from the visual art project comes to mind where my own prejudices became embarrassingly apparent. I was interviewing a woman in her late 50s where I started the interview using "reality orientation", by stating both time and place and what had just happened, saying: "well now we have just been at the art museum experiencing an exhibition by Munch…". How clumsily this was executed really dawned on me when listening to the interview while making the transcription. The woman became quite annoyed (which I didn't really understand at the time of the interview), answering in a surly voice: "yes, sir! We were. I was there too" (clearly throwing me off a bit). When I asked about which picture she enjoyed the best, she said: "well… this picture was of course *morbidly fascinating*", which I now hear is said in a quite sarcastic way, underlining how she has no problem in mastering the subject. The "subtle" message is more or less "I am not stupid, stupid!". Later in the interview it became clear that she had been quite sceptical and concerned about how the guide at the museum had met them and talked to them, something she was very sensitive about. This scepticism towards how we approached them at the exhibition, how we talked to them, and what we expected of them was a significant concern to some of the participants ("we need quality, not Donald Duck", as one man said to me in an interview). An ethics of the unconscious as part of a cultural citizenship must recognize how much the larger stories of society of dementia impacts on the ongoing narrations and exchanges between us and persons living with dementia.

"A TUNE BEYOND US, YET OURSELVES": THE NEED FOR AN ENDLESS INTERPRETATION

According to Oliver (2004), a true revolution can only come from imagination, where the abject and suppressed can see themselves in a different light, in another possible world of belonging. A nuanced understanding of cultural citizenship for persons living with dementia must open up new ways of agency and meaning making, revealing arenas of participation and an enhanced understanding of poetic capabilities.

However, an ethics of the unconscious also challenges us to acknowledge that we can never truly understand the other. But for this we also need imagination, poetry, stories, examples that show us where we misstep, or where we can never fully grasp other people. Wallace Stevens' words, "A tune beyond us, yet ourselves", might not only underpin poetry's potential to redescribe reality but may also

involve an ethics of recognizing the other as beyond us, yet ourselves. This demands of us an everlasting process of interpretation, of humility, of compassion.

I will thus end this chapter with an anecdote of my wife and I visiting her mother at the nursing home, where she is living with dementia.

> My mother-in-law was having a difficult day and she was distressed and agitated. My wife tried to calm her, by sitting down, talking to her and saying: "Mum, I understand that it's difficult". Promptly she got the reply: "You understand nothing!"

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4. Participation, civil society and citizenship later in life

Kjersti Helene Haarr and Karen Synne Groven

Abstract Due to demographic changes, Norwegian municipalities have to rethink ways of cooperating with regards to public, private and voluntary support offered to/involving the elderly living at home. In this chapter, we explore two cases dealing with the occupation of eating dinner, alone or in company with others. With occupational justice as our theoretical lens, we address how civil society can strengthen (the home dwelling of) elderly persons' participation and citizenship as part of their everyday life.

Keywords civil society | municipalities | participation | elderly

INTRODUCTION

Because the Norwegian population is growing older and many elderly people want to live in their home communities as long as they can, an increasing number of individuals will need long-term rehabilitation and other services in the coming years as a consequence of complex health conditions and old age (Otnes, 2017; Rogne & Syse, 2017). The Norwegian government recently published a quality reform for the elderly, "A full life all your life" (Meld. St. 15, 2017). This reform emphasizes five points: an age-friendly society, activity and community, food and meals, healthcare and coherence in services. Food and meals are highlighted as "the most important" aspect of everyday life. At the same time, the text highlights the need for civil society and volunteers to be part of this age-friendly society to more systematically develop sustainable and holistic services for its elderly inhabitants, thereby also strengthening their citizenship (Meld. St. 15, 2017, pp. 105, 127). This implies adopting a welfare mix perspective in line with other Nordic and European countries (Storgaard Bonfils & Bangshaap, 2019).

Background: Reablement and civil society

Public papers such as Future Care (Meld. St. 29, 2013) highlight the need for innovation in public healthcare and rehabilitation in the years to come. In this paper the health authorities emphasize the notion of *responsible citizens* (Meld. St. 29, 2013). This involves shifting certain complex tasks from the specialist level to the community health services. Moreover, the idea is that these task shifts should take place between public services and civil society (Hagen & Johnsen, 2013; St. Meld 47, 2009). This implies that everyday life will increasingly be an arena for interaction, and civil society, friends, family and next of kin will play a more visible role in professional practice. It also implies the need for the more holistic involvement of service users as unique citizens in their social community (Navne & Wiuff, 2011; Vabø & Vik, 2017).

When elderly people are expected to stay in their homes for as long as possible, there are some risks involved. One such risk is malnutrition, which has undesirable consequences for health and quality of life (Bjørner, Korsgaard, Reinbach, & Perez-Cueto, 2018). Moreover, psychological factors such as depression and dementia strongly correlate with malnutrition (Besora-Moreno, Llauradó, Tarro, & Solà, 2020; Bjørner et al., 2018, p. 125). Given the complexity of this aspect, contextual and social factors must be considered to ensure adequate nutrition and healthier ageing.

Given this reform's emphasis on an age-friendly society in which food and meals are acknowledged as essential, we will explore ways of implementing this emphasis in local communities. More precisely, we will explore this issue through two cases dealing with the occupation of eating dinner – alone or in the company of others.

The research gaps and research question

Public health documents do not properly address how elderly individuals' citizenship can be strengthened through the involvement of non-healthcare professionals. Nor do they address potential dilemmas involving the interaction of health professionals, volunteers and private entrepreneurs in the best interests of society's elderly members.

Debate over the role civil society should play in renewing the welfare state is not new (Loga, 2018). Civil society has interacted with public services in various ways throughout history. However, research on voluntary work in connection with elderly people has mainly focused on medical help and care (Rønning, 2011; Rønning, Johansen, & Schanke, 2009; Veenstra & Daatland, 2012). In the Norwegian context, we have little knowledge about this topic, especially when it comes to

rehabilitation and citizenship (Enjolras, Salamon, Sivesind, & Larsen, 2018; Trætteberg, Eimhjellen, Ervik, Enjolras, & Skiple, 2020).

An ongoing government-supported project on community-based rehabilitation in south-eastern Norway launched in 2015 has shown that the societal perspective is increasingly being prioritized (Eide, Fuglerud, & Lauritzen, 2017; Fuglerud, Lauritzen, & Eide, 2018). Why civil society involvement still has not been systematically developed has not been elaborated on in published reports from the project (Fuglerud, Lauritzen, & Eide, 2020).

A Delphi study conducted by the World Federation of Occupational Therapy (WFOT) – a consensus process amongst member states and organizations – identified eight research themes (Mackenzie et al., 2017). Amongst these, healthy ageing will be one of the fields prioritized for future research. The health and well-being of older adults, including determinants of social inclusion/exclusion, poverty, environmental barriers and facilitators, theoretical understanding of ageing, common age-related impairments, care-giving and occupational choice, are listed as elements of interest (Mackenzie et al., 2017). Several of these topics are relevant to the issues of nutrition and eating meals.

Seeking to fill a gap in the literature, this chapter explores how professionals, volunteers and private entrepreneurs can address the *occupational needs* of home-dwelling elderly individuals together with these individuals and thereby facilitate citizenship. More precisely, we will take a closer look at public, private and voluntary support for elderly people living at home and address the following question:

How does public, private and voluntary support, in connection with elderly living at home, reinforce their participation and citizenship?

THEORETICAL FRAMEWORK: AN OCCUPATIONAL PERSPECTIVE ON CITIZENSHIP

Our theoretical framework builds on *an occupational perspective* on human rights. In particular, we draw on an occupational justice perspective based on intertwined knowledge concerning occupation, enabling and justice (Morville & Enemark Larsen, 2017). Engaging in diverse and meaningful occupations is considered vital to meeting an individual's needs and developing people's potential (Durocher, Gibson, & Rappolt, 2014; Hammell, 2020). Conversely, restrictions on participation in occupation can affect health, making them ultimately an injustice (Townsend & Wilcock, 2004).

A human rights-based framework for the rehabilitation of persons with disabilities, as described in both the UN Convention on the Rights of Persons with Disabilities (CRPD) and the new Norwegian guidelines (Helse- og omsorgsdepartementet, 2012), involves social and societal perspectives. The CRPD emphasizes the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support (Preamble, j). This will become increasingly relevant in Norway because the population is growing older and more individuals will be living with long-term and complex conditions involving disability in some way (Meld. St. 15 (2017)). According to § 26 b) of the CRPD, rehabilitation services and programmes should support participation and inclusion in the community and all aspects of society and should be voluntary and available to persons with disabilities as close as possible to their own communities, including in rural areas. The CRPD sets high goals, which means there will always be room for improvement.

The World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) points to activity and participation as factors that mutually affect health conditions, body function and structure, and personal and environmental conditions (WHO, Sosial- og helsedirektoratet, & Kith, 2003). Activity and participation imply understandings of the noun *occupation* as used in the literature about humans as occupational beings who need and want to engage in doing, being, becoming and belonging (Wilcock & Hocking, 2015). Together, these notions, which emphasize that everybody has occupational rights, provide a point of departure for thinking about access to meaningful occupations as a matter of justice (Durocher et al., 2014, p. 418).

In line with this, Hammel (2008, p. 61; 2020, p. 195) defines occupational rights as "the right of all people to engage in *meaningful* occupations that contribute positively to their own well-being and the well-being of their communities". Hence, Hammel's focus is occupation and meaningfulness. Moreover, she emphasizes inclusion, autonomy and diverse participation. Hammel's definition can be read as an extension of the concept of *occupational justice* focusing on "meaningful and purposeful occupations (tasks and activities) that people want to do, need to do, and can do, considering their personal and situational circumstances" (Durocher et al., 2014; Stadnyk, Townsend, & Wilcock, 2010). According to Hammel (2020, p. 79), meaningful occupations are an important dimension of well-being since human well-being is ultimately an issue of engagement in living.

Besides, we have to take in account that human occupations have seldom been presented only as an individual affair. However, research on occupation has had a strong individual focus, making it difficult to acknowledge transcending dimen-

sions (Josephsson, 2017). According to Laliberte Rudman (2013, p. 306), an individualistic orientation "stifles the capacity to address issues of equity and justice".

Our theoretical framework is also inspired by Solvang and colleagues' (2016) *matrix of key agents and levels of society in rehabilitation*. According to Solvang, Hanisch and Reinhardt (2016, p. 2), the micro, meso and macro-levels of a society are all involved in rehabilitation. This holistic view of rehabilitation is depicted in a nine-cell table as a relational structure that can serve as a point of reference for understanding the type of knowledge essential for embracing a holistic perspective of rehabilitation. The vertical dimension of the table represents the structuring of society in individual, organizational and policy levels. The horizontal dimension represents agents and the actions they direct towards the different levels of rehabilitation practice (Solvang, 2019; Solvang et al., 2016, pp. 2–3). For example, the first cell of the table, which corresponds to the individual at a micro level, incorporates the person's everyday life, family and neighbourhood, while cell six, which illustrates the meso-level in connection with governmental policy and practice, includes user organizations and other civil actors. However, as previously noted, policy papers point to civil society and private entrepreneurs taking a more active role in elderly individuals' reablement/rehabilitation.

These people – volunteers and private entrepreneurs – act in a less formal mode of (political) participation, which corresponds to the notion of *lived citizenship*. Kallio and colleagues argue that lived citizenship comprises what people experience and practice as part of their everyday living, personally as well as in groups and movements, including more and less intentional civic activities (Kallio, Wood, & Häkli, 2020, p. 714). Citizenship can be constituted through agency rather than status or territorial belonging – by contributions that shape society in the direction in which citizens want to live (Kallio et al., 2020, p. 724). Finally, Kallio and colleagues differentiate four dimensions of lived citizenship: spatial, intersubjective, performed and affective (Kallio et al., 2020). In this chapter, our focus will be on the intersubjective dimension. More specifically, we argue that the notion of occupational justice and participation can be understood as an intersubjective dimension of lived citizenship.

METHODS, MATERIALS AND ETHICAL REFLECTIONS

Our empirical material draws on two cases from a previous study – performed in two municipalities in western Norway. The study was conducted during 2013–2017 and focused on the process of establishing reablement services in the

municipalities. Vabø and Vik (2017) were the main researchers, and economic support was provided by Regional Research Fonds, West (Ref. 235696).

A previously published article and report explored voluntary and private initiatives, focusing on the potential for co-creation with local actors that already existed in the communities (Haarr, 2019; Vabø & Vik, 2017). The results showed that both new and established exchanges of resources among citizens had taken place. In connection to the efforts to make elderly inhabitants more self-reliant, both municipalities had initiated a strategy for partnerships with volunteers and social entrepreneurs. After a three-year period, the public sector employees and volunteers shared a willingness to cooperate (Haarr, 2019). Building on this study, in this chapter we focus on food and dinner meals, which will be explored through two cases – one from each of the communities. The first case involves a cafe distributing ready-made dinners while the second case involves the creation of a collective dinner event (table fellowship) in an apartment complex. A case study can be characterized as an intensive qualitative study made together with one or a few survey units (Andersen, 2013, p. 13). Each survey unit is looked upon as a complex whole whose sub-units, and their interrelatedness, can be described in a detailed manner. The municipalities, described briefly below, constitute the survey context, while the processes of establishing private-public and voluntary-public cooperation are the cases. The positioning of these cases of cooperation in meal-making ("the casing") was established after the first study period and will be analysed in relation to this as a decontextualization and further recontextualization (Andersen, 2013, p. 23). Empirically, each case is unique, thus generalizability is weak. The theoretical perspective upon which we draw might provide more representativeness.

In both cases, the empirical material was derived using various qualitative approaches, including interviews with volunteers and public sector employees, participation in local meetings and events, and observations while walking and talking (Jones, Bunce, Evans, Gibbs, & Hein, 2008; Tjora, 2017). Empirical material was also drawn from focus group sessions for municipal employees, team leaders, volunteers and local (private) service companies facilitated as part of the study. Some of the focus interviews were done with mixed groups, and some of the groups met twice: once at the launch of the reablement services and then again some seven to eight months later (Halkier & Gjerpe, 2010; Vabø & Vik, 2017).

In our analysis of the two cases, we critically observe and track the process illuminating some of the cultural significance of a phenomenon (Andersen, 2013, pp. 32–33). The phenomenon in these cases is the occupation of eating dinner.

Ethical reflections

The study was approved by the Norwegian Centre for Research Data (NSD, 2020) and the participants signed informed consent forms. We have emphasized the importance of anonymity and created fictive names during our analytical process without losing significant meaning and points, which will be discussed in the examples illustrated in our findings.

Case 1: Dinner delivery

The municipality in case 1 is located in a rural area on the west coast of Norway. Fishing used to be a major source of income, but is no longer as important. Petromaritime activities, in addition to farming, now constitute the largest sources of income. In addition to paying taxes, inhabitants pay out of pocket for public services. Since 2012, inspired by the Coordination Reform (Meld. St. 29, 2013), the municipality has begun to rethink how to organize their services (Vabø, 2018). The specialized hospitals only treat major health issues, and the length of stay for any illness is kept to a minimum. This means the municipality must be prepared to take care of and provide rehabilitation or reablement services to a lot more people – especially frail and ill elderly inhabitants.

The municipal administration started to feel the pressure on resources available for public services. In her interview, which took place two or three years after the onset of the Cooperation Reform, the director for health and social affairs emphasized the importance of innovation:

> We have to think out of the box…
>
> The elderly inhabitants can buy services like other adults and adolescents. Receiving [ready-made] food, for instance, is not about privatizing but normalizing. Practical help will change the same way – [we are] not yet into privatizing these businesses, but it will be developed.

As context for her comments, politicians in this municipality had decided to stop dinner delivery for home-dwelling individuals as part of their public offering. Seeking to find alternative ways to deliver, the director for health and social affairs contacted a local cafe suggesting that they could establish the delivery of dinner for frail or immobile citizens. The owner of the cafe found the idea interesting and decided to have a go at it. This entailed using the full kitchen capacity and making a leaflet and a website for the dinner delivery service with the menu and prices for the whole week. Individuals who wanted to receive dinner were instructed to order

for an exact number of days every week – every other day was a popular choice. In addition, the cafe owner entered into a cooperative agreement with the local taxi driver, who would deliver the dinners to clients' doorsteps several days a week. In this way, the taxi driver's job was extended to involve food delivery – a task that also involved communicating with the elderly service users upon delivery.

The way that dinner delivery was presented during our interviews suggests that it was part of a bigger plan for further privatization or commercialization of services in the municipality. The delivery by private companies, including the cafe and taxi, was presented as a user-friendly service that allowed elderly individuals to choose for themselves what to eat for dinner, order more if they expected guests, and so forth.

Case 2: Table fellowship

This case concerns a small municipality on the south-western coast of Norway whose main industries are fishing, shipbuilding and oil. Some of the retired men still meet at their former workplace at the shipyard.

Civil services in this community were launched to meet the needs of the growing population of elderly people living at home with minor functional decline. The volunteer centre, in collaboration with public healthcare services, sought to develop a practice involving volunteers to meet the needs of the elderly. The centre did a great job recruiting and maintaining volunteers for different purposes. It must be added that the volunteers themselves mainly consisted of persons over the age of 65.

One of the new practices developed was a table fellowship, which was organized at a municipal apartment building. A group of volunteers took the initiative to establish this event, inviting residents to an informal dinner once a month. Elaborating on this initiative, the volunteer initiator, a woman in her 60s, explained how it all came about:

> We just started! No meeting, unbureaucratic – we just started with inviting some of the residents. They own their apartments – a mix of people, mostly elderly……What are we going to call this? A dinner fellowship? It is a bit social to be there – to do such things. Then we – the volunteers are setting the tables, the food is delivered from a local catering company, and the residents pay for themselves. Some 22 persons took part from the start – now we are close to 45. In the autumn we have to divide this into two table fellowships a month. …. And things like this, you know – the volunteers will take part, it is social. The residents don't have dementia, they are all included in the conversation – and it's all super!

Later, in a second interview, the same woman added,

> We could have been there all the time – the residents are so in need of company!

As illustrated in this quote, the table fellowship programme serving dinner on a regular basis was a very popular social event that attracted an increasing number of older people. The threshold for participation was low, and the group of participants grew; the volunteers struggled to serve a full dinner to almost 50 people and had to divide it into two table settings a month.

DISCUSSION

At first glance, the two cases illustrate how municipalities collaborate in fruitful ways with volunteers and private entrepreneurs. Both cases demonstrate how local initiatives can meet the needs of elderly citizens with the first one showing a substitute for and the second one more of a supplement to public dinner delivery. Volunteers provide opportunities for marginalized elderly citizens to have a proper meal occasionally, thereby enhancing their well-being. The way these interactions outside the realm of formal politics are carried out can be interpreted as lived citizenship, while these gatherings place emphasis on flexible notions of space and interrelationships of some elderly citizens (Kallio et al., 2020, p. 714). Even though they are relatively few in number, the volunteers acting on behalf of an NGO have the collective capacity to act in citizen positions on behalf of the elderly (Kallio et al., 2020, p. 722). The elderly themselves often experience a lower status or position and appear to be left out as citizens and participants in city and regional planning and decision-making.

At the same time, one could argue that none of the municipalities are offering citizenship practices that include *all* elderly inhabitants in need of meaningful, social dinner meals.

Looking critically at case 2, one could argue that there are some challenges related to the fact that the home-dwelling older people themselves are not active participants in planning and decision-making. One challenge is that the programme depends on a few idealistic volunteers, and recruiting enough new volunteers to prepare the events is hard. Another issue relates to dinner meals on all other days during the month, when elderly people have to eat by themselves if they do not make their own arrangements for company. And finally, what about the frailer elderly people, especially single ones, living in detached houses spread around the community? By identifying ways in which the status quo benefits cer-

tain groups and disadvantages others, we discover attitudinal and environmental barriers that hinder full and inclusive participation (Hammel, 2020, p. 7). Exploring alternative ways of thinking and doing – on a meso and/or macro-level – might give us some insight into how to achieve a more just and equitable society (Feiring, Juritzen, Knutsen, & Larsen, 2017; Hammell, 2020, p. 20) and thereby expose gaps in existing forms of political belonging (Kallio et al., 2020, p. 714).

The needs of elderly citizens can be different depending on their private condition and resources, whether they live alone or with someone, have family close by or not, are healthy, frail, ill or immobile etc. For the majority of these individuals, it will be insufficient to rely solely on family and friends. As for the municipalities, they are looking for diverse private and voluntary solutions to supplement, and perhaps even replace, some of their services. To illustrate how a public-private-voluntary emphasis can be taken into account in the rehabilitation process, Solvang et al.'s (2016) *matrix of key agents and levels of society in rehabilitation* is helpful. Addressing how institutions, organizations, municipalities and services enable or limit occupational possibilities for the elderly – and thereby also their experiences of lived citizenship regarding community inclusion (Townsend & Polatajko, 2007; Kallio et al., 2020) – one could argue that civil society actors or entrepreneurs should be considered separate agents at all levels.

	Civil society or private/social entrepreneurs
Micro	Single occupations or meeting one-to-one/face-to-face. Local community *doing together*
Meso	Local civil authority and organizations facilitate activity (advisory boards, management teams etc)
Macro	National authority and regional/national third-sector organizations, structural planning and organizing

Figure 4.1: The matrix of civil society in rehabilitation.

When we look at the professionals engaged in cases 1 and 2, these experiences of lived citizenship regarding community inclusion will be most evident at the meso-level. And the optimal result for community-based initiatives and innova-

tions is found where government authorities and civil society cooperate at all levels.

In case 1, the community administration tried to meet the need of home-dwelling older adults for warm, ready-made meals and their desire to eat together with someone. Their solution was to cut the public cost by involving a cafe to take over the whole "package" of the delivery of dinner. As a result, the elderly people participating in this practice were able to enjoy the pleasure of selecting from a menu and having a ready-made dinner delivered to their doorstep. This practice also involves social interaction, namely through encounters with the taxi driver. Perhaps this social encounter represents a little shining light in the monotony of everyday life? Those living nearby, or still driving a car, could also go to the cafe and be served in a cosy atmosphere. Another possible positive outcome is the creation of some new jobs or networks. The flip side of the coin is that this new practice still leaves elderly people to eat alone. Besides, this solution seems to be created for only a few, namely those who are able to pay for dinner and a taxi or to move by themselves or with the help of family, friends or neighbours.

In the long run, we have to figure out if such a service entails the division of the population into a hierarchy of social classes: those who can afford it and those who cannot; those who have the network and those who do not. Along with the economic dimension, there is a technical or practical one: the elderly person is expected to read the menu and order online. Orders can also be placed by phone, but not every older person has the ability to figure out when and how to do this, making them dependent on others. Digital competence also divides people between those who can manage and those who cannot (Holthe, Halvorsrud, & Lund, 2020; Nilsson & Townsend, 2010). In addition to a financial and digital divide, we can identify a social divide between those who have family and friends in the community and those who lack such connections.

Solutions like privatizing the delivery of dinner can be seen as being embedded in neoliberal ideology, enhancing individual choice and leaving each person to fend for themselves rather than addressing structural changes that might more effectively equalize participation opportunities for all, or at least for more people (Hammel, 2020, p. 29).

How well are we doing together?

The demographic changes of the coming decades, with a growing population of people living into their 80s and even 90s, will require us to consider the following aspects. What does later life at home mean to different people, namely to those

with close family relationships and nearby friends and those without? Will municipalities provide arenas and meeting places for people of all ages – and will there be a willingness to provide the support elderly people with impairments need to participate in the occupations they want to do, need to do and can do? In Norway and Denmark, reablement services have been criticized for providing rehabilitation that prepares people only to manage in the frame of their own apartment or housing, which can lead to loneliness (Langeland et al., 2016; Wahl, Iwarsson, & Oswald, 2012). Feelings of loneliness and isolation can easily result, and, as Hammel (2020) points out, isolation plays a role in occupational injustice.

Social eating serves several purposes including preventing loneliness and promoting proper nourishment. According to Bugge (2019), dinner and food fellowship comprise an important aspect of everyday life for most Norwegians. Even though the Norwegian population is not a uniform group when it comes to lifestyle and ways of eating, the dinner has traditionally been the main social point of gathering for the majority of households (Bugge, 2019). However, for many elderly people living alone, the social practices accompanying family meals are no longer possible. Widows and widowers, or people whose spouse is living in a nursing home, often eat alone day after day. Bjørner et al. (2018) show that positive mealtime practices are very complex and consist of many contextual factors, including individuals' attitudes and social factors. Nutrition is not the only factor that counts in relation to health. The social dimension also needs to be prioritized in inclusive ways that can accommodate elderly people of all kinds (Eide et al., 2017; Fuglerud et al., 2018; Storgaard Bonfils & Bangshaap, 2019).

Norwegian municipalities are concerned with developing cooperative relations with families and civil society to build and develop rehabilitation and reablement practices for the future – as illustrated in our second case. More and more, this type of collaboration goes under the name of co-management or partnership (Røiseland & Vabo, 2016). Some politicians have invited private market actors and entrepreneurs to take part in this development – as we have seen in cases 1 and 2. Seen through the matrix of rehabilitation agents, the success of such co-creation of services depends on connections and cooperation on all levels. But first and foremost, the community at the meso-level has to establish a solid foundation for public-private-voluntary initiatives (Guribye, 2016, 2018) to support lived citizenship for both voluteers and elderly citizens (Kallio et al., 2020). While positive and sustainable results take time and are far from certain, it is still worthwhile to work on these issues since the outcomes are promising (Guribye, 2018, p. 77).

Services and practices involving civil society and private companies/entrepreneurs are solicited to serve the elderly so that their lives can be more fulfilling and

meaningful. Hence, the intentions behind such initiatives are good. In many ways, it is tempting to limit our discussion to the individual or group level – where the food is made and delivered to and where the meal is served and eaten. However, to establish lasting practices that are more robust and do not privilege certain groups of elderly people over others, it is necessary to address the meso-level and perhaps even a higher level. At these higher levels, the foundations are laid for sustainable, co-created solutions. It is perhaps necessary to rethink the area of living reforms for the elderly to answer some of the recurring questions related to social meals and transport to social events (Koster, 2015). Hammel (2020, p. 195) contends that to reinforce elderly's citizenship, professionals within community-based services must make an effort to address equal opportunities and access to participation and occupation for all kinds of older people living by themselves – "as most barriers are socially constructed".

According to Hammel (2020), local responses and local solutions need to be collective to foster sustainable communities and municipalities. Finally, municipalities can enable elderly individuals to be "responsible citizens" inclusively by involving residents in the planning of joint activities (Hindhede & Lid, 2019). This line of argument echoes the Sustainable Development Goals (SDG) which have been adopted by more and more cities, towns and villages that are working to make their settlements more inclusive, resilient and safe – together.

SUMMING UP AND CONCLUSIONS

In this chapter we have argued for the importance of understanding how we approach being together – how we grow, flourish and develop; how we create hindrances, exclude or discriminate – through occupation strengthening or weakening lived citizenship of volunteers and elderly living at home. As illustrated by our analysis of two cases, communities and individuals interact to strengthen elderly people's lived citizenship. This entails shifting the focus from person-centred initiatives to people's interaction with their environments, without losing sight of less visible socio-political processes.

The practical implications of these findings include a better understanding of what it takes to prepare reablement services to support meaningful occupations and lived citizenship for service users in the future. This entails elevating the discussion and thinking strategically, which require broad community involvement – not only among the elderly but also among other adults and adolescents, who have the potential to contribute to interactive, community-based thinking. With respect especially to the oldest citizens, those over 80 years of age and those who are

immobile, strategies and plans have to go further and emphasize social meeting places, alternative forms of housing and, by extension, inclusive meals, as these promote diverse participation and social inclusion, which go hand in hand with human rights.

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5. How may digital healthcare influence citizenship for people with chronic conditions? A narrative review

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Abstract This narrative review aims to clarify existing knowledge on how digital healthcare may influence citizenship for adults with chronic conditions. We screened existing literature, and seven articles were included and analysed according to the research question. Three main aspects were abstracted: 1) digital healthcare empowers patients through health literacy, 2) digital healthcare demands differentiation and 3) supporting lived citizenship challenges the responsibilities of healthcare professionals.

Keywords digital healthcare | chronic conditions | lived citizenship | empowerment

INTRODUCTION

The ageing population, as well as the increase in people living for many years with chronic conditions, is challenging the sustainability of global healthcare systems (Ofori-Asenso et al., 2019). Policy documents demonstrate that an increasing number of people with chronic conditions and those receiving healthcare live at home (Helse- og omsorgsdepartementet, 2015). Digital technologies offer new opportunities to identify needs and deliver healthcare, both in terms of prevention and health promotion as well as therapeutic interventions and self-management support interventions outside of institutions (European Commission, 2019).

Chronic conditions are commonly defined as being of long duration (>3 months), generally of slow progression, and require ongoing medical attention as well as self-management (Bernell & Howard, 2016). Adults with chronic conditions such as diabetes mellitus, chronic obstructive pulmonary disease, heart

and lung conditions, chronic pain and fibromyalgia and people with serious mental illness, to mention a few, are required to constantly act on and self-manage symptoms and potential consequences (Dwarswaard, Bakker, van Staa, & Boeije, 2016; Pulvirenti, McMillan, & Lawn, 2014). People with chronic conditions often find that the conditions reduce their abilities to participate in activities they value, their sense of personal control as well as the possibility to make decisions and take actions that are beneficial for their overall health and well-being (Megari, 2013). Therefore, they may need long-term care related to both health and social issues. The way these services are delivered may or may not support citizenship.

There have been many studies articulating the benefits, challenges and implementation of digital healthcare services and health technologies (Awad et al., 2021; Nagel & Penner, 2015; Muller, Ormstad, Jacobsen Jardim, Johansen, & Berg, 2020). However, to our knowledge, little work has been done to reflect on how digital healthcare may influence citizenship for people with chronic conditions. Therefore, this narrative review focuses on how digital healthcare facilitates citizenship for people with chronic conditions in order to clarify present knowledge and identify further research opportunities. The research question we seek to explore is: *How may digital healthcare influence citizenship for adults with chronic conditions?*

Background

Digital healthcare includes technologies where healthcare professionals are involved, such as eHealth solutions (telemedicine, telehealth and telecare), as well as assistive living technologies (such as telemonitoring and smart house technologies), which can assist healthcare professionals and their clients to manage acute or chronic conditions and promote health and well-being (European Commission, 2019; WHO, 2021). Digital healthcare may offer possibilities to improve participation and self-determination. Digital healthcare may provide timely care, information and education to people with chronic conditions, all of which are essential parts in active citizenship (Boje, 2017). Moreover, digital healthcare affects the experience of citizenship. Kallio, Wood, and Häkli (2020) underpin the need to understand lived citizenship as performed practices based on dialogue between material and spatial context, the personal affective and the access to relational resources of everyday life. Technologies particularly represents a spatial dimension of everyday life affecting lived citizenship as practice. However, it does presuppose learning and performance of skills, and should be understood in a relational and pedagogical context (Kallio et al., 2020). For digital healthcare services to promote

citizenship, it is imperative that developers and stakeholders understand what specific resources digital healthcare provide in everyday life for citizens with chronic conditions, as well as what the innovations put at stake.

Citizenship in democratic welfare is expected to value both autonomy and self-determination as well as vulnerability and care (Lid, 2015). Payne (2017) described citizenship as an ongoing developing process, meaning people may continuously lose or regain aspects of it (Payne, 2017). Citizenship entailing duties and responsibilities of both citizen and society (Marshall, 1950; Boje, 2017) will change when citizens are expected to change their participation and roles in healthcare. Moreover, citizenship in professional care is relational. It involves communication to acknowledge and enable service recipients to actively influence their healthcare services (Fjetland & Gjermestad, 2018). Citizenship is executed in society and in relationships between people; one cannot be a citizen alone (Lid, 2017). Thus, citizenship has to do with empowerment and participation in healthcare (Askheim, 2017). Empowering patients means providing citizens with real management capabilities; encouraging agency and allowing them to take an active role in managing their own health and transforming the traditional patient–healthcare professional relationship (Calvillo, Román, & Roa, 2015). Citizens with chronic conditions, who are dependent on health and welfare services, have the right to sufficient access to healthcare services to ensure lived citizenship.

METHOD

Narrative review

We performed a narrative review to identify and provide an overview of previously published evidence concerning digital healthcare related to citizenship. Narrative reviews are useful when analysing diverse studies or fields (Baumeister & Leary, 1997; Cronin, Ryan, & Coughlan, 2008; Ferrari, 2015). In our process we: (1) conducted a review of article titles or abstracts with any mention of aspects related to citizenship and digital healthcare; (2) conducted a full review of abstracts of the identified studies to evaluate their relevance for the subject; (3) reviewed full articles of abstracts we classified as relevant to the topic, and (4) analysed the identified articles concerning digital healthcare, citizenship and chronic conditions to find similarities or connections and provide an overview of the current knowledge in this specific topic. In this way, this narrative review links together several studies for the purpose of presenting quality and timely knowledge, and it also identifies further questions to be addressed.

Literature searches

We conducted literature searches in March and April 2019 in the following databases: Academic Search Elite, CINAHL, CINAHL with Full Text, ERIC, SocINDEX with Full Text, Education Source, Health and Psychosocial Instruments. Five components were used to build the search terms for the identification of studies on the use of digital healthcare and citizenship: (1) digital healthcare, (2) adults with chronic conditions, (3) citizenship & empowering patients, (4) original articles in English, and (5) last eight years (2011–2019). This resulted in the following chain of keywords: citizenship or citizen participation or inclusion or empower* or empowering patients or participation **AND** digital healthcare or telecare or telenursing or telehealth or eHealth or e-health or telemedicine or telehealth or digital health or digital health technology or DHT **AND** all adults. The authors independently screened the results, and identified original studies based on the inclusion criteria.

Inclusion and exclusion criteria

This review was limited to peer-reviewed articles written in the English language. The inclusion criteria were original articles, articles about adults explicitly described as "all adults" aged 18 and older – "older adults" or "older people" or "elderly" and focusing on chronic conditions (specifically chronic pulmonary obstructive disease, type 1 and type 2 diabetes mellitus, older people with chronic illness and complex conditions) and their combination in comorbid and multimorbid patients. Articles were excluded if the full text was unavailable or if the research did not concern digital health or citizenship. We also excluded books, chapters, posters and doctoral theses, because we wanted to explore recent, peer-reviewed research. Duplicates were removed and the remaining articles were screened against the criteria based on title, abstract and full text. See Figure 5.1 for an overview of the selection process.

Search outcome

A total of 628 articles were identified using the search strategy described above. After excluding duplicates and articles in other languages (n=178), we screened n=450 articles' titles and abstract for relevance. Through screening, n=364 were excluded. We read 86 titles and abstracts and excluded 58 due to a lack of relevance. Full-text reading of the remaining 28 articles resulted in the further exclusion of 21 articles because they did not meet the inclusion criteria, leaving **seven**

articles for further analysis. The review sample included original empirical studies: qualitative, quantitative, and mixed methods studies (pre/post-test/follow-up studies, questionnaire survey, individual and group interviews).

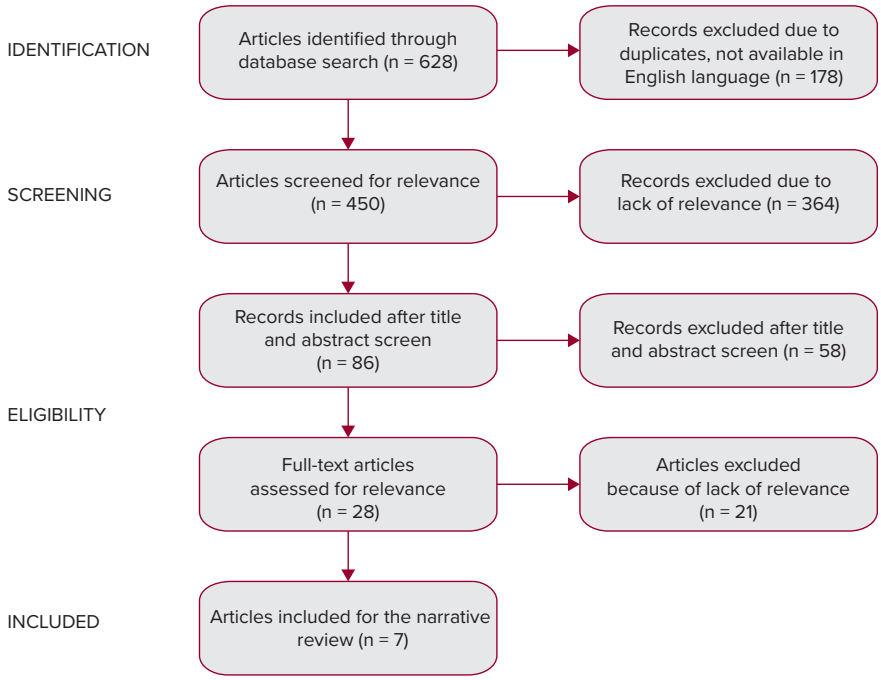

Figure 5.1. Flow diagram.

RESULTS

Five studies described adults with one chronic condition (chronic obstructive pulmonary disease or diabetes mellitus), and two studies included people with multimorbidity. Five of the included articles were from Europe, one from Australia and one from the United States.

Key information from the seven articles is presented in Table 5.1.

Table 5.1: Summary of the studies included

Reference and country of origin	Method for data collection and analysis	Participants, setting and response rate if stated	Key findings/ Summary of results	Conclusions / Contributions to the field
Buysse et al., (2011). Main characteristics of type 1 and type 2 diabetic patients interested in the use of a telemonitoring platform Belgium	Quantitative method: 2 Questionnaires (DES + THERQ). Nonparametric descriptive statistics: Kruskal–Wallis one-way ANOVA and Mann–Whitney U-tests were performed for comparison of continuous variables, Chi-squared test for contingency tables and Fisher's Exact test where applicable. Spearman correlation coefficients	sent to 172 patients – 137 returned – response rate = 79,9%	Most patients showing interest were insulin treated and did not have adequate metabolic control, or they were treated with insulin and oral treatment and showed low empowerment scores. This suggests that implementation of a telemonitoring platform for these patients makes sense and can be used to improve metabolic control by increasing empowerment.	For type 2 diabetic patients with a combined treatment regimen the telemonitoring platform could be used to improve empowerment. Those with lower empowerment scores seem to be more prone to use a telemonitoring platform – it suggests that type 2 diabetic patients would improve their empowerment scores by using such a platform. Some patients could be monitored/followed up from their home environment instead of coming to the hospital. This way, time may be liberated for face-to-face consultations with other patients. However, it is important that also the follow-up of telemonitoring should be managed by HCP, and that the use of a telemonitoring platform does not replace the face-to-face contacts with HCP.
Depatie & Bigbee (2015). Rural Older Adult Readiness to Adopt Mobile Health Technology: A Descriptive Study USA	Descriptive exploratory research design. Mixed method of data collection: 16 question survey with both quant and qual questions. Data entered to excel, ordinal data analysed for mean, SD and range. Qual data analysed by content analysis to identify recurring themes.	30 participants convenience sampled from senior centres	Participants indicated they wanted control over their health data by choosing when and where to share the information, except for alerts sent in a crisis.	Mobile health technology that is easy and convenient and individualized has the potential to facilitate patient empowerment and individual responsibility in the areas of health and wellness. The technology can help people care for themselves, and it has a great potential to increase access to care for older adults living in rural communities.

Reference and country of origin	Method for data collection and analysis	Participants, setting and response rate if stated	Key findings/ Summary of results	Conclusions / Contributions to the field
Doñate-Martínez et. al. (2016). Impact of a primary-based telemonitoring programme in HRQOL, satisfaction and usefulness in a sample of older adults with chronic diseases in Valencia Spain	Quantitative method: A longitudinal and cross-sectional study. An exploratory and descriptive design with descriptive statistics.	A random sample of 100 older adults (comorbid and multimorbid patients) initially included for the baseline analysis. In the follow-up analysis after one year 27 patients had dropped out. The sample was 73 patients.	The whole sample experiences improvement, although not significant, on HRQOL. People with diabetes had a significant increase in HRQOL. However, patients over 75 years showed impairment in HRQOL.	Patients' perception of satisfaction and usefulness were highly positive. The results indicate decreased use of health resources. Both patients, GPs and nurses entails a positively assessed patient empowerment and self-management using ICT.
Fairbrother et al. (2013). Exploring telemonitoring and self-management by patients with chronic obstructive pulmonary disease: A qualitative study embedded in a RCT UK	Qualitative method: Semi-structured interviews with patients and healthcare professionals participating in a RCT of telemonitoring. Transcribed data were analysed using the framework approach.	38 patients with COPD (mean age 67,5 years) and 32 professionals (70 interviews)	Patients considered that telemonitoring empowered self-management by enhancing their understanding of COPD and providing additional justification for their decisions to adjust treatment or seek professional advice.	Telemonitoring assisted many patients to embrace greater responsibility for their health. However, the healthcare remained clinician centred. A medical model of "compliant self-Management" may paradoxically have promoted dependence on professionals. Patients and professionals shared responsibility for meeting the central objective of prompt management of exacerbations of COPD. Care is needed, however, to minimize the risk of telemonitoring increasing dependence on practitioner support for some patients.

Reference and country of origin	Method for data collection and analysis	Participants, setting and response rate if stated	Key findings/ Summary of results	Conclusions / Contributions to the field
Halcomb et al. (2016). Telemonitoring is acceptable amongst community dwelling older Australians with chronic conditions. Australia	Descriptive statistics. Quantitative method: A pre- and post-test survey	21 participants (aged over 65 years and chronic and complex cardiac or respiratory conditions) completed both pre- and post-test surveys	Experience and exposure to telemonitoring technology resulted in increased acceptance and improved positive attitudes towards telemonitoring. Moreover, telemonitoring can play an important role in supporting chronic disease self-management.	The use of telemonitoring seems to be beneficial in managing various chronic diseases. Older, community dwelling people are likely to accept telemonitoring (in Australia). Moreover, using telemonitoring does not require experience with computers or technology. In addition to the benefits of transmitting physiological data to health professionals, telemonitoring has benefits for self-management, improving individuals' feelings of confidence, involvement in their care and understanding of their health. Such benefits have implications for supporting people's health and well-being.
Long and Gambling (2012). Enhancing health literacy and behavioural change within a telecare education and support intervention for people with type 2 diabetes UK	Quantitative method: RCT evaluation of a proactive, call centre treatment support (PACCTS) intervention, observatory study. Mixed method of data collection: Analysis: Spearman's rho for correlations + analysis of five in-depth interviews	319 patients with type 2 diabetes	Changes in the depth and detail of diabetes-related knowledge and confidence, from the specific to the more general, were observed and enhanced competence in translating knowledge into practice.	The intervention could be interpreted as operating at two levels: 1. Health literacy, enhancing knowledge, developing personal skills onto enabling self-control and self-agency 2. Social psychological, behavioural change, working on levels of motivation, empowerment, supportive problem-solving and support general.
Nissen & Lindhardt (2017). A qualitative study of COPD-patients' experience of a telemedicine intervention Denmark	Descriptive design and semi-structured interviews Used manifest and latent content analysis	14 patients (between 55–83 years) with COPD in a 6-month telemedicine intervention	Through monitoring patients developed increased awareness and better self-management of their disease. Patients experienced more focused and less stressful meetings via video consultations, than in respiratory outpatient visits.	Participation in telemedicine increased the patient empowerment primarily by the sharing of data with a permanent staff of nurses. This knowledge was used to keep control of the disease in the form of extra readings and the systematic use of learned initiatives. This gave patients and relatives a sense of security.

We abstracted three main categories of how digital healthcare may influence citizenship for people with chronic conditions. The categories were labelled 1) digital healthcare empowers patients through health literacy, 2) digital healthcare demands differentiation, and 3) supporting lived citizenship challenges the responsibilities of healthcare professionals. These categories are described in detail in the text below.

1) Digital healthcare empowers patients through health literacy

The included articles suggest that digital healthcare, such as eHealth or telehealth initiatives, may support empowerment, through amongst other things greater control and a sense of autonomy for patients in their healthcare services. Digital healthcare may enhance knowledge, develop personal skills to enable self-control and self-agency, as well as support motivation and problem-solving. These findings from the included articles were interpreted as digital healthcare empowers patients through health literacy.

Both patients and healthcare professionals positively assess patient empowerment and self-management when using information and communication technologies (Doñate-Martínez, Ródenas, & Garcés, 2016). Mobile health technology that is easy to use, convenient as well as individualized, and renders possible sharing data with healthcare professionals has the potential to facilitate patient empowerment (Depatie & Bigbee, 2015; Nissen & Lindhardt, 2017). Moreover, patients with type 2 diabetes scoring low on empowerment (measured through The Diabetes Empowerment Scale) are more likely to use a telemonitoring platform. This suggests that digital healthcare may be supportive of health literacy and empowerment (Buysse et al., 2011). The use of technology also indicates decreased use of health resources (Doñate-Martínez et al., 2016).

Telemonitoring give participants with chronic conditions a sense of security and confidence. Moreover, telemonitoring supports self-management of chronic conditions and improves understanding and self-efficacy. Better understanding of one's own health leads patients to feel empowered and confident (Halcomb, Purcell, Hickman, & Smyth, 2016). Changes in health literacy are evident in the shift from specific to more general knowledge, lesser reliance on external support, greater self-responsibility and enhanced confidence (Long & Gambling, 2012).

2) Digital healthcare demands differentiation

The included articles suggest that digital healthcare is most beneficial when it is sufficiently individualized and differentiated, and most importantly provided to

people who need and want it in their healthcare services. This indicates the necessity of differentiating based on individual needs and wishes. These findings from the included articles were interpreted as digital healthcare may support citizenship if it is sufficiently differentiated.

When digital healthcare is desired, convenient, and individualized it may facilitate responsibility of one's own health and may therefore help people care for themselves. People living in rural areas may experience increased access to care when digital healthcare is introduced (Depatie & Bigbee, 2015). When patients are presented with the opportunity to share data through telemedicine, healthcare professionals can assist in controlling symptoms of the disease by extra readings and the systematic use of learned initiatives. This gives patients and relatives a sense of security (Nissen & Lindhardt, 2017).

Even though it seems as though digital healthcare may provide positive results for some people, the articles indicate ambiguous results concerning the relationship between digital healthcare and the quality of life, for example. In the article by Doñate-Martínez et al. (2016), the whole sample experienced improvement, although not significant, in health-related quality of life. Most interesting was that people with diabetes experienced a significant increase in health-related quality of life. However, patients over the age of 75 years showed impairment in health-related quality of life. The findings indicate that it is important to provide sufficient possibilities of differentiating and provide face-to-face consultations with those who are not interested in or capable of using telehealth initiatives (Buysse et al., 2011).

3) Supporting lived citizenship challenges the responsibilities of healthcare professionals

The included articles suggest that digital healthcare relies on healthcare professionals' work, even though it increases the empowerment of the patients in the healthcare services. Digital healthcare such as telemonitoring seems to enable patients to embrace greater responsibility for their health when supported and permitted to do so by healthcare professionals. These findings from the included articles were interpreted as supporting lived citizenship in digital healthcare changes and challenges the responsibilities of the involved healthcare professionals.

There are several benefits of transmitting physiological data through digital technology to healthcare professionals; telemonitoring has potential benefits for self-management, improving individuals' feelings of confidence, involvement in their care and understanding of their health (Halcomb et al., 2016). However, patients and professionals need to work together to define their roles and responsibi-

lities in relation to telemonitoring-supported self-management, identifying the consequences of compliance and concordance models on care and treatment and the implications on service development (Fairbrother et al., 2013). Both patients and healthcare professionals stated that continuity and cooperation was important to obtain effective telemonitoring, and for building trust. A trustful relationship may be developed through the sharing of data and information as well as digital communication between patients and healthcare professionals (Nissen & Lindhardt, 2017). However, it is important to note that digital healthcare cannot replace all face-to-face contact between healthcare professionals and patients (Buysse et al., 2011). Thus, digital healthcare changes and challenges the healthcare professionals' responsibilities to support the experience of agency in lived citizenship.

DISCUSSION

The purpose of this narrative review was to synthesize and describe what is currently known about how digital healthcare may impact citizenship for adults with chronic conditions. From the included articles, we identified three categories: 1) digital healthcare empowers patients through health literacy, 2) digital healthcare demands differentiation and 3) supporting lived citizenship challenges the responsibilities of healthcare professionals. The first category indicates positive aspects of digital healthcare related to citizenship for people with chronic conditions. The second category suggests that digital healthcare increases the need for differentiation in order to support citizenship. Lastly, the third category implies that healthcare professionals have great responsibility in supporting lived citizenship through digital healthcare. Below we discuss these findings briefly.

Digital healthcare seems to improve individuals' feelings of confidence, involvement in care and understanding of their health. It appears digital healthcare may assist people to embrace a greater responsibility for their health. Lived citizenship includes managing material and digital technologies as well as acknowledging relationships (Kallio et al., 2020). Positive aspects of engaging people in their own healthcare include the possibilities of empowerment and self-government when self-managing a chronic condition through many years. Living in an environment that supports participation and influence is a prerequisite for citizenship (Lid, 2017). Knowledge about their own chronic conditions in combination with education and improved acceptance may therefore support quality in lived citizenship, as this may improve people's opportunities to impact their environment. These aspects indicate that digital healthcare may support lived citizenship for people with chronic conditions. As citizens with chronic conditions will be demanded to

manage their own health to a larger degree in our future societies because of ageing populations and other demographic changes (Helse- og omsorgsdepartementet, 2015), these findings are of interest.

Using technology to move care into people's homes instead of at primary healthcare centres, clinics or hospitals may support citizenship for people who are unable to travel or who wish to receive care at home. Although this may be conducive for empowerment on the one hand; on the other hand, it may demand larger health literacy, cognitive skills, knowledge and understanding. This may increase the individual responsibility of each patient. The well-meaning intention of using digital healthcare to empower citizens may paradoxically put them in a situation where they are disempowered, depending on their function and status (Vedsegaard, 2019). This may put citizens' rights in danger. It may also diminish citizens' trust and attachment to public welfare, which is a crucial value for supporting citizenship practices (Boje, 2017). Moreover, if health technology demands that people use their own digital devices, it may also increase the risk of digital healthcare being inaccessible for certain groups in society. Both the demand for skills and the demand for access to digital devices may potentially increase the difference in society based on socioeconomic and intellectual status. Thus, there exists the potential that some people with chronic conditions may experience a reduction of citizenship when digital healthcare is implemented, cf. the de-citizenship process described by Payne (2017). Healthcare professionals using digital healthcare may therefore have an increased responsibility to promote citizenship (re-citizenship). One may speculate that digital healthcare increases the responsibility of the healthcare professionals, even though more care is moved into patients' homes which also may lead to an increased responsibility for the patients. Supporting citizenship therefore presupposes that healthcare professionals understand the complexity of lived citizenship, being both spatial, performed, intersubjective and affective (Kallio et al., 2020).

Moreover, the articles indicate that rural recipients of healthcare may value digital healthcare more than city-dwellers (Depatie & Bigbee, 2015; Halcomb et al., 2016), as it renders possible a further reach of healthcare. This advocates the need for differentiation; not only based on patients' knowledge and wishes, but also on their address. In addition, digital healthcare demands patients to oversee their own health (Lupton, 2017). It is vital that healthcare professionals are aware that they potentially increase the patients' responsibility when delivering digital healthcare in their homes. Transferring responsibility to patients does hold a somewhat normative orientation which may bring with it both positive and negative aspects related to agency and citizenship. Will it be possible for the healthcare system in the

future to provide both aspects to secure sufficient differentiation; both digital healthcare as well as "traditional healthcare"? We suggest that the digital transformation of healthcare may require additional planned differentiation, meaning that healthcare professionals know more about the patients before meeting them. This will demand changes in the current healthcare services, as well as the education system for healthcare professionals.

In summary, the findings indicate that even though digital healthcare may support citizenship for some patients by allowing them to take greater responsibility in their healthcare, these technologies also place larger demands on the patient, as well as inflict changes in the way healthcare professionals work. Therefore, changes to digital healthcare should be understood and worked for in a relational and pedagogical context to support citizenship, in both the healthcare and healthcare professionals' education system.

Strengths and limitations

Our review has several limitations. Even though we searched systematically and thoroughly for all relevant articles, this is not a systematic review. The narrative review methods do not employ as much rigour as would be applied in a traditional systematic review and evidence summaries may therefore be subject to a greater degree of bias and/or error (Khangura, Konnyu, Cushman, Grimshaw, & Moher, 2012). We identified both qualitative and quantitative articles, and there may be variability in the quality of the studies included. Also, the variation of chronic conditions and complexity of digital healthcare makes the scope of our review broad, and the investigation of the related subtopics may be less comprehensive than with a more focused review.

A second limitation is that we included articles in the English language only. Articles exploring experiences from countries with other native languages may therefore have been unknowingly excluded.

A third limitation is the diversity in the technology used in the studies, and the sample, as well as the complexity of citizenship related to digital health. Since all the studies have different population, sampling and methods, we could not undertake a meta-analysis, either quantitatively or qualitatively. Nevertheless, this narrative review provides an up-to-date discussion of how digital healthcare may impact citizenship for people with chronic conditions. It is important to note that two of the articles had included mostly participants who had not yet used telehealth services, hence they gave their opinions on a hypothetical basis (Buysse et al., 2011; Depatie & Bigbee, 2015).

CONCLUSION

Our review suggests that digital healthcare may support citizenship for people with chronic conditions by encouraging and providing the means to enable them to actively manage their own health. This indicates that digital healthcare provides a positive impact on citizenship. However, digital health technologies may also exacerbate inequalities between patients based on their skills and abilities. This leads to a greater need to differentiate between patients based on individual needs and wishes, and identifying in advance who may benefit and master digital health technologies. In turn, this leads to a continuous, or even larger, responsibility of healthcare professionals to know their patients. It may seem as though digital healthcare creates new demands of healthcare professionals to support citizenship. Therefore, changes to digital healthcare should be understood and worked for in a material and spatial as well as relational and pedagogical context to support citizenship, both in healthcare and the education system for healthcare professionals.

Implications for research

For future research, it would be of great interest to look specifically at evidence related to adults with learning or intellectual disabilities and the use of digital health to promote lived citizenship. We did not search specifically for articles concerning this in our review, and thus no such article was identified in our searches with these terms. We are aware that a few studies within this area of interest exist (Cumming, Strnadová, Knox, & Parmenter, 2014; Darcy, Maxwell, & Green, 2016), and point to the need for such a study.

Even though digital healthcare has been implemented and used several years already, research identified for this review (two out of seven articles) still concerns how people hypothetically would prefer digital health interventions, rather than actual experiences with concrete interventions (Buysse et al., 2011; Depatie & Bigbee, 2015). Therefore, it is of great interest and importance to increase the research on specific interventions that test out various digital healthcare options and explore both clinical outcomes as well as people's experiences with such interventions.

Further quantitative research, employing multivariate methods and following patients over time, would be useful to develop a better understanding of causation and to better understand how patients' preferences might change over time and with experience. Our findings indicate that it would be interesting to do a comparative study and explore differences between rural and urban dwellers, and whether their use and acceptance of digital health measures and telemedicine vary.

Further qualitative research would be useful in exploring digital healthcare to improve citizenship from both caregivers and patient perspectives. Moreover, involving citizens with health challenges when developing and doing research on digital healthcare is vital to ensure the interventions support lived citizenship.

Practice implications

It seems of great importance to increase differentiation when implementing digital healthcare, to reach and recruit patients who will value and benefit from these services. By identifying patient resources and factors which might affect their preference for digital healthcare, we may better be able to develop and provide digital healthcare that promotes citizenship. Moreover, using technology to support lived citizenship for citizens with chronic conditions requires both formal preparation and a contextual understanding of citizenship. This should not be assumed as general knowledge in the current working health force. Therefore, including these topics in the healthcare education seems central to offering patients digital healthcare which supports citizenship.

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Lived citizenship in the context of intellectual disability

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6. The significance of relations. Rethinking autonomy in a disability perspective

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Abstract Persons with intellectual disabilities have been excluded from equal status and citizenship in terms of dependency and assumed lack of capacity for individual autonomy. Drawing on theoretical perspectives from Hannah Arendt and Martha C. Nussbaum, the chapter discusses the normative foundation of autonomy and dignity in the context of disability as a human condition. I argue that the human rights concept *individual autonomy* must be reformulated and interpreted as relational.

Keywords autonomy | dignity | human rights | Hannah Arendt | intellectual disability

INTRODUCTION

Persons with congenital intellectual disability are often in need of health and welfare services throughout their lifetimes. These services are meant to secure well-being, a meaningful life and the opportunity to have as good health and living conditions as possible. The most recent Norwegian welfare reform for persons with congenital intellectual disabilities was carried out in the early 1990s. Prior to this reform, welfare services for persons with intellectual disabilities were offered at a minimum level, tailored for living life in institutions and seldom individually adapted to meet the needs for persons living life as autonomous citizens in a community (Lid, 2019; Tideman & Tøssebro, 2002; Johnson, Trausatdottir, Bigby & Kristiansen, 2005).

Both service provision and support from family, friends and local community are of importance for understanding to what degree persons with intellectual disabilities have access to rights and duties on a par with their fellow citizens (Tideman & Tøssebro, 2002). The UN Convention on the Rights of Persons with Disabilities (CRPD) is the UN's most recent convention, entered into force in 2008. As

a human rights treaty, the CRPD emphasizes respect for inherent dignity and individual autonomy, including the freedom to make one's own choices. The CRPD can be seen as a zenith with regard to human rights for persons with disabilities. Norway ratified the CRPD in 2013; Norwegian disability policy aims at equal status and participation in society for all citizens (Chhabra, 2019, p. 93).

Norwegian policy follows the principle of sector responsibility; thus, the various sectors have a responsibility for inclusion of persons with disabilities in the context of the sector (Chhabra, 2019, p. 88). For persons in need of health and welfare services, these individual services constitute a precondition for participation in society as equal citizens. In other words, the way in which individual services are organized functions as a condition for persons' activity and participation. The principle of sector responsibility thus implies that service design and service provision should be organized in accordance with contemporary political aims for equal status and participation. Consequently, the welfare state can support the realization of human rights for persons with intellectual disabilities.

The CRPD promotes access to citizenship for persons with disabilities, expanding the formal and political conceptualization as offered by Marshall (1950). The convention sets up a framework for how persons with disabilities can live as citizens on a par with others. The term *Lived citizenship* was conceptualized by Kallio, Wood and Häkli; it was described as having four dimensions, as presented in the introduction of this book. One of these is characterized as intersubjective. The intersubjective dimension of citizenship "shed[s] light on the more immediate, localised and relational experiences that make up citizenship" (Kallio, Wood & Häkli, 2020, p. 717). This intersubjective, relational aspect of lived citizenship is productive for exploring autonomy as a human rights concept.

Autonomy and inherent dignity are central concepts in the CRPD (Articles 1 and 3), and for an understanding of the person as a citizen with rights and duties (UN, 2006). The concept of autonomy addresses personal freedom, whereas dignity is about the respect owed to all persons as equal human beings. Together, autonomy and dignity are fundamental to human rights treaties. In this chapter I will explore the theoretical foundation of autonomy and dignity as included in the CRPD, aiming to reformulate these as relational concepts and practices.

In developing a theoretical foundation for a general and universal right to have rights, I draw on Hannah Arendt's political philosophy and Martha C. Nussbaum's theory of justice, the Capabilities Approach (Arendt, 1998 (1958); Birmingham, 2006; Nussbaum, 2007). The question discussed in this chapter is how inherent dignity and autonomy can be understood in light of disability as human condition, and what role health and welfare services play in supporting autonomy and dig-

nity. The context of the chapter is the everyday lives of persons with intellectual disabilities, in need of services throughout the lifetime.

CONTRIBUTION TO A FOUNDATION OF HUMAN RIGHTS IN HANNAH ARENDT'S POLITICAL THEORY

Disability often has an effect on the individual's health (Bickenbach, 2013). However, if disability is reduced to health problems, most effort may be put on supporting the individual in achieving a high standard of health. Therefore, there are arguments for separating health and disability as incommensurable (Bickenbach, 2013, p. 822). With regard to persons with intellectual disabilities, who are often in need of health and welfare services, health, welfare and disability must be closely connected to understand the fundamental role health and welfare services play in order for these citizens to practice citizenship in everyday life.

Individuals' capacity for autonomy is context-relative; children, for example, have less autonomy than adults. The need for care that is associated with living with an intellectual disability is often understood as standing in contradiction to personhood, autonomy and the status and role as citizen (Nussbaum, 2004; Nussbaum, 2007). Persons with disabilities have thus been seen as patients rather than as citizens of equal status and with equal rights.

The German-American political philosopher Hannah Arendt has examined what it means to be a person with rights. In her political theory, Arendt started out by identifying the most general condition of human existence, namely birth (Arendt, 1998 (1958)). We are all born to the world as unique human beings. From this point of departure, Arendt developed the principle of natality as an ontological foundation for human rights (Birmingham, 2006, p. 12). The principle of natality (from Latin, *natus*) simply refers to the fact that all humans are born as newcomers; we come in to the world with a potential to start something new. This fact is interpreted by Arendt as a foundation for human rights.

Natality is a universal condition for all humans; all people come into the world by birth. Arendt developed the principle of natality throughout her works, beginning with her doctoral thesis "Love and Saint Augustine" (1996 (1929)). The conception was most fully developed in "The Human Condition" published in 1958 (Arendt, 1998 (1958); Fry, 2014, p. 26). From the start of her work, Arendt linked natality to plurality. Plurality concerns the fact that all humans are unique and different, but also political equals (Fry, 2014, p. 30). In order to describe how to approach plurality normatively, embracing the person different from oneself and supporting this person's capacity to be, Arendt employed the phrase "I want you to

be" (Latin: *volo ut sis*). To *be* involves both having life in itself and to be able to act as oneself (Arendt, 1996 (1929)). Following Arendt, then, also human action is ontologically rooted in natality and can only take place in plurality, since no one can act alone (Arendt, 1998 (1958), p. 247).

According to the philosopher Peg Birmingham, Arendt does not anchor the right to have rights in a metaphysical understanding of human beings. The right to have rights as a human being is founded on the fundamental event of human existence – namely natality. (Birmingham, 2006, p. 57). Arendt anchored the right to have rights in an event that all humans take part in, the event of being born. The fact that human beings are born as new beginnings with each person different from other persons forms the principle of natality that lays the premise for the understanding of human rights. Coming into the world by being born is a joint condition, and, by this, human beings appear as different individuals.

The principle of natality makes action and freedom possible for human beings; each newborn comes into the world with the opportunity to initiate something new. Each person is, by birth, a new beginning, and is different from her fellow human beings. Plurality is therefore both a fact and a law of life (Arendt, 1998 (1958), p. 7; Mahrdt, 2018). Plurality as a condition for human life is significant in a disability perspective, as disability is part of human plurality.

Hannah Arendt argued that human rights are political and must be guaranteed by a responsive state in order to be effective (Arendt, 2004 (1951), pp. 292–293). Human rights are also individual rights based in the principle that all human individuals are morally equal, and states are obliged then to respect human rights of individuals (Freeman, 1995, p. 25). This obligation is in line with Arendt's understanding of human rights as *political*. As individual rights, human rights relate to humans as individual and autonomous subjects.

The dignity of humans, consequently, is rooted in an understanding of the inherent dignity of all humans, *qua* humans. Moreover, human dignity must, according to Arendt, comprehend the whole of humanity and needs to be guaranteed politically (Arendt, 2004 (1951), p. ix). Throughout history, human dignity and plurality have been characterized by vulnerability. Arendt was writing against the backdrop of the German Nazi regime, and was herself a refugee without any national citizenship for 12 years. It is precisely the vulnerability of human dignity and plurality that Arendt addresses in her final accusation articulated in *Eichmann in Jerusalem* (1994 (1963)). Eichmann's crime is that he acted as if he and his superiors "had any right to determine who should and who should not inhabit the world" (Arendt, 1994 (1963), p. 279). The crime against humanity was the political endeavour to reduce human plurality in the Holocaust.

Following Arendt, both human dignity and the right to have rights needs political protection by responsive states. For the individual to be able to enjoy rights and duties, a national authority and democratic institutions must be established to support and guarantee the rights of the citizens. Without a political and institutional authority to support the human rights, these become merely theoretical. Arendt took seriously the vulnerability of human dignity and plurality and called for political responsibility to support human rights for all human beings. One concrete and practical way of providing political responsibility is by incorporating human rights treaties into national law structures and implementing these as practical politics, such as by ratifying and incorporating the CRPD.

THE UN CRPD AS A HUMAN RIGHTS INSTRUMENT

The UN CRPD is a comprehensive human rights treaty, structured as follows: Article 1 articulates the purpose of the convention, Article 2 provides the definitions, while in Article 3 the eight fundamental principles of the convention are presented. Thereafter, Articles 4 to 8 point out the state parties' responsibilities. Articles 9 to 30 present different topics such as education, health and work. Lastly, Articles 31 to 50 focus on technical issues related to the implementation and monitoring of the convention's duties (UN, 2006). The CRPD addresses individual rights that focus on the human rights for persons with disabilities.

Disability in the CRPD is conceptualized as the product of an interplay between individual and environmental factors (Shakespeare, 2018; Lid, 2014). At an individual level, the term impairment is used, and the impact impairment has on the person's functioning is emphasized. This is what Carol Thomas has identified as "impairment effects", the effect that impairment has for the person's everyday life in the social world (Thomas, 2012, p. 211). Individual factors include physical, cognitive, phycological and emotional dimensions. At the environmental level, there are a rich variety of factors such as economy, health and rehabilitation services, assistive technologies and design of the environment (Shakespeare, 2018, p. 20). Thus, both intrinsic and extrinsic factors matter when disability emerges. We can, I suggest, call this interaction of a multitude of factors *relational*, and approach disability as a contextual and relational phenomenon.

I will illustrate disability as relational through the effects Covid-19 pandemic have upon persons with disabilities. In 2020–2022, the Covid-19 pandemic led to a global and national health and social crisis in most countries. As politicians and citizens experienced a fundamental vulnerability in terms of the threat against their lives from an unknown virus, protecting life became the most salient task.

For persons with disabilities, this strategy comes with ambivalence. On the one hand, most countries carried out strategies in order to protect the vulnerable citizens, i.e. older persons or persons with chronic diseases. On the other hand, persons with mental, intellectual, and physical disabilities lost their care services and treatments. In the context of the Norwegian welfare state, persons with intellectual disabilities living in group homes have been subject to stricter infection control measures at home than other people (Norwegian Board of Health Supervision, 2021).

In this situation, persons with disabilities became the victims of the state's response to national crises such as the Covid-19 pandemic (Heumann and Wodatch, 2020). Persons with disabilities are more vulnerable in a pandemic for a number of reasons; this vulnerability is relevant for equitable pandemic policies in the future (Dimka & Mamelund, 2020). Disability as a dynamic interaction is thus both situational and context-relative.

Living with disability or impairment is, however, not incompatible with living a good human life (Garland-Thomson, 2012; Bickenbach, Felder & Schmitz, 2013). But in order to facilitate for the impairment effects that may lead to disability in concrete situations, it is important to develop political strategies to specifically support good human life for persons with disabilities. The CRPD's use of the political ideas *inherent dignity* and *individual autonomy* is fundamental for understanding the anthropology of the convention and interpreting these concepts in a disability perspective. A political conception of the human can be articulated and developed on the basis of the CRPD, where human beings have equal rights, experience vulnerability differently, and are all in need of supportive communities and political authorities.

INDIVIDUAL AUTONOMY AS A PREDICAMENT

The CRPD explicitly describes autonomy as individual autonomy (UN, 2006, Art. 3.1). This specification of autonomy as individual autonomy calls for a rethink of autonomy in the context of persons with intellectual disabilities in need of health and welfare services. If autonomy is dependent upon certain capacities in the individual, persons with intellectual disabilities are vulnerable to not being recognized as subjects with capacity for autonomy. A mis-recognition as an autonomous subject has led to discrimination and structural violence expressed in institutionalization, poverty, powerlessness and inequality of opportunity.

A relational approach to autonomy can include autonomy both as capacity and as status (Mackenzie, 2019, p. 147). Autonomy as status refers to recognition of

individuals as autonomous subjects and the state responsibility to support persons in realizing this status. Autonomy as capacity refers to the individual dimension of autonomy, which, in the context of this chapter, includes welfare services supporting the individual's capacity. The feminist philosopher Catriona Mackenzie argues that normative individualism, understood as the view that the rights, welfare, dignity, freedom and autonomy of individuals matter, is significant. In her relational theory of autonomy, Mackenzie (2019) holds that even with little access to practising individual autonomy, all persons have, at the ontological level, capacity for autonomy. She contends that precisely because persons with disabilities have been excluded from being recognized as autonomous, they have been vulnerable to neglect and exclusion from society (Mackenzie, 2019, p. 146). She argues that a workable concept of autonomy must be sensitive to considerations of social justice (Mackenzie, 2019, p. 146). Supporting autonomy for persons with intellectual disabilities is highly relevant for social justice. In concrete contexts, such support can take the form of supported decision-making through relational practices.

The work of Mackenzie is useful for clarifying autonomy as relational and rights as individual. Her theoretical distinction is a useful lens for comprehending how autonomy and rights can be understood in the context of disability and human rights. Mackenzie does not argue for leaving the concept of autonomy behind all together but rather to reframe this as a relational instead of an individualistic concept.

According to the human rights treaty, all human beings are born free and equal in dignity and rights (UN, 1948). Intellectual disability understood as a limitation in intellectual capacity challenges understandings of autonomy. Complex intellectual disabilities are also a test for Nussbaum's theory of justice as she risks to establish a lower threshold for humanity through the capacity of agency: "any child of human parents who is capable of some type of agency or striving (who is not, then, either anencephalic or in a permanent vegetative condition) is fully equal in worth and entitlement to every other human being" (Nussbaum, 2013, p. 120). In Arendt's theory, the capacity for speech and action similarly risks establishing a threshold for belonging to humanity.

To demarcate humanity based on the person's individual capacity is deeply problematic as it enables other people to evaluate a person's capacity for autonomy. Thus, if a person's capacity is not understandable for the person who is doing the assessment, the person who is subject to evaluation becomes extremely vulnerable. Moreover, it seems almost impossible that a person judged to be either "analphabetic" or in a "permanent vegetative condition" can be recognized as a person at all. As a consequence, persons with profound intellectual disabilities still risk being excluded from dignity and autonomy.

Nussbaum argues that "at the heart of our societies' conception is the idea of *human equality*" (2013, p. 119). This implies that all human beings are of equal inherent or intrinsic worth, not dependent on having a relationship to other human beings. Following Nussbaum, the idea of human dignity captures what human equality is all about. Therefore, at a societal level it is important to respect the equal dignity of persons with intellectual and physical impairments (Nussbaum, 2013, p. 121). The CRPD Article 1 uses the term "inherent dignity" (UN, 2006). The CRPD, however, does not establish a threshold for humanity with reference to capacity for agency and may therefore create a sound basis for a critique of the demarcation line based on human agency or abilities.

In the Western tradition, autonomy has been theorized in ways that support the individualistic understandings of the autonomous subject. Precisely the impairment has been seen as disqualifying for individuals to be recognized as a person that holds capacity for autonomy. Persons with disabilities have not been recognized as being capable of autonomy (Mackenzie, 2019). Also, in a human rights context people with disabilities have been excluded and not recognized as "endowed with reason and conscience" (UN, 1948). Disability is seen as an expression of vulnerability and dependency, and for this reason as incompatible with autonomy. Even in civil life, disability is often seen as a negative status, which disqualifies people from social roles and gives poorer access to resources (Wolfensberger, 2011 (1983)). Moreover, this dependency has led to exclusion from citizenship as one is not recognized as a full person with rights and duties (Nussbaum, 2004).

It is precisely as an individual that the person holds rights and duties. Therefore, the rights subject must be an individual person rather than a social or cultural group. Human rights are, as stated above, individual rights. However, this does not imply that the subject is an autonomous subject in line with the Western philosophical tradition. On the contrary, when including more subjects as rights holders, it is necessary even to rethink and change the conception of the subject (Kittay, 1999). The rights of the individual person are, as already addressed, crucial. However, the *person* is not an independent subject. On the contrary, we all live in relation to others characterized by dependency and interdependency.

The use of the concept of autonomy in the CRPD calls for a reformulation of autonomy in light of disability as human condition. It is necessary to take a critical approach to the concept without leaving it all behind as irrelevant. Disability, when used as a social category, indicates that persons with disability are equal citizens. People with disabilities have, at group level, been excluded from citizenship and equal status (Nussbaum, 2004, p. 304). One reason for this is an individualistic understanding of autonomy conceived of as an achievement.

RETHINKING AUTONOMY

Autonomy, as a concept, is used in this chapter with reference to practical and empirical contexts rather than as a theoretical or philosophical concept. However, autonomy is loaded with philosophical pre-understandings that we need to take into consideration when using the term in context. In this section I will therefore expand on some perspectives on autonomy and discuss the anchoring of freedom in natality as proposed by Hannah Arendt (Arendt, 1998 (1958); Birmingham, 2006).

In the Western philosophical tradition, autonomy is related to self-determination and freedom: freedom to make choices and take responsibility for one's own choices, freedom as opportunity to flourish and live life with meaning. The opposite of freedom is coercion or neglect of the right to freedom. For persons with intellectual disabilities in need of care or welfare services, freedom is often reduced due to either the lack of, or the structure and organization of welfare services. If there is little room for individual accommodation, making plans and following dreams may be difficult. Thus, people with intellectual disabilities are often more dependent on assistance than others.

Feminist philosophers have argued that autonomy understood as self-determination must be reformulated as a relational concept, as exemplified above with reference to Mackenzie (Pettersen, 2008; Mackenzie, 2019). This reformulation builds upon feminist ethicists' understanding of the moral subject as relational (Pettersen, 2008). The conception of a relational moral subject opens for a relational understanding of autonomy. However, this understanding builds on the argument that women are capable of autonomy, thus self-determination has been important for feminists for centuries as women have been seen as dependent. The feminist-informed concept of autonomy is useful when developing the concept further with respect to persons with disabilities. There are, however, also some differences between gender and disability when discussing autonomy. These differences become clear when we discuss autonomy in context.

A person in an institution, such as group home for persons with intellectual disabilities, a hospital or a nursing home, has less access to individual autonomy than a person living in a private home. Thus, practical organization, such as living facilities, is one precondition for self-determination. In a historical perspective, poor conditions for self-determination were an important motivation for de-institutionalization. The Independent living movement fought for the right for persons with disabilities to live more independent lives (Pelka, 2012).

One of the guiding principles for the CRPD, independence, should be reformulated as interdependence, as we are never independent of others. Dependence on

others has been a reason for not being recognized as a person with capacity for autonomy, and thus, not autonomous. This dependence itself seems to exclude individuals from autonomy. This may be a historical and contextual reason for why the CRPD insists on individual autonomy as one of the guiding principles in Article 3; it is of fundamental importance that persons with disabilities are recognized as autonomous at an individual level.

Martha Nussbaum takes human dignity as a starting point when developing her theory of justice, the *Capabilities Approach* (Nussbaum, 2007). All humans are equal in dignity but have inequal access to a life worthy of that dignity. Nussbaum, however, does not approach dignity as an abstract or general concept. Rather, in her theory of justice, she frames the concept of dignity as closely related to social justice. Thus, what Nussbaum does is to contextualize dignity and ask what a decent society, aiming for justice, owes to its citizens. Moreover, she argues that the dignity of all individuals should lead to a state and institutional responsibility for supporting all persons' right to live a life worthy of their dignity (Nussbaum, 2007).

Nussbaum argues, as pointed out above, that the idea of human equality is at the heart of our societies (2013, p. 119). Humanity comes in many forms, and persons with, for example, intellectual impairment are not less human due to less calculative or moral capacity (Nussbaum, 2013, p. 119). The diversity of humanity is inherent in the conception of human, and therefore also in concepts of social justice.

The sociologist Andrew Sayer is inspired by Martha Nussbaum when analysing dignity as a relational concept, and holds that the vulnerability inherent in the human condition is closely related to autonomy. There is, Sayer argues, both a tension and a complementarity between autonomy and dependence (2011, p. 203). The fact that we *need* respect and recognition of our dignity illustrates our dependence on others (Sayer, 2011, p. 203). Disability, then, is related to dignity in complex ways as we should, on the one hand, avoid treating disability as a stigma, and on the other must recognize disability as a factor when relevant (Sayer, 2011, p. 202). It is thus a discriminatory practice not to recognize that a student with intellectual disability may need support and individual accommodation. Being able to maintain autonomy is a source of dignity (Sayer, 2011, p. 203). However, in the context of persons with congenital intellectual disabilities, it is necessary to recognize autonomy not despite of dependency and vulnerability but as an aspect of dependency and vulnerability.

Here we can unfold individual autonomy as expressed in the CRPD as a complex and multi-layered concept. At the macro-level, autonomy can be seen as a basic value and as a dimension of the anthropology inherent in the CRPD. We can find

this use of the concept in Articles 1 and 3 of the CRPD (UN, 2006). At a meso, institutional level, the convention makes current the states' and institutions' responsibility for supporting individual autonomy through promoting respect for all citizens and ascertaining equal recognition before the law. At this level, we can analyse individual autonomy in the CRPD as an institutional responsibility, the convention focuses on the conditions for individual autonomy, for example as seen in Articles 8 and 12 (UN, 2006). At the micro level, individual autonomy in the CRPD can be interpreted as self-determination, for example with regard to living conditions, welfare services, health, work and culture, and carried out through supported decision making in contexts.

SUPPORTING AUTONOMY THROUGH SERVICE PROVISION

For persons with intellectual disabilities who are service users relying on service providers in everyday life, the relativity and relationality of autonomy is highly present as a brute fact. This situation is also relevant for persons with dementia. If the service providers neglect the persons' capacity for autonomy and thus fail to provide appropriate support, individual autonomy is weakened as the power and perhaps even autonomy of the service provider increases, sometimes to such a degree that the individual's will is subject to the institutional power that conducts the work of the service providers (Guddingsmo, 2019). Therefore, being aware of autonomy as relative to contexts is crucial for a responsive understanding of professional ethics. The service provider needs to recognize the service user as a person with capacity for autonomy.

There has been a shift in the study of citizenship from studying institutions of citizenship, such as legal status and the citizen as individual agent, towards studying acts of citizenship, collective and individual deeds that rupture social-historical patterns (Isin & Nielsen, 2021, p. 2). As argued, the nation state is instrumental for recognizing and supporting individual citizenship and human rights (Arendt, 2004 (1951); Birmingham, 2006). Citizenship may emerge in contexts as acts of citizenship, i.e. ethical, cultural, sexual and social (Isin and Nielsen, 2021, p. 2). Isin's work on developing the acts of citizenship has advanced performed citizenship (Kallio et al., 2020, p. 718).

In this book, the terminology *lived citizenship* guides both the theoretical and practical understandings of citizenship. Intersubjectivity and performed citizenship are of most relevance. These dimensions of citizenship are inter-connected as the intersubjectivity can enable performed citizenship through relational prac-

tices. The intersubjective perspective enables us to understand the intersection between the political sphere and relationships between people (Kallio et al., 2020, p. 717). In the context of citizenship for persons with intellectual disabilities, the service design can enable and support performed citizenship for these persons. Then the persons in need of services are recognized as persons with rights and duties by means of the support from service providers.

According to Arendt, the person as citizen takes part in the common world through speech and action. Reading Arendt through the lenses of disability, we recognize speech and action can be performed as relational modes of acting in the common world. The subject is then autonomous in a relational way (Mackenzie, 2019; Arendt, 2004 (1951)). In the different articles of the CRPD, we can distinguish analytically between three scales of citizenship. The first three articles set out the purpose, definitions, and principles of the convention. These articles express the foundational level paraphrased as inherent value of all persons (CRPD, Art. 1). The next five articles, 4–8, propose what citizenship implies at a national and institutional level. The articles that follow, 9–31, are a mixture between the individual level, concretized citizenship as experienced by individuals, and institutional responsibilities, including legal status, education, health, work, intimate life, social and cultural life and belonging to a community. Dignity is a political concept in the human rights treaties (Habermas, 2010). Regarding implementation of respect for human dignity in politics and practice, all the three analytical levels are important.

The CRPD makes it explicitly clear that persons with intellectual disability have the same inherent value as all persons. By using one key term from Arendt, persons with intellectual disabilities must be recognized as persons with a *right to have rights* (Arendt, 2004 (1951); Birmingham, 2006). State institutions should therefore work systematically to include persons with disabilities as equal citizens. Following Nussbaum, a good human life is a life that is worthy of equal dignity of all humans (Nussbaum, 2007). A political instrument and mechanism such as the UN Conventions in general and more specifically, the CRPD, are never stronger than the support of institutions aiming for justice. Endorsement of the human rights conventions is thus the responsibility of the states that are party to the conventions. Such support does not come as a given but is often a result of civil movements and struggles for justice and equal opportunities as acts of citizenship. A concrete way in which institutional support can be seen is through service transformation that is aimed at supporting persons who are service users as equal citizens.

CONCLUSION

As indicated here, the concept of individual autonomy is both significant and problematic. Above I have linked autonomy to a political conception of human dignity and argued that it should be recognized as a part of welfare practice in a society striving for justice to support the autonomy of persons with intellectual disability. As included in the CRPD, the concept of individual autonomy must therefore be interpreted as relational and include the design and organization of welfare services.

Persons with intellectual disabilities have been seen as humans with less capacity for autonomy and thus risk being excluded by the terminology. Autonomy, understood as self-determination, needs to be practised and learned through practice. Therefore a transformation of welfare services towards supporting self-determination for citizens with cognitive disability is a necessary precondition for autonomy practised at the individual level. The importance of individual autonomy as a general principle must thus be re-contextualized in everyday lived practices.

Autonomy is context-relative and relational, therefore the contexts where individual autonomy function as a threshold, excluding persons with disability from personhood, need to be further investigated. The concept of individual autonomy, when included in the CRPD, calls for a critical revision of the concept focusing on supporting individual autonomy with an emphasis on supporting the capacity for autonomy.

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7. Citizenship and human rights

Simon Duffy

Abstract Human rights provide an important framework for social change, but on their own they are insufficient. Rights must be enlivened by active citizenship. Moreover, our ideal of citizenship must be rooted in the lived experience of disabled people and others threatened by exclusion. This chapter offers the *Keys to Citizenship* as a framework for an emancipatory conception of citizenship that could also have a significant bearing on a wide range of the social and environmental challenges ahead.

Keywords citizenship | human rights | freedom | self-advocacy

INTRODUCTION

This chapter offers a conceptual framework, a way of seeing the world and the challenges before us. It is a conceptual framework that some have already adopted, but which also tries to address practical and theoretical challenges in a new way.

The chapter begins by considering human and disability rights, their importance, but also their inevitable limitations. It is proposed that we see the realization of human rights as a goal that can only be achieved if we also adopt the role of an active citizen. Rights cannot be defined or realized independently; it is the willingness of people to take responsibility for creating practical forms of those rights that gives human rights their true meaning. It is argued that it is particularly important that the people who are most impacted by diminished rights organize to make rights real, both for themselves and with others. This means adopting an emancipatory conception of citizenship – to see oneself as a citizen, even when others do not treat you as a full and equal citizen.

This model of inclusive and empowering citizenship is known as the *Keys to Citizenship* and many have found it useful as a focus for planning, action and advocacy (Duffy, 2003; Sly & Tindall, 2016). The model was further developed in partnership with Wendy Perez, a woman with intellectual disabilities (Duffy & Perez, 2014). The framework offers a basis for building a life of meaning and it also encapsulates important aspects of human rights thinking. The chapter ends by

suggesting that emancipatory citizenship is also the means to tackle many of the wider-ranging systemic problems we face today. We cannot solve the problems we face as passive subjects or as consumers, we must become active citizens.

Human and disability rights

After the horrors of World War II and the Holocaust, the nations of the world largely united in affirming the *Declaration of Human Rights,* whose first article sets out a strong and universal statement to the equality, value and freedom of all human beings:

> All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

The *Declaration* goes on to articulate in more detail the rights that national states are expected to honour and build into their own legal systems and state actions. In the following years, these rights have been both reaffirmed and further refined in respect of groups whose rights may be at particular risk of being ignored or misunderstood. In 2006, the UN General Assembly adopted the *Convention on the Rights of Persons with Disabilities* (CRPD) whose purpose was:

> …to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Of course, the fact that people with disabilities have required the publication of a separate *Convention* indicates the existence of a long-standing problem: the formal acknowledgement of human rights doesn't necessarily lead to the creation of meaningful and effective actual rights. In fact, as Arendt observed, when discussing the Eichmann trial in Jerusalem in 1961, we only appeal to human rights when our legal and political systems let us down:

> For Israel the only unprecedented feature of the trial was that, for the first time (since the year 70, when Jerusalem was destroyed by the Romans), Jews were able to sit in judgement on crimes committed against their own people, that for the first time they did not need to appeal to others for protection and justice, or fall back upon the compromised phraseology of the rights of man – rights which, as no one knew better than they, were claimed only by people who were too weak to defend their "rights of Englishmen" and to enforce their own laws. (Arendt, 1963, p. 271)

This problem is not just caused by an unwillingness to live up to our obligations; it is also caused by ignorance about how to meet our obligations. For instance, Article 12 of the CRPD states that all "persons with disabilities have recognition everywhere as persons before the law" and that they should "enjoy legal capacity on an equal basis with others". Yet this remains a challenge in all jurisdictions, for the social innovations necessary to enable people with severe intellectual disabilities to exercise full and equal legal capacity are only at an early stage of development (Martin, Michalowski, Jutten, & Burch, 2014). At best such claims to human rights are a work in progress, and at worst, they are empty aspirations.

For instance, in the UK the gap between rhetoric and reality is very significant, and it seems to be getting worse. In the years following the financial crisis of 2008, the UK Government began an austerity programme which saw cuts in programmes, benefits and rights for disabled people. The UN has launched several investigations into UK policy, including one by the UN Committee on the CRPD itself (UNCRPD, 2016).

> The CRPD, upon completing its investigation, concluded that there was reliable evidence of grave or systematic violations of the rights of disabled people in the UK. Not only were there numerous examples of regression, but many disabled people had been left unable to manage the bare essentials of life. (Benstead, 2019, p. 18)

The UK Government has rejected all the various reports by the United Nations and its social policies continued largely unchanged. Without adequate protections in law and without the necessary organizational or political structures to help people to defend their rights, disability rights seem to be ineffective.

Defining citizenship

If national governments can ignore human and disability rights, then it may seem that human rights are what the English utilitarian philosopher Jeremy Bentham called "nonsense on stilts" (cited in Waldron, 1987). However, there is a different way to approach this matter, for the claims of human rights do not rest upon the assertions of the UN General Assembly; rather the United Nations is building on a way of thinking and acting that has its own independent validity. In fact, this is reflected in the words of Eleanor Roosevelt, one of the original architects of the UN Declaration.

> Where, after all, do universal human rights begin? In small places, close to home—so close and so small that they cannot be seen on any maps of the

> world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world. (Roosevelt, 1958)

As Roosevelt claimed, the experience of being respected or respecting others starts in our daily lives, our homes and our communities. We do not understand what respect means by reading the law; rather the law seeks to reflect our experience of being properly respected. It is also natural that Roosevelt appeals to the idea of citizen action as the bedrock for human rights. For it is citizen action which sustains and advances our respect for human rights. The law is empty if there is no ongoing effort by citizens to understand it and shape it.

However, this raises many important questions; for there is no doubt that the concept of citizenship is sharply contested. For instance, some try to limit citizenship to a merely legal relationship between the individual and the state. In this understanding, citizenship is restricted to those who are deemed by the state to members of their own society, "passport holders". It is this narrow and nationalistic conception of citizenship which lurks behind this statement by Theresa May:

> "But if you believe you're a citizen of the world, you're a citizen of nowhere. You don't understand what the very word 'citizenship' means" (May, 2016).

A different, more political, understanding of citizenship treats citizenship as a status associated with carrying out critical functions in the formation of law and policy. Political citizenship is limited to those who are entitled to be politically active, for instance those who have reached the voting age. This political understanding of citizenship goes back at least as far as Aristotle:

> "A citizen is one who has a share in both ruling and being ruled" (Aristotle, Politics, III.1).

A third understanding of citizenship is what we sometimes call social citizenship. Social citizenship is limited to those who benefit from the first rank of rights and benefits, perhaps contrasted with second-class citizens, those who may legally be citizens, but who have reduced rights and lower benefits. T. H. Marshall defined social citizenship like this:

> Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed. There is no universal principle that determines what those rights and duties shall be, but societies in which citizenship is a developing institution create an image of an ideal citizenship against which achievement can be measured and towards which aspiration can be directed. (Marshall & Bottomore, 1992, p. 18)

All of these three definitions of citizenship are inadequate for our purpose, for they all place the definition of citizenship outside the reach of those who are excluded from citizenship. They all align citizenship with the central power of the state or with a ruling elite. However, there is at least one other use of citizenship, one which might think of as emancipatory citizenship. For we can claim to be a citizen, even when we are excluded from full citizenship by the current machinery of law, democracy or society. This is more than merely asserting a right to be treated as a citizen by others, it is an assertion of one's actuality as a citizen, even in the face of prejudice or exclusion. For instance, Nelson Mandela uses citizenship in this emancipatory sense when he says:

> The time will come when our nation will honour the memory of all the sons, the daughters, the mothers, the fathers, the youth and the children who, by their thoughts and deeds, gave us the right to assert with pride that we are South Africans, that we are Africans, and that we are citizens of the world. (Mandela, 1994)

When people with intellectual disabilities state that they are citizens, it is in the same spirit as Nelson Mandela's statement. They are claiming that they are entitled to the status of an equal: even if they suffer from diminished rights, even if they have limited access to political power, even if they are excluded from equal access to the community. In my view, it can be argued that this is the central definition of citizenship. For to allow the powerful to define what citizenship means actually contradicts the essence of citizenship. On this reading, citizenship means being equal to others, even when nobody else recognizes the fact of that equality.

Emancipatory citizenship

It is certainly this emancipatory conception of citizenship that lies behind the *Keys to Citizenship* model, which was first published by the author in 2002. It was established as a framework around which a person (perhaps supported by family or

other allies) can create the best possible life for themselves as a valued human being. The framework is purposefully universal and inclusive; its purpose is to enable everyone to live a life as an equal and to explain how human diversity can be reconciled with human equality through our shared citizenship (Duffy, 2016a).

The framework was also developed in order to solve two parallel problems that continue to confront people with intellectual disabilities. The first problem is a failure to create the right kind of practical support and social arrangements to enable people with intellectual disabilities to be fully included as equals. From the 1970s, increasing numbers of countries began a process of deinstitutionalization; large hospitals and institutions were closed and new community services were developed (Brend, 2008). However, these new services were often still very large, segregated and institutional in character: large residential homes, residential schools, day centres, respite centres and workshops (Duffy, 1996; O'Brien, O'Brien, & Jacobs, 1998).

One factor amongst many that sustained this unimaginative and institutional practice was a lack of awareness of the many practical steps that can be taken to help people organize personalized support alongside the individual so that they could build a good and meaningful life as a full member of the community. So the *Keys to Citizenship* framework was developed as a practical tool to help share inspirational stories and practical advice on matters ranging from getting a job, buying a house or organizing your own support (Duffy, 2003). The purpose was to offer tools that enabled people, families and their allies to work together to help people build a life of citizenship without relying on institutional or professionally controlled services.

However, the *Keys to Citizenship* framework is also a response to a theoretical problem that was inherent in the policy environment of the time. From the 1970s onwards, the most important intellectual framework for challenging the institutional system was *Social Role Valorisation* (SRV). This model, developed by Wolf Wolfensberger and colleagues, proposes that systems, like social services, can reduce the stigma and prejudice faced by people with intellectual disabilities if they are organized in ways that are in harmony with dominant social values (Wolfensberger, 2013). For example, if society values paid employment, but day services are organized to exclude people from paid employment, then this reinforces negative social prejudices about people with intellectual disabilities.

Nonetheless, a major problem with SRV is that it rather takes social value as a given. It is essentially a strategy that assumes people who are at risk of stigma must organize themselves to fit into mainstream society. Furthermore, this strategy indirectly reinforces the questionable status of the disabled person as someone whose nature doesn't automatically appear sufficiently "normal". This also makes

SRV a "special" philosophy that only applies to those whose status is at risk (Duffy, 2017). This involves SRV in a kind of pragmatic self-contradiction, showing people who are deemed too different to appear normal how they can be supported to pass as normal so that they will be deemed worthy of equal status.

The *Keys to Citizenship* deploys a different strategy. It asserts that people with disabilities are already equals, already citizens, even when society does not deem them as such, and it offers a universal framework for being a citizen, one that is inclusive and which is designed to ensure that this status is not defined using exclusionary concepts (Duffy, 2010). Being a citizen is a moral and political claim that asserts equal status as a fact – whatever the current system or society within which you live. The *Keys to Citizenship* builds on this fact to explain how we can build lives that best exhibit this equal status. This is an emancipatory strategy because it asserts equal status and challenges the bases of any society that devalues disabled people. This approach builds on the work of thinkers and practitioners like John O'Brien and Beth Mount:

> Citizenship is related to three ideals of democracy that are at the core of person-centred work. First, all people are created equal, which means that everyone is equally entitled to reach for their higher purpose. Second, in order to reach for higher purpose there must be equal opportunities to do so. Third, our work as citizens is not simply to receive but to give back; not to reach for our own higher purpose, but to do so in a way that contributes to the greater good. Pursuing these ideals strengthens society and enriches culture for us all. (Mount in O'Brien & Blessing, 2011, p. 23)

The *Keys to Citizenship* has undergone some important changes since 2002. In particular, the author has worked closely with his friend and colleague Wendy Perez, a woman with intellectual disabilities, to improve the model. For Wendy Perez, the attraction of citizenship lies in its triple invocation of freedom, equality and community. She wants people with intellectual disabilities to have the right to make their own decisions and to be able to play their full part in community life:

> Citizenship means being part of everyday life – not being stuck in a box. Why is there still a question when people with learning disabilities want to do ordinary things for themselves? (Perez in Duffy & Perez, 2014, p.8)

Since that time, we have made significant changes to the model. The original six keys to citizenship have now become the seven *Keys to Citizenship* with the addition of the key of *love*. Also, many of the key words have been changed to make the

ideas clearer and easier to understand. For example, the word "self-determination" was replaced with the word "freedom" and the word "support" was replaced with the word "help". These are both examples of where the original word was rather more technical or professionalized, not a word that people use in everyday life.

THE SEVEN KEYS TO CITIZENSHIP

The model offers a framework for understanding how we can treat someone as an equal. It is of course possible to respect anyone as an equal, no matter how they seem to appear to others. However, there are real-world factors that make it psychologically much easier, or harder, to treat another person with respect. I wanted to develop these ideas in a positive direction, not just to avoid stigma, but to understand how to enhance status. These are the seven *Keys to Citizenship*. In practice you do not need to focus on them in this order; however, there is a certain theoretical logic to the ordering below:

1. Meaning

Everyone can have a life of meaning and a sense of purpose, if we are willing to listen to and support each other's hopes and aspirations. Moreover, if you are doing something that has meaning to you then this will change how you present yourself to the world and how the world sees you. It is easier to respect someone who loves what they do, even if you do not share the same enthusiasm. So, when we support someone we must take great care to discover what people really enjoy and enable people to try out new things so that they can discover their gifts and potential (O'Brien & Lovett, 1992).

This same idea is reflected in Article 24 of the CRPD where the Convention stresses the importance of enabling everyone to develop their "personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential". Only the search for meaning can unlock this kind of personal or human development. We can hardly develop talents that we don't care about. Personal development is the realization of the search for meaning.

In practice, tools like person-centred planning can be useful to help people in the search for meaning (O'Brien & O'Brien, 1998). In this approach it is assumed that everyone's life has meaning and value, and that the process of living a good life also requires us to actively discover how to realize that meaning. People who work alongside people with disabilities must be careful to ensure that planning is a process led by the person, and which allows them to build on their own gifts:

> Planning should always build on positives (the hopes, dreams, gifts, skills and talents of a person). Also during planning it is very useful for the person and their family to tell their "story", as these details will help those working with the person understand who they are and what they have experienced in the past. (Sly & Tindall, 2016, p. 17)

Everyone has talents, gifts, needs and resources that are uniquely their own. Living a meaningful life, a good life, means making best use of our gifts. This often means not only overcoming prejudices, but also developing a positive and hopeful vision for our lives in partnership with those who we love and who love us.

2. Freedom

Everyone can make decisions about their own life, if we listen carefully and with respect. It is also much easier to respect someone if you believe that they are doing something that they have genuinely chosen to do for themselves. When someone is seen to be under the control of someone else it is much harder to respect them. This is why we must always work to support someone's own decision-making capacity and if someone does not use words then we must pay attention to every other way that they determine what it is they want to do.

People with intellectual disabilities often find their freedom under threat and the Convention also tries to respond to these threats in various places. Article 12 stresses the importance of ensuring that each person can make their own decisions and that any support people receive to make decisions is appropriate. Article 14 underlines the right to liberty and security; this is a right which is severely threatened by institutional practices which can deprive people of almost all personal freedoms. It is perhaps helpful to understand these challenges as part of the long-standing battle that many different peoples have had to achieve their freedom (Raventos, 2007).

For people with severe intellectual disabilities, a new level of creativity is often required to make freedom real (O'Brien & Mount, 2015). If people do not use words to communicate then those around them must act as interpreters of their intentions and seek meaning and value in their physical movements (Duffy, 2013). This turns out to be quite possible; for people who love others do pay attention to what people really want and need and can learn to see meaning where strangers may not.

Creativity is also needed in challenging legal or bureaucratic barriers to freedom. In order for people to own their home, employ supporters or exercise their rights, it may be necessary to use social innovations. For example, people can cre-

ate legal bodies or trusts to act on behalf of an individual or to manage resources on their behalf. In addition to listening to the voice of the individual, it is also important to support collective advocacy.

> People with disabilities may find it hard to speak up confidently for a range of reasons: low self-esteem; they haven't been listened to before; they need communication aids; they are not confident in being assertive; other people taking control and many other reasons. This is where advocacy, and especially self-advocacy, groups run by and for people with disabilities are important. One person's voice may not be as strong or as powerful as a group of people with the same life experiences. (Sly & Tindall, 2016, p. 23)

3. Money

Everyone must have enough to live on, and to live without being in debt or unduly dependent on others. Having sufficient money to enable independent living makes it possible for people to pursue their goals or ambitions without having to get agreement or permission from others. Poverty and extreme dependence on others changes how we feel about ourselves and how we are seen, and makes it harder for us to hold our heads up high (Bregman, 2017). This is one of the reasons why disabled people demand the ability to control their own funding for support, so that they can shape their own lives (Glasby & Littlechild, 2009).

Article 27 underlines the fact that people with intellectual disabilities have the right to work and to earn money in the normal way and be subject to the same protections as others. Article 28 stresses the importance of social protections and access to water, food, clothing, housing and all other basic needs or the economic resources necessary to purchase those things. These resources are critical for turning theoretical freedom into purposive action.

For many people with intellectual disabilities, these rights rely on social and economic securities built into the welfare state. People often need benefits or pensions to live on and there are ongoing challenges to ensure that such benefits do not lead to poverty traps that create unhelpful dependencies or poverty. There is currently a global movement to advance the idea of a basic income so that universal economic security can be achieved while also ensuring that people are free to earn, save or form families without undue risk of losing their income (Torry, 2015).

There is also a global movement to try and convert funding for care services into individual entitlements which can be controlled directly by people with disabilities (Duffy, 2018). In practice, some people with intellectual disabilities are now begin-

ning to take advantage of systems like personal budgets that give them control over their own support:

> Money gives status and control to people. Control over money gives us a means to fulfil our plans and gives other people an incentive to act in a person's interests. Money is power. (Sly & Tindall, 2016, p. 24)

4. Help

Everyone can be supported and connected to other people. Indeed, in this respect, the needs of people with intellectual disabilities are an important reminder that our need for help is an essential and universal element of citizenship (Gillinson, Green, & Miller, 2005). Someone who does not need help from anyone else cannot be a citizen, because they are playing no part in the collective effort of mutual support and contribution. However, the challenge for people who need extra support and who rely on social services is to get assistance without being forced to sacrifice their freedom.

Articles 9, 19 and 20 all underline the importance of help which is respectful and which supports people to live their own lives, in their own way. Article 26 states the importance of supporting people to develop their independence, including through peer support, recognizing that people with disabilities also have a critical role in supporting others.

It is particularly important to recognize that people with intellectual disabilities need not be passive recipients of support. They should be partners, working alongside those who are paid to offer support and receiving support should not lead to people being forced to live according to the rules of a home or a system (Fitzpatrick, 2010; Hyde, 2012). People also provide support to others: they can offer opportunities for paid work, they can be advocates and champions for change and they can provide peer support – offering practical support, friendship or inspiration to other people with disabilities (Duffy, 2012).

It is important to reverse the historical situation where the professionals paid to help people also had enormous power over them. Instead, the person must be able to shape the support to their own needs and desires:

> Truly involving people and families in recruiting and retaining their paid help is very important as this gives them the power and control over who and how they are supported… (Sly & Tindall, 2016, p. 35)

5. Home

Every one of us should have a safe and secure place where we can have privacy and where we feel we belong. Having a home within a community has often been a basic requirement of citizenship, because it makes it clear to others that you have a shared stake in the fate of the community. This is one of the reasons why advocates demand full housing rights, so that they are seen as belonging to the community, rather than to a service system that can control where they live (Kinsella, 1993).

Article 19 asserts the right to independent living, to live where you wish, with people you choose and to get support in your own home rather than having to live in institutional care. Article 22 affirms our right to privacy and to be able to keep our personal lives secure from interference. These rights enable people to establish themselves with roots in their community.

The battle to obtain meaningful housing rights for people with disabilities continues in most countries. The large institutional services that developed in the middle of the twentieth century, even when they are shut down, tend to be replaced with other, smaller institutional services. New organizations have developed to support people with intellectual disabilities to live in homes of their own, with personalized, peer or neighbourhood support, but these remain innovative models and progress towards community support has not been fast (ASL, 2011; Animate, 2014). Often standard social services fail to respect some of our most basic human rights:

> People should choose who they live with, if they share, and be in control of what happens in their home. Equally people should get any help they need in their home from who they choose, without this affecting their tenancy or right to stay where they are if things change for them. This power and control is often restricted or non-existent for people with disabilities, especially in shared houses. (Sly & Tindall, 2016, p. 32)

6. Life

Everyone can join in and contribute to community life. Citizens contribute to the community and through this contribution they build community. This contribution can take many forms: from political action to going to the pub, from environmental campaigning to helping at the local church, from taking care of family to going to the local shops. Contribution creates community and it creates respect for those who get involved in the life of the community.

When we support people, we must seek to create support that enables contribution. In principle, this is not difficult, because almost every meaningful activity that someone might seek to carry out opens up possibilities for community action. However, social services are often organized to exclude people from the normal places where people meet and act. Many people with intellectual disabilities find themselves cut-off from community and so they cannot share their gifts with others in their community. Article 9, and many others, stress the right to an accessible community, while Article 29 clarifies that people with disabilities must be enabled to participate in the political process. These rights to access the community are also the means to enable contributions to the life of the community.

In fact, people with intellectual disabilities can be agents of radical change at a community level. The very exclusion they often experience can lead to people challenging communities that have often stopped functioning effectively for everyone. As Judith Snow puts it:

> The gift of surviving and growing through change belongs to the outcast. Ancient writings tell us this and modern experience confirms it. Living on the edge of chaos changes the people who survive it. You become very aware of the value of things ordinary citizens take for granted; things like having your opinion listened to, having the chance to make a mistake, to be forgiven and to have the chance to try again; things like having friends and family who celebrate holidays with you and who will tell their friends that they are looking for a job. Living on the margin either burns you out and kills you, or it turns you into a dreamer, someone who really knows what sort of change will help and who can just about taste it; someone who is prepared to do just about anything to bring about change. If these dreamers are liberated, if they are brought back into the arms of society, they become the architects of the new community; a community which has a new capacity to support everyone's needs and interactions. (Snow in Pearpoint, 1990, p. 124)

People with disabilities understand the importance of having streets, shops, work, civic and democratic places that are accessible and which function to bring people together in acts of citizenship. The "small places" which Roosevelt describes are also the everyday places we all need to function effectively for citizenship to be valued:

> Life is about having fun, experiencing highs and lows and getting together with other people in many different situations. It is about taking risks, and joining in. (Sly & Tindall, 2016, p. 36)

Even today, over 50 years since institutions started to be shut down, far too many people find their lives boxed in and controlled, unable to access ordinary opportunities in the life of their communities. The overwhelming importance of community life is not yet reflected in the practical reality of social services.

7. Love

Everyone can find friendship, love and family. Love is not only the most important part of life, but being loved is also vital to the respect in which others hold us. Also, being active in community life is the way in which we can develop new friendships, form relationships, create families and make new life (Snow, 1994). Article 23 in particular states everyone's right to grow up in a loving family and, in turn, to form a family and to have children of our own.

Love in fact may be the most important key to citizenship and it is important to recognize that people's need for love, including sexual relationships and marriage, is often the most important dimension of citizenship. The eugenic beliefs which lurk behind public policy for people with intellectual disabilities also conspire with a general unwillingness to talk about love in modern welfare states. Love seems to be too powerful, personal and challenging.

Yet without love human beings can neither exist or flourish. So, it is important for people and professionals to start talking about the importance of love, family and relationships (Duffy, 2016b). Greater openness about these things can also help people navigate the important transitions into adult life and to help families evolve and change as they must, but without breaking up families. For family is the foundation for citizenship:

> Love is the foundation of life. Without love people die. Loneliness is proven to kill people. Love is the connector key without which citizenship has no meaning. Love gives you permission to be vulnerable at the same time as being the protective factor against abuse. (Sly & Tindall, 2016, p. 40)

It is critical that social workers are willing to talk openly about the importance of love and that social services are organized to encourage and support love.

CONCLUSION

These seven keys are not qualifications for citizenship, rather they are the capacities we need to develop to realize our citizenship. There is no reason to exclude

anyone from citizenship and no constraints that stop communities from welcoming everyone into full citizenship. Even those keys that seem resource-dependent – like money – only require resources to be distributed fairly so that nobody is unduly dependent. It is extreme inequality that undermines citizenship, by making some people too dependent on others (Rousseau, 1968).

The *Keys to Citizenship* framework is used by people in several different countries and cultures both to enable people to think about the decisions they make in their own lives and also to better organize support for people with intellectual disabilities. For social workers, the framework implies the need to look beyond existing services and to help people explore what is meaningful for them, and to maximize people's access to the necessary community resources to help people achieve a life of meaning, contribution and love. This framework may seem ambitious, but it is actually very practical. It connects people in a conversation about universal needs and desires, and it looks to the resources of the wider community in order to solve problems.

In fact, it is useful for anyone working with people with intellectual disabilities to start by asking themselves whether they actually know how to be a citizen, in their own life. It is people with intellectual disabilities who often understand that meaning and relationships matter much more than the more materialistic goals that dominate modern society. We must not assume that we know what is important or that our values are correct; we must start by examining our own values and assumptions (Vidyarthi & Wilson, 2008).

If we start with an emancipatory conception of citizenship, that is by assuming those that are excluded really are citizens and that they often have a better understanding of what matters, then this can challenge and undermine narrower conceptions of citizenship. For instance, if the ideal of citizenship is not defined by those who have power then we can re-evaluate the conceptions of citizenship that are defined by the powerful. We can propose different values to those that dominate the social conception of citizenship. We can advocate models of democratic power to make them more inclusive and reject nationalistic conceptions of citizenship that treat those who are refugees, asylum seekers and immigrants with less respect.

Today there are powerful forces driving us towards nationalism, centralization, automation and consumerism: these forces also seem to be destructive of much that makes life worth living. There is a crisis which is ecological, political and economic. However, emancipatory citizenship may offer us a way of responding to a wide range of social, economic and environmental problems.

Citizenship is an important concept, partly for its own sake. For it offers a vision of human life which is potentially inclusive, egalitarian and responsible. It is also

possible that citizenship offers an ideal which is very helpful at a time when above all we need individuals to take responsibility for their impact on the world and each other. However, as we have seen in the past, citizenship is not natural and it requires action and thought in order to create the conditions in which citizenship can thrive.

In this context, the work of people with intellectual disabilities, and their allies, including professionals, is critical. The clear call from people to be treated as equals, to live amongst others, offers hope of a better world where we can celebrate, rather than fear, our diversity and where we can work together to solve the many problems we face without giving away our power. It is our capacity to be citizens, to act as citizens, which is essential to turning the aspirations described in the Declaration of Human Rights and then the Convention on Rights of Persons with Disabilities into living and breathing realities.

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8. Citizenship of resistance

Kirsten Jæger Fjetland

Abstract This chapter explores how workers at a sheltered workshop for people with intellectual disabilities in Norway support each other in understanding everyday life as being part of professional practice. The study explores the workers' narrative co-authorship in a perspective of agency and lived citizenship. The results point to challenges due to disempowering professional practice as well as the workers' competence in enhancing agency and a citizenship of resistance, supporting equal rights to influence ones' everyday life.

Keywords narrative understanding | narrative resistance | co-authorship | agency | lived citizenship

INTRODUCTION

There are practices in both professional welfare and civil society of not perceiving persons with intellectual disability as competent of having a voice in their own affairs. Examples refer to both lack of knowledge and discriminatory attitudes and practices, and are presented as a challenge in scientific studies, white papers and by people with intellectual disabilities themselves (Duffy & Perez, 2014; Fjetland, 2015; NOU 2016, 17; Bach, 2017; Lid, 2017; Glørstad, 2019). Oppressive traditions towards groups of citizens illuminate the challenges in the understanding and practice of citizenship; there have been several calls for studies on citizenship concerning people in vulnerable situations such as intellectual disability (Sandvin & Hutchinson, 2014; Duffy, 2016; Fjetland & Gjermestad, 2018; Halvorsen et al., 2017; Kallio, Wood & Häkli, 2020). Kallio et al. (2020) call for studies that explore citizenship as lived experience as opposed to status-based, which focus on performed practices including material and spatial as well as relational, intersubjective and affective dimensions of citizenship.

With this background, the aim of this study was to explore lived citizenship by focusing on how people with intellectual disabilities assist each other in understanding and resisting oppressive professional practices of everyday life in their

own homes. The paper will narrow the study of citizenship to the narrative ways that people with disabilities are co-authors of everyday life narratives, claiming their rights as citizens. Narrative practice implies social and relational ways of describing and interpreting the meaning of lived experience (Riessman, 2008). The paper takes as a point of departure an empirical extract from a narrative study of co-authorship in sheltered workplaces in Norway (Fjetland, 2015), mediated by the question: *What characterizes voices of resistance in an everyday dialogue between people with intellectual disabilities and how can the characteristics illuminate the understanding of citizenship?*

Citizenship and narrative understanding

This study explores the narrative process of understanding and constructing identity as a citizen. Understanding citizenship as a relational, social, cultural and historical phenomenon is a way to shed light on experiences pertinent in everyday life for people in vulnerable situations, as for people with intellectual disabilities. Citizenship as a historical and cultural phenomenon illustrates ideologically based changes in insider – and outsider – conceptions of citizenship (Marshall, 2009). Different inherent positions, like being a male, owning a business and an income, or being physically and cognitive fit, traditionally provided statuses as a citizen and roles of influence in everyday life as well as public and political spheres. Although these perspectives have been opposed and changed by writers within a feminist care as well as a critical disability paradigm (Young, 1997; Lanoix, 2007; Lid, 2017), being in a vulnerable life situation still presents challenges to performing citizenship as a universal human right with expectations of making a meaningful contribution and impact in one's own and others' lives (UN, 2003; Fraser, 2009).

Being a citizen includes both civic, political and social aspects of living; this means that the social and relational practices of care in everyday life as well as public and voluntary welfare are part of a citizenship discourse (Boje, 2017; Kymlicka, 2002; Baldwin & Greason, 2016). Isin (2017) underscores the importance of perceiving citizenship as performed, social and relational acts of practice. The four dimensions of citizenship pointed to by Kallio et al. (2020) – spatial, performed, intersubjective, affective – enable a focus on lived citizenship as both the content or issue in question for the citizen, as well as the process of doing and acting as a citizen. Halvorsen et al. (2017) further describe lived citizenship as mediating influence, security and autonomy in practice:

> (…) being an active citizen involves exercising social rights and duties, enjoying choice and autonomy and participating in political decision-making processes that are important for one's life and society as a whole. (Halvorsen et al., 2017, p. 3)

Narrativity represents a way towards relational and dialogical understanding of experience, named *narrative understanding* (Ricoeur, 1984). Narrativity is a way of describing, exploring and making meaning of experiences together with other people who are able to confirm, acknowledge, expand as well as resist or reject the story being told. Narratives are relational resources for the construction and exploration of identities, morals and ethics.

Being relational, social and linguistic constructions of understanding and meaning, narratives concern care and power (Ricoeur, 1984; Fjetland, 2015; 2019). By means of constructing a narrative plot, the storytellers present their choices and understanding of relevant agents and their agency, what circumstances must be presented, whose goals, values and wishes are at stake and what kind of cooperation and conflicts are immanent in the presented situation. The process of emplotment and constructing meaning from experience is co-constructed by both the teller and the listener (Ricoeur, 1984). "By talking and listening we produce narrative together" (Riessman, 2008). Narratives are co-authored (Fjetland, 2015; Fjetland & Gjermestad, 2018). Narrative understanding is thus a relational process influenced by the participants' perceived possibilities and considerations due to narrative care, as well as influence and choices made through the relational and structural embedded power of the storytellers.

The phenomenon of care and relational power is crucial for understanding the challenges of citizenship concerning agency, self-determination and contribution for people with learning disabilities. Narrative care concerns the possibility, ability and will of the narrators to use ethical and moral perspectives of power to act narratively. Ricoeur (1992) refers to Hannah Arendt (1958) when he differentiates the phenomenon of power by "power over" as in dominate, "power in common", as to contribute, and by "power to do", as in *em*power (Ricoeur, 1992, p. 194). Power over other people refers to personal and relational as well as systemically organized asymmetrical perceptions of other people, as people with intellectual disabilities experience (NOU, 2016, 17; Tøssebro, 2019). Power in common refers to the understanding of relational and collective practice that constitutes agency, *power to do*, which is necessary to resist and change oppressive practices and traditions.

What kind of meaning does previous experience represent for the understanding of tradition and power? How can citizens change oppressive practices? To

mediate the voices of resistance that are immanent in the narrative in this study, a perspective of critical and new understanding is useful.

Critical hermeneutics refers to Ricoeur's multiple understanding of the phenomenon *tradition* (Ricoeur, 1973a,b). Ricoeur (1973a) underscores that one cannot understand anything without a tradition, or as Gadamer (2010, p. 427) puts it: "Understanding is an encounter with preunderstanding or prejudices". This conservative understanding of hermeneutics represents one perspective of tradition, namely the *traditionality* of all hermeneutic understanding (Ricoeur, 1973a). But Ricoeur as well as Habermas points to the limitations of conservative hermeneutic perspectives by presenting a different perspective; understanding is also embedded in tradition in the plural – *traditions* (Ricoeur, 1973a). This perspective gives us the analytical tool to point to different traditions that we have been raised in and influenced by. Traditions are bearers of ideologies and values that can raise persons to be subjects and citizens or keep them objectified and oppressed.

Unlike Habermas (1971), who considered hermeneutic understanding incapable of critical reflection, resistance and change, Ricoeur (1973a,b) points to a new possible understanding of experience and texts (Piercey, 2004). This new critical understanding is mediated both by the analytical difference between narrative description and meaning, as well as the regulation of nearness and distance in the process of understanding. Nearness can strengthen the identification and empathy with the process of understanding the experience in focus; distance can contribute to freeing the actors from traditional and oppressive previous norms in understanding and acting.

The process of critical understanding and insight are fundamental for grasping the resources of narrative identity as elaborated by Ricoeur (1992). Narrative identity implies the complexity of both sameness and ipseity: change by new insight. Narrative identity includes the idea that persons have both a moral and ethical character to be recognized and trusted, as well as an ability to resist, oppose and change according to values mediated by experience and insight.

Citizenship and resistance

In 1993, Linda Myrsiades wrote a paper on the value of narrativity in "Constituting Resistance". With reference to theories of power as cultural habitus (Bourdieu) and narrative understanding (Ricoeur), resistance as a social and intersubjective phenomenon represents agency as mediated by the possibility of multiple meanings in understanding experiences. Resistance is mediated by the articulation of a problem or a crisis and the collective's answer, constructing new truths and norms of

understanding and action (Myrsiades, 1993). Andrews (2004, p. 1) points to the coherence between resistance and counter-narratives when defining the phenomenon of counter-narratives as "the stories people tell and live which offer resistance, either implicitly or explicitly, to dominant cultural narratives." Counter-narratives emerge in social relationships in local contexts and situations, and mediate the investigation of power and hegemony, rejecting totality and former consensus (Bamberg, 2004). Narrating resistance represents very different practices. Both by removing self from an oppressive environment and reframing dominant cultural narratives – totally or partially – are ways of individual resistance to the cultural oppression of people with intellectual disability (McDonald, Keys, & Balcazar, 2007). The narrative circulation of dominant beliefs of ableism represent epistemic injustice that can be resisted and changed if citizens get access to narrative spaces of new understanding (Tarvainen, 2019).

Iqtadar, Hernandez-Saca & Ellison (2020, p. 2) emphasize that counter-narratives represent resistance which mediates alternative stories of identity, as the stories that people share about "who they are and how their lives and communities stand up to resist the negative assumptions and misconceptions prevalent in the dominant society". In a qualitative research synthesis of empirical studies, they show how citizens' health and well-being are influenced negatively by culturally constructed labels of disability. They point to a need for increased attention on performed acts of resistance by citizens' own "voice", being crucial for promoting social and political changes that benefits the identity and well-being of people with disabilities. The identity as "ordinary citizens" rather than "disabled people" is a fundamental issue in disability activists' claims for citizenship, according to Sépulchre (2020).

McKenzie-Mohr & Lafrance (2017) stress the importance of narrative resistance in social work. They call for the strengthening of focus in professional practices for mediating support for people's efforts to resist harmful storying and oppression by "seeing" and "nurturing" people's efforts to construct counter-narratives. Facilitating counter-narratives can thus resist victimization and devaluation of citizens and support agency and the experience of lived citizenship.

An everyday narrative

In a lunch break at a sheltered workshop in Norway, the following dialogue took place between workers receiving assisted living facility due to their intellectual disability:

> "I want to visit my colleague Magne for dinner and to stay overnight, but it is so difficult. I've got permission from the social workers Anne and Mette, but if

> Marthe is on duty, I will not get a permission. She always says no. And my mom doesn't know either." (…) Hilda says: "It's so annoying!". And Arne continues: "These matters we ought to decide for ourselves!" (…) "You just walk out in the morning and do it – don't ask them!" Another colleague says: "You can put a yellow post-it-note on the door when you are leaving in the morning, telling them that you will be back the next day." Two other colleagues are suggesting adding a favorable activity, like football or walking-tour to the explanation, to please the social workers. (Worker Knut and colleagues) (Fjetland, 2015).

As a point of departure, this quotation calls for increased attention and understanding of the social phenomenon of resistance practiced by people with intellectual disabilities; this study will explore the presented narrative according to the following research question and four sub-questions:

1. What characterizes voices of resistance in an everyday dialogue between people with intellectual disabilities and how can these characteristics illuminate the understanding of citizenship?
   a. What characterizes the context of the narrative?
   b. What characterizes the themes developed in the narrative?
   c. What values and point of views are at stake for the workers in the narrative?
   d. What characterizes the understanding of citizenship presented?

METHODS, ETHICS & ANALYSIS

To explore mundane speech practices of everyday life, fieldwork with observation of narrative co-authorship is a relevant method (Thagaard, 2018; Clandinin, 2007). The narrative presented in this study is extracted from a published study (Fjetland, 2015) approved by the Norwegian Centre for Research Data (nsd.no). Josselson (2007) underpins, however, that ethical considerations regard all aspects of narrative research. Narrative research implies a duty for the researcher to acknowledge the voice of the participant as well as to take responsibility for the interpretation of the results.

Narrative analyses in this study represent exploring meaning according to a perspective of critical hermeneutics (Ricoeur, 1973a). Narrative analysis of mundane speech implies an understanding of context to be interpreted (Chase, 2011; Blix, 2017) and is inspired by Ricoeur (1984), Riessman (2008) and Labov & Waletzky, (1967). It underscores the resources of both narrative process and structure, the content of the story and the storytellers' interpretation of meaning.

A narrative four-step model of interpretation has been used (Fjetland, 2015). This includes first a naive reading to give insight in the context of the narrative, presented and discussed with the heading "Introduction" and "Resistance and context". Second is a thematic reading which results in exploring the narrative process of co-authorship and content of the narrative. The third reading explores the challenges, evaluations and choices discussed by co-/authors. The results of the second and third reading are presented under the headings of "Relational resistance; narrative care & power in common" and "Resistance; ethics and identity". The fourth reading represents a critical interpretive reading that seeks to sum up the results according to the aim of the study, presented principally in "Concluding; A perspective of citizenship of resistance".

RESULTS & DISCUSSION

The results of the first naive reading were a starting point for understanding the importance of co-authorship for the experience of lived citizenship. Further the naive reading made visible implicit values, ethical and moral dilemmas and injustice of everyday life for people who depend upon professional practice and care. The story told provided insight in a struggle to be a citizen with basic civil, political and social rights and the unjust and arbitrary professional practices hampering agency and lived citizenship, as pointed to in recent research (Sépulchre, 2020; Tarvainen, 2019; Kallio et al., 2020; Chalachanová, Lid & Gjermestad, 2021). The message of the story points to the importance of including both material and spatial – the context of housing and work – as well as relational and affective dimensions – the context of professional relationships, friends, family, colleagues – in the understanding of lived citizenship.

The acts of citizenship (Isin, 2017) are further co-authored, pointing to speech-acts including emotional and practical support, sharing experience, presenting suggestions and possible solutions both within a framework of professional care, as well as in opposition to established norms of welfare; "You just walk out in the morning and do it – don't ask them." As McKenzie-Mohr & Lafrance (2017) points out, narrative resistance is co-authored, representing a resource in supporting lived citizenship mediated by the acknowledgement of relational, emotional and political agency.

Resistance and context: Contextual resistance

A basic condition for the co-authored exchange of experience from everyday life is that the narrators all are workers at a sheltered workshop. Another basic contextual

premise of understanding is the participants' familiarity with accommodated living conditions for people with intellectual disability. Citizenship in this study is practised in these contexts.

The right and access to work is a traditional and historical central element in the perspective of social citizenship (Boje, 2017). Not having a job is a major factor in health challenges, loneliness and social marginalization (HOD, 2018). Multiple studies point to ordinary or sheltered work as an important living condition for health and quality of life for people with intellectual disability (Fjetland, 2015; NOU, 2016, 17; Sly & Tindall, 2016; Wangen, 2019). Work is a basic human right according to Article 27 of the CRPD (UN, 2003), and provides citizens with an income, meaningful activity, social network and friends. Work as a basic living condition is challenged as sheltered work is increasingly difficult to access for people with intellectual disabilities. An increasing number of people with intellectual disabilities in Norway lack the right to an evaluation of employability and an adjusted activity to ensure an income, social needs as well as meaningful everyday activity (NOU, 2016, 17; Wendelborg, Kittelsaa & Wik, 2017; Wettergreen, Karlsen & Jensen, 2020).

The context of sheltered work has been criticized as a marginalizing way to organize work that lacks inclusion in society according to the general principles for the ordinary workforce (Reinertsen, 2015; Wendelborg & Tøssebro, 2018). This study gives arguments to underscore the importance of people with intellectual disabilities getting the opportunity to have colleagues as co-authors with the same living conditions and experiences as themselves. The narrative of this study shows that colleagues at a sheltered workshop get the opportunity to explore their lived citizenship, develop agency and construct resistance by narrative understanding. The results point to the importance of contexts that mediate autonomy and influence as a dimension of lived citizenship (Halvorsen et al., 2017). Access to spaces for narrating new understanding of everyday life situations is a premise for opposing identities of victimization and social othering (Andrews, 2004; Tarvainen, 2019). A model of organizing work for people with intellectual disability should, according to this study, mediate the possibility of exploring and exchanging point of views at work and in everyday life.

Being at work gives workers a right and access to a lunch break. As many workers before them, working for better living conditions, they use the lunch break strategically, talking together about important issues in everyday life. The lunch strategy provides the necessary nearness to each other as well as distance to the situation at home, so they are able to explore the situation of the narrator and think critically. Balancing nearness and distance are a quality of importance for under-

standing and new insights, underscored by both Gadamer (2010) and Ricoeur (1973a). The emotionally and rationally based suggestions expand the story and make possibilities and challenges visible for the participants. This is underscored as central for the process of the critical understanding mediated by narrative emplotment, according to Ricoeur (1973a). The participants in the narrative have access to an arena of work that respects the rights of workers to have a lunch break and communicate. This context of the narrative is a basic condition both for practising and developing agency and citizenship.

The context of the narrative – assisted living – further represents the context of the relationships to be changed by the intentions and narrative resistance of the co-authors. Assisted living accommodation represents a context of care, development and education as well as rules and regulations (Mjøen, 2019; Kittelsaa, 2019). It is a context of innate asymmetrical relationships that challenges both civil rights such as equality and freedom of speech, political influence on frames of basic living conditions, and social citizenship as access to building friendship. The results in this study support the study by Kallio et al. (2020), which emphasizes the importance of the material and spatial dimension of living conditions such as housing and work in exploring and facilitating lived citizenship.

Relational resistance: narrative care & power in common

The thematic reading of the narrative gives insight into lived citizenship as a collective narratively performed act in process. The collective resistance is based on the caring relations between the colleagues having lunch together co-authoring a narrative of agency and relational resistance.

As Myrsiades (1993) underscored in her studies as fundamental for mediating resistance, the narrative of this study starts out by presenting the storyteller's challenge. The background for the challenge and complicating action (Labov & Waletzky, 1967) is a wish that every citizen has some experience with – inviting friends for dinner and staying overnight. The challenge is presented as an issue of *permission* constituted by organized welfare and professional practice. Though the reason is not explicit in the narrative, studies show how the understanding of professional care implies a notion of protecting and educating care-receiver against their own unfortunate choices in everyday life. This experience is a common experience, well documented in research regarding self-determination in everyday life for people with intellectual disabilities in Norway. One of the main issues is the predominant focus on small-scale questions of everyday life, like decisions on clothing, eating, bedtime, friends (Kittelsaa & Tøssebro, 2011; 2013; NOU, 2016,

17; Mjøen, 2019; Tøssebro, 2019). Living in a life situation in need of professional care implies a context of control by professional carers, social workers as well as parents, and experiencing not being listened to. The emotional answer from the co-authors in the narrative confirm this interpretation; the first response that the storyteller gets is a comment of acknowledgement, recognition and familiarity: "Hilda says: 'It is so annoying!' And Arne continues: 'These matters we ought to decide for ourselves!'"

Ricoeur (1992) describes dominating relations as "power over", highlighting the characteristics of asymmetrical relationships and the silencing of agency. "Power over" is identified by its hierarchical, objectifying, rule-based and instructive practices. Power is a complex characteristic of relations. Unconsciousness and prejudices can cover up the use of dominating power. Juritzen & Heggen (2009) analysed everyday – small-talk – practices in Norwegian nursing homes; they showed how very kind talk also may represent a power over people's own agency in everyday life. A psychological interpretation of utterances and actions might have care as the intention but might also diminish the agency of other persons.

Another ethical challenge for professional practice regarding the experience of control and permission is the lack of unity in the carers' judgements. They differ in what seems to be the wise decision, and the citizens in need of care are in a situation of no impact other than to accept and produce strategic knowledge about who will answer what, as the narrative shows: "I've got permission from the social workers Anne and Mette, but if Marthe is on duty, I will not get a permission. She always says no. And my mom doesn't know either."

The practice of permission that represents the challenge in the narrative and is dominant in professional care for persons with intellectual disability encompasses an ethical and moral disagreement in professional care. While the intention would be to make the citizen take part in wise decisions, this practice supports strategic and superficial behaviour that undermines relationships and the means to lived citizenship.

In the narrative, the storyteller is, however, repositioned as a responsible agent by his colleagues and co-authors of the narrative. Narrative understanding is practice and action (Ricoeur, 1984; Iqtadar et al., 2020; Chalachanovà, Fjetland & Gjermestad, 2021). The workers change their fortunes and everyday life conditions by narrative action. This action is co-authored by the workers acting in common (Arendt, 1958), distributing power, presenting several examples of suggestions and possible actions, what Ricoeur called "power to do" (Ricoeur, 1992). Co-authorship is embedded in care as well as in power (Fjetland, 2015, 2019). This means that the intentions of the narrators are based on ethical and moral choices.

Co-authors have the "power to do" by making the persons in the narrative agents with the possibility to make changes in their own life, or the opposite. The perception of agency concerns the acknowledgement of both emotional and verbal responses as acts of citizenship (Kallio et al., 2020; Isin, 2017). The co-authors of this study are all positioning possible actions that represents agency, resisting being objectified and silenced.

The narrative emplotment concerns the co-authors' care for the main storyteller. They oppose the role he has been given by the social workers and his parents. Their co-authorship follows up on the storyteller's intentions of shaping his own social network and activities of everyday life and assist him in his narrative understanding; holding onto and keeping on constructing an identity of agency which encompasses resistance. Citizenship practices are narratively constructed with the assistance of a co-authorship of resistance (Tarvainen, 2019). Citizenship represents the relational power of the colleagues in common.

Resistance: Ethics and identity

A critical and important question for exploring the process of understanding and insights, posed by Ricoeur (1973a) and Habermas (1971) as well as the workers in the story, is: how is it possible to free oneself from oppressive ideologies and practices when tradition is what we are offered in order to understand what is going on in our lives? Is it possible to change my fortunes through the process of narrative understanding?

As the studies by Bamberg (2004) and McDonald et al. (2007) emphasize, the workers in this study obviously identify several ideological different actions as well. Opposition and resistance is one, communication and argumentation is another, and strategic avoidance on the premises of the system is a third. These choices are ideologically different but represent action and agency. On a relational as well as a contextual level, all these possibilities presented by the co-authors in the narrative might be interpreted in accordance with Ricoeur's (1973a) recommendation: when choices and ideologies are questioned, ask for the legitimacy of the arguments, actions and ideologies.

The choices might be interpreted as answers to the possibilities and challenges of the context of assisted living accommodation for people with intellectual disability in Norway (cf. Kittelsaa & Tøssebro, 2013; Helsetilsynet, 2017; Mjøen, 2019). Previous studies demonstrate that practices of self-determination and involvement are an important issue in social workers' perception of quality in professional practice (Nordlund, Linde, & Tronsen, 2015; Fjetland et al., 2019). However, practices of self-determination lack competence in communication to mediate dialogue

according to involvement in everyday matters (Skarstad, 2018; Lorentzen, Pettersen & Næss, 2018; Guddingmo, 2019). One of the participants in a study of involvement at sheltered work (Fjetland, 2015, p. 211) puts it like this: "I can object, but only a little."

The co-authors' advice can further be understood as elaborating the meaning of the proclamation: "These matters we ought to decide for ourselves!" (Arne). This proclamation opens a voice of legitimate resistance towards the contexts included, the concrete situation at stake as well as the relations to the persons responsible for the actions of permission.

The storyteller and the co-authors take the ethical and moral obligations towards a fundamental human condition of the self; to be accountable for your own decisions. To fail to be perceived as an accountable person is to reduce the identity of oneself, implying that the character of the person is dominated by rules and principles, rather than by moral judgement. A narrative understanding of identity includes "character", meaning a dynamic dialogue between ethical and moral principles and the values at stake in a unique situation; identity as sameness as well as change and diversity (Ricoeur, 1992, p. 143). A dynamic identity implies that a person represents an agent; a character to be recognized as well as tested and developed. The spatial, social and relational possibility to narratively resist traditional choices that are presented in everyday life is fundamental to opposing oppression and mediating lived citizenship (cf. McKenzie-Mohr & Lafrance, 2017; Tarvainen, 2019; Kallio et al., 2020). It is this dynamic identity of integrity that is constructed by the co-authors of the narrative. By proclaiming the storyteller's right and the duty to decide, the following suggestions in the narrative represents possible actions for resistance and responsibility, what Ricoeur (1992, p. 240) describes as "practical wisdom".

> a morality of obligations […] produces conflictual situations were practical wisdom has no recourse […] other than to return to the initial intuition of ethics, in the framework of moral judgement in situation; that is, to the vision or aim of "the good life" with and for others in just institutions.

The narrative of this study illustrates how co-authorship can support the construction of a narrative identity that explores the ideology of institutions as well as social relations in professional practices. Common experience and relationships as colleagues, mediate narrative care and the construction of agency, implying the resistance of entering a "permission discourse". Narrative care in this story presupposes supporting and exploring resistance. And the resistance represents an answer to the "power over" – the phenomenon and practice presented as the challenging point of departure in the

narrative. Citizenship of resistance constructed by the storyteller and the co-authors in this study is based on a contextual and relational act of citizenship.

CONCLUSION: A PERSPECTIVE OF CITIZENSHIP OF RESISTANCE

To produce knowledge of lived citizenship, this study has explored a narrative constructed by workers at a sheltered workshop. Results of a narrative analysis points to citizenship practices connected to the narrative process of co-authorship and the knowledge of resistance produced by the co-authors. To understand processes of citizenship, both the importance of context and tradition, care and power, are emphasized. A citizenship of resistance is constructed due to narrative care and the realization of power in common is developed in the process of co-authorship.

The perspective of citizenship of resistance in this study challenges ideologies, ethics and competence of professional practices in both welfare and society – represented by the context of assisted living accommodation and sheltered work – as well as the actions of social workers. The narrative thus provides a civil, a political as well as a social understanding of citizenship (cf. Boje, 2017; Kymlica, 2002). The results add answers to the devaluation of agency and citizenship – competence of people with disabilities – put forward in previous studies (Lid, 2017; Fjetland & Gjermestad, 2018; Iqtadar et al., 2020). Further, the study illustrates the importance of a spatial and material, affective and emotional as well as relational dimension in exploring the performance and acts of lived citizenship as put forward by Kallio et al. (2020) and Isin (2017).

A citizenship of resistance as explored in this study represents a relational perspective in lived citizenship that can be considered a basic quality of democratic dialogical influence as put forward in rights-based perspectives in citizenship (Fraser, 2009). The study implies further exploration and research regarding professional practice according the inclusion and systematic acknowledgement and the use of the knowledge of citizens involved when systemic changes to assisted living accommodation and work affiliation for people with intellectual disabilities are initiated.

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9. From struggles of belonging to struggles of becoming: Acts of resistance in the drama *I Answered a Dream*

Vibeke Glørstad

Abstract This chapter highlights a theatrical performance, *I Answered a Dream* (2011), by Marte Wexelsen Goksøyr, a woman with Down's syndrome. It is the written drama which is in focus. In the performative approach to citizenship, I use acts of citizenship, with a focus on ruptures, as a conceptual tool to ask which acts of citizenship create the becoming of Goksøyr's citizenship in the text. My specific contribution is how theories of citizenship may support an understanding of artistic representation as resistance, creating new spaces.

Keywords dramatist | theatre | acts of citizenship | interdependent political agency | intellectual disability

INTRODUCTION

I Answered a Dream (Jeg svarte på en Drøm, 2011) is written and performed by Marte Wexelsen Goksøyr and actor/dramatist Siv Svendsen. As well as being an actor, author and activist, Goksøyr is a woman with Down's syndrome as well as being an actor, author and activist. From a sociology of culture perspective (Hall, 1997; Larsen, 2019), I ask what this hitherto unstudied drama's representations say about living as a woman with a learning disability. I conduct a literary exploration of how citizenship studies can cast light on this dramatic text through the lens of "acts of citizenship" as a methodology (Andrijasevic, 2013; Kallio, Wood, & Hakli, 2020). I have formulated the following research questions: *Which acts of resistance visualize the "becoming" of Goksøyr's citizenship in the drama? How does Goksøyr enact and extend her citizenship in this text?*

The theoretical approach is elaborated through three intertwined perspectives: the notion of interdependent political agency; a performative approach to citizenship and the concept of acts of citizenship as acts of becoming.

Background

Despite limited attention paid by government to the field of the arts, people with learning disabilities in Norway are increasingly visible in the public sphere as actors in film and theatre and as musicians; thus, they are moving beyond care regimes (Gjærum, 2017). Some professional inclusive theatres have been established, including Theatre nonSTOP (2016). However, there are only a few writers with a learning disability who are visible (Morlandstø & Sandvin, 2014).

At the same time, violations of the Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006) are referred to in governmental papers (NOU, 2016:17); these describe violations of the rights to education, work, and participation in society, including cultural participation.

In the Norwegian context, studies on inclusive theatrical productions address the political dimension and the lack of participation; they see the artist as a mediator between disability culture and society and value artistic production as "art for art's sake" (Gjærum & Rassmussen, 2010). Saur and Johansen (2013 a,b), in their study of Theatre nonSTOP, discuss how performances with a Foucauldian approach may be seen as micro-resistance. For instance, in its performance of *The Story of Me* (Theatre nonSTOP, 2011), the actors visualize their dreams on stage, which stands in contrast to being dependent on care providers who have the power to limit their possibilities. This aesthetic establishes counter stories and may bring about democratic change, as dissensus lies at the heart of political acts. Saur (2017) argues that the quality of learning-disabled theatre relates to destabilizing and disrupting identity and conduct which creates a new space for agency.

Previously, Saur and Johansen were concerned that artistic expression for people with learning disabilities was often understood in terms of therapy and education "as [a] means to develop their dis-abilities, and not looked upon as a genuine expression of art" (2013b, p. 47). The growing field of international studies in theatre and learning disabilities (Disability Arts, 2020; Hadley et al., 2019) is moving beyond therapeutic, post-therapeutic, health and specifically well-being approaches, which reflects the new international scene of diversity-oriented art theatre.

Ames, Calvert, Glørstad, Maguire-Rosier, McCaffrey & Shmidt (2019) analyse the production *Dis-Sylphide* by the Novi Sad-based inclusive theatre group Per.Art, who value the distillation of "otherhow" knowledge (p. 98). McCaffrey (2019)

argues that theatre that involves actors with intellectual disabilities makes radical promises of emancipation. Umathum and Wihstutz (2015) relate theatre with learning-disabled actors to the intersection of politics and aesthetics, identity and empowerment. Schmidt (2017) analyses the possibilities of learning-disabled actors as directors. Natalija Vladisavljević, an actor with Down's syndrome in Per.Art, contributes text and poems to their drama.

The works of Marte Wexelsen Goksøyr

Goksøyr's work represents an independent approach to the arts that is supported by a network of family and friends who are also artists. Goksøyr studied drama and uses her voice in public to speak out against stigmatization in film, theatre and literature, and as author of two books (Goksøyr, 2012, 2016). In *I want to live* (2012), she tells the story of her life; the challenge of having a proper education and living as an actor. She has also recorded interviews with politicians. These included the then prime minister, Jens Stoltenberg*;* she asked about his suggestion for early ultrasounds in pregnancy (Goksøyr, 2012, pp. 75–85). Goksøyr is worried that people with Down's syndrome, like her, will be endangered. In *No matter who we are* (2016), Goksøyr reflects on her experiences of being excluded and bullied and talks with others who have also had this painful experience. She was nominated for Amanda Norwegian Film Prize best female supporting role for her performance in the film Gritt (2021), the first actor with Down's syndrome to be nominated for this prize.

Her latest theatre performance, *What the fuck is the problem?* (2017), performed at Theatre MANU (director Bjørn Birch and dramaturg Ragnhild Mærli), argues that the criteria for what is considered normal are narrowing from one day to the next, asking "Are the arts the last tool we have that can open the eyes of those who do not want to see?". The text of the drama *I Answered a Dream* (2011) is based on Goksøyr's life and was performed by Goksøyr, Eindride Eidsvold (Norwegian National Theatre) and Siv Svendsen at the National Theatre in Oslo and in Stavanger in 2012. The drama centres on Jeanne d'Arc, the French Catholic saint who had a powerful vision of fighting the English for Charles VIII, King of France, around 1430. She was captured by the English, put on trial and burnt at the stake in 1431. Jeanne d'Arc is a hero to Goksøyr because she shows how one can change the world by believing in one's vision.

Wexelsen Goksøyr arrives dressed in a simple, medieval-style tunic, which she wears throughout the performance. In Scene 1, she appears as Jeanne d'Arc at a table with young noblemen together with the heir to the throne, Charles (Eidsvoll). The performance alternates between different levels of reality, such as when

Svendsen talks to Goksøyr, but is it Marte Goksøyr or the actor she is talking to? The performance was well received. Culture journalist IdaLou Larsen reviewed the performance (Larsen, 2012): "With humour, irony and commitment, *I Answered a Dream* expresses something universal about being human". The review celebrates shared humanity. Can the drama also be read as utterances of the becoming of citizenship?

THEORETICAL APPROACH: FROM STRUGGLES OF BELONGING TO STRUGGLES OF BECOMING

Scholars such as Donaldson and Kymlicka criticize the homogenizing approach in certain citizenship studies when they deny difference as a source of identity and community building:

> (M)any members of society are still relegated, both de facto and de jure, to the status of passive subjects, not active citizens […]. People with cognitive disabilities have the formal status of citizenship, yet these members […] are disenfranchised and precluded from enacting substantive citizenship […] [and] denied the right to participate in democratic shared rules which define modern ideals of citizenship (Donaldson & Kymlicka, 2017, p. 839).

They explained this by deficits in modern political theory which create internal exclusions by limiting citizenship to those who are "politically mature" and neurotypical adults. Donaldson and Kymlicka emphasize that this capacity contract, where some members of society are deemed naturally to be governed by others as subalterns and/or within a wardship, is a theoretical mistake (2017, pp. 839–841).

However, through citizenship struggles, perceptions of who is naturally governed by whom have been changed by women, workers, racialized minorities and people with disabilities, and thereby challenging assumptions of incompetence that have been used to justify paternalistic rule. What is established are new forms of intersubjective recognition and participation, with relations based on equality.

But these citizenship struggles have rarely challenged the capacity contract itself, as Donaldson and Kymlicka argue. They propose a membership model (Donaldson & Kymlicka, 2017, p. 839). The fundamental purpose of citizenship is to ensure that all members of the community have a chance to realize their own understanding of their subjective good, to exercise meaningful forms of control in their lives and to participate in shaping the social norms by which they are governed (Donaldson & Kymlicka, 2017, p. 841). To realize this, it is necessary to look for the

constitution of political subjectivities in liminal space as well, such as in drama writing here (Turner, 2016).

Interdependent political agency

People with cognitive disabilities do share the goods and burdens as members of society and are subject to the exercise of political power. This generates a right to make sure the government enacts political power in a legitimate way. Artistic means such as drama writing are one way to hold the government accountable. Political agency should then be seen as a social and relational accomplishment, as opposed to how liberal tradition relies on inner self asserted individual capacity. The alternative model for equal citizenship is based on the idea of interdependent agency (Donaldson & Kymlicka, 2017, p. 854).

They argue that developing "one's script of the good life" – the values and meaning that everyone wants to achieve – can be an interdependent process. This process may occur through trial and error, doing and redoing, in the context of trusting and supportive relationships. "One's script" may be brought into the process of public deliberation through other modes of effective representation and not only through rational speech capacities. Representations can rely on creative projection and inherited cultural knowledge, where it is possible to construct new spaces and places of citizenship that allow all members to have a say in the norms that govern our shared life (Donaldson & Kymlicka, 2017, pp. 853–854).

Furthermore, it is necessary to elaborate on the performative aspects of citizenship, which are the basis for understanding acts of citizenship as transformative acts, which can also be seen in a dramatic text.

Performative citizenship

A performative perspective means understanding people as acting beings in their objective and subjective situations, focusing on how they enact their subjectivity (Isin, 2017, p. 500). The approach to citizenship as performative acts is drawn from language philosophy and performance studies. Performativity involves the moment in which a subject – a person or a collective – asserts a right to an entitlement to a liveable life, when no such prior authorization (claim) exists. Performing acts of citizenship often then invokes a break with convention. To Isin, analysing citizenship from a performative perspective means appreciating that the extent of our claims both refers to and reiterates social conventions, yet has force and effects that exceed them (2017, p. 501).

Acts of citizenship as acts of becoming

As mentioned, contemporary citizenship studies have mostly been occupied with struggles for the inclusion of citizens. "From aboriginal rights, women's rights, civil rights, […] and disability rights, we have experienced […] major trends toward the formation of new claims for inclusion and belonging" (Isin & Turner, 2002, p. 1 in Strandli Schmidt, 2013, p. 58). The focus has been on establishing proper habits for facilitating inclusion. The emphasis has been on continuities to ensure belonging rather than on discontinuities. Isin and Nielsen argue (2008, pp. 20–21) that we have been "fascinated by how bodies, habits and practices are intertwined to produce conduct".

The aim of acts of citizenship as a conceptual tool can be understood as shifting from this focus on habits/conduct (behaviour) to *breaks – situations where claims are made – the act itself* (the notion of becoming). Theorizing the deed rather than the doer shifts the focus away from the individual to the specific act that makes the citizen (Isin, 2017).

> Acts of citizenship are understood as deeds that contain […] interdependent components. They disrupt habitus, create new possibilities, claim rights, and impose obligations in emotionally charged tones; pose their claims in enduring and creative expressions; and, most of all, are the actual moments that shift established practices, status and habitus (Isin & Nielsen, 2008, p. 10).

The word "act" as a verb means putting something into motion and it being directed towards something. *Acts have a virtual* existence and can come to life through actions, which may be actualized under certain conditions. Isin (2009, p. 379) emphasizes that to act is to actualize a rupture.

The act of looking for *acts of citizenship* may be used as a critical methodology. Attention is paid to how subjects constitute themselves as citizens. In doing so, they make collective and marginal struggles the entry point of analysis by identifying mobilization, contestation and the way citizenship is negotiated on the ground (Andrijasevic, 2013, p. 49). An epistemology of feminist standpoint theory (Harding, 2004) supports this, arguing that conventional objective research methods are not neutral but reflect the institutional interest of dominant political positions. To produce a less distorted analysis of the social and political world, investigations should begin with the lives of oppressed groups and their histories (Andrijasevic, 2013).

METHODOLOGICAL APPROACHES

Feminist standpoint theory (Harding, 2004) is the philosophy of science that serves as the foundation of this text, and I make use of qualitative thematic content analysis (Granheim, Lindgren, & Lundman, 2017). Knowledge development here is seen as socially constructed, and I view my interpretation during the analysis phase as a co-creation between the researcher and the text; thus, the text is assumed to have more than a single meaning. Content analysis is seen as a value-based process that offers opportunities for manifest and descriptive content as well as for latent and interpretative content (Granheim, Lindgren, & Lundman, 2017, p. 29). My focus is on latent content.

Firstly, in next section, I present excerpts that I have chosen from the manuscript's eight scenes. In the last section, I present my analysis and parallel discussion. The approach to the analysis has been partly deductive, with an *acts of citizenship* approach when reading the manuscript, highlighting *specific enactments of breaking with ordinary practice, rules and conduct.* In the parallel discussion, I elaborate on three textual strategies as steps that have emerged from these breaks. This leads to what I consider to be the expression of more latent content: the *concept of becoming*.

This, then, is my literary textual reading of the written drama, including its stage direction. As I have not seen the performance, the reading is not a full-performance analysis (Schechner, 2013). An embodied analysis would point to additional ruptures, which also would provide a more comprehensive interpretation. Due to the ethical implications of the research and the challenges of the analytical approaches without having seen the actors on stage, I must emphasize that this is my own specific reading of the text.

Ethical considerations

Goksøyr and her mother, who is Goksøyr's manager, and Svendsen have given me their permission to analyse the manuscript. I have met and talked with them, and discussed the performance and Goksøyr's books. I have been following Goksøyr's work in the news and her artistic contributions for decades. The translation into English is my own. As an art product, the manuscript represents a distinctive way of approaching reality in which artistic means lift personal experience to a more abstract level.

SCENES FROM THE DRAMA *I ANSWERED A DREAM*

Scene One opens on a dark stage where the song "Joan of Arc" by Leonard Cohen is being played. Goksøyr watches a huge screen with a picture of knights inside a castle. She then walks behind the screen and into the bluescreen and is now Jeanne d'Arc, asking "Where is the king? I want to talk to him! Are you deaf?" Charles VIII (Eidsvold) comes onstage and bends down towards her and scares her: "Boo!" She jumps and says that she is Jeanne d'Arc. The scene continues with Charles laughing and asking if she is the famous Jeanne d'Arc. She confirms that she is and says that God has asked her to come. Charles replies ironically: "Really?" Jeanne d'Arc explains that she wants Charles to come with her and fight the English.

In Scene Two, Goksøyr steps out of her role as Jeanne d'Arc and talks with Svendsen about how as a child she didn't realize that she was different. When applying to acting school, she reached round two and then realized that because she has Down's syndrome, she did not get many offers for roles. Svendsen asks: "They're not tearing down your door?" Goksøyr: "No".

In Scene Three, Charles suddenly calls after Jeanne d'Arc. On the screen we see a picture of Charles entering, ready for the struggle on the battlefield. Behind it, we see a picture of a huge army that is ready to attack. Goksøyr as Jeanne d'Arc comes onstage waving a large red flag. Charles runs towards the picture of the army on the screen with a sword in his hands, ready to take part in battle. The screen now appears as a wall facing the audience. He runs the sword repeatedly through the wall, making holes. Then he kicks a board down towards the audience while yelling at both the audience and Jeanne d'Arc: "Get them! In the front! Get them, Jeanne d'Arc!"

In Scene Five, they are once again Goksøyr and Eidsvold. Goksøyr asks: "Excuse me, but were you going to kill the audience just now?" Eidsvold agrees that it was a bit too much, but that it would have been exciting. Goksøyr is surprised. "To kill the audience?" Eidsvold says no, but "it would have been exciting to have a performance where the audience gets killed every night". Goksøyr answers: "No, no, everyone has the right to life." Eidsvold argues that "[s]ometimes you have to exaggerate when you are an actor. It's good to overdo it. At the National Theatre, we don't do anything else but exaggerate. Sometimes when you have a text that's a bit big, like Jeanne d'Arc for instance, it's good to overdo it. Make it greater, make it fly. Because sometimes... theatre is written a bit larger than reality; a bit more than reality."

In Scenes Six and Seven, Goksøyr reads the story that Jeanne d'Arc told in her diaries and she reflects: "Jeanne d'Arc tells those in power what is important to her, what makes her feel alive. […] I do not want others to govern my life. I will believe in what is important to me. I wish to join the forces of change." In the coronation

ceremony in Scene Eight, Charles is celebrated as King of France. It ends in humorous wordplay. Goksøyr's previous interview with the prime minister of Norway about the sorting society is used as the text. Eidsvold rises and stands behind Goksøyr and gives a speech: "I want to live in a country where everyone is the same […] [and] every human has the same value, the same meaning, but [where] people are very different […]."

ANALYSIS AND DISCUSSION: DEVELOPING A DIFFERENCE-CENTRED CITIZENSHIP OF BECOMING

I asked which acts of citizenship as resistance in *I Answered a Dream* relate to the becoming of Goksøyr's citizenship. By analysing the breaks and the parallel discussion, it was possible to crystallize three main steps of becoming in the written drama.

Step one: Acts of citizenship

Step One relates to specific acts of citizenship, through interdependent agency, that break with convention, especially in Scene One, Scene Three and Scene Eight. In Scene One, Charles grows impatient with Jeanne d'Arc when she says she has been sent by God. Charles: "This was fun for ten minutes. Now it's not fun anymore (….) [G]et out of here before I cut your head off." He lifts his sword and threatens her. Then Jeanne d'Arc pulls the sword from her scabbard and strikes Charles's sword out of his hands. Seeing this, Charles takes fright and asks God to forgive him for his prejudice in not believing that he had sent Jeanne d'Arc: "I am only a louse, a small mosquito who didn't believe that your words came from this person." Charles is completely overcome by feelings of shame and remorse. Jeanne d'Arc says that many have not believed her, but that "you are the one I like best of all", thus manifesting their interdependency (Donaldson & Kymlicka, 2017).

Goksøyr, who has visions, and Eidsvold, who is afraid, break with their given identities. Their breaks are related to a strange shift in roles. Latently it is as if Charles is assuming the guilt for his prejudices. This may be associated with the general levels of prejudice in society towards differently abled people. Jeanne d'Arc presents herself and enacts herself as a person with a superpower who has been sent from God. As if magical powers exist in the language, her acts break with common expectations (McCaffrey, 2019).

This is further emphasized when Jeanne d'Arc invites Charles "to go with me – to fight the English – the time is now!" Charles admits that he is afraid: "To fight,

Jeanne d'Arc, I must tell you and make a confession to you – I have never fought before and I am afraid. I am just a cowardly louse." Jeanne d'Arc: "I believe you. I am not afraid. We shall fight together on the battlefield." In the way that Charles expresses that he does not know how to fight, he seems latently to be stating that he does not have the language or capacity for this, our community as a battlefield, this being diversity-oriented and valuing difference-centred citizenship (Hadley et al., 2018). However, this sort of interdependent agency is expressed by Jeanne d'Arc when she says that she is not afraid: "We shall fight together on the battlefield." This is a sort of kindness that is also seen in the work of Per.Art (Ames et al., 2019).

In Scene Three, Charles encourages Jeanne d'Arc to speak out loud and clear to their small army so that they hear her in the back rows: "God is with us, and even if we are few, we will win by love. We just must follow our hearts." Charles gets a bit worried: "Are you quite sure?" Jeanne d'Arc confirms this and along with their army they scream "Aaaaaaattack!" Jeanne d'Arc holds her red flag while Charles runs along with the army with a sword in his hands.

Their attack on the English army is achieved through a superpower, where it is chiefly Goksøyr who believes in her power. The screaming out of the word "attack" is in one way inspiring, resonating with both the unthinkable and the implicit needs for strength in this battle, for an inclusive society. The act of the attack can be seen as what Isin describes as citizenship in acts that disrupt what we do in practice and relate to how he describes citizenship as appearing in theory, law, practice (habits) and acts (2019, p. 51).

Further breaks with convention appear when Charles suddenly turns towards the audience, shouting out "Jeanne d'Arc – in the front! Get them Jeanne d'Arc!" Jeanne d'Arc walks through the open hole in the screen towards the audience while waving the flag back and forth. Charles shouts, "Kick them in their balls, Jeanne d'Arc. Do whatever you want to do. I'll take the rest of them." Charles gets very involved and in the heat of the moment, he takes off and runs towards the audience to get them as well. Jeanne d'Arc screams "Stoooooop!"

Engaging with the audience is a central performative strength (Calvert, 2010), but how is one to understand the wish to kill the audience? Latently this may indicate first of all Goksøyr's real struggle: the audience is portrayed as those who watch the differences on the stage, and Goksøyr is an object of their gaze. One way of reading a performance of a person with a learning disability is as a performance by someone who needs pity or care (Reason, 2019). Eidsvold and Goksøyr want to stop that gaze. Perhaps they are too rude to their audience, but the work also stages their citizenship struggles through acts that break with the convention for how to address the audience, the spectators. Ultimately, they realize that they need the

audience and respect their right to life, again in the sense of interdependent agency and constituting political subjectivities in liminal spaces (Turner, 2016).

Another break with convention occurs when Eidsvold and Goksøyr play, disrespectfully, with and in the coronation ceremony in Scene Eight. This is a satirical scene – but which is also warm-hearted, with a kind of softness – that reaches its pinnacle with the inclusion of parts of Goksøyr's interview and critique of the Norwegian prime minister about the sorting society (Goksøyr, 2012, pp. 75–85) in the coronation speech, as if the speech, read with love, has been twisted out of the hands of those in power, and a voice from below finally comes out of the mouth of the "king" to the prime minister. The coronation ceremony can then be seen as celebrating Goksøyr's life, when Eidsvold, as "the non-disabled", reads her speech to the prime minister. In this way it is Goksøyr who is crowned, becoming – or reaching, fulfilling – her citizenship within an interdependent agency, while also holding the authorities accountable through political agency as a relational accomplishment (Donaldson & Kymlicka, 2017, p. 853).

It is the deeds rather than the doer which are in focus. Goksøyr and Eidsvold perform Goksøyr's citizenship, bringing it into reality on the stage. By breaking with convention through acts that create ruptures in commonly held norms regarding abled/disabled, woman/man, poor/rich, popular art/fine art, fiction/history, Goksøyr asserts a certain right to entitlement; the acts refer to and reiterate social conventions while taking forms that exceed them (Hildebrandt & Peters, 2019).

Step two: The audience and post-dramatic aesthetics

The process of becoming in Goksøyr's citizenship is also facilitated by the attack on, and, in this way, dialogue with the audience as part of their interdependent agency. Goksøyr demands respect from the audience, including the public sphere, through the performance, and displays an aesthetic "way of knowing" that expresses a human dimension that the dominant version of society appears to exclude (Reason, 2019, p. 32, with reference to Raymond Williams). Calvert (2010, p. 513) emphasizes that these performances with disabled and nondisabled actors establish a communicative space and may be one of the few spaces in which individuals with learning disabilities are actively regarded at all, let alone given respect (literally given an "audience") within the public sphere. The reception and reviews of the performance may also be seen as breaks into the public sphere (Balme, 2018). These acts are visual activism (Lid, 2017, p. 1565) but they stretch the activism and make the acts virtual.

Furthermore, the use of metatheatrical devices, the aesthetics and then the ethics of the performance supports the meaning of becoming. The play within the

play – how the performance shifts between different realities, the direct address to the audience, the inclusion of music heavily loaded with meaning and parallel performance screens – provides different frames within the already explicitly referenced frame of theatre itself. The screens show films from Goksøyr's childhood and from battlefields. This opening up of an event to dual framing "draws spectators into a liminal space in which attempts to apply habitual, ready-made responses are deferred, delayed or thwarted" (Reason, 2019, p. 69).

Step three: Claiming rights and doing right with things

Step Three of becoming relates to how these breaks lead to claiming rights and filling them with content, *doing rights with things* as Isin describes it (2019). Performative citizenship signifies both a struggle to claim rights and what the struggle *performatively creates as reality: the right to claim rights*. The drama creatively enacts citizenship instead of following a script (such as for conduct) and makes visible how the actors construct citizenship anew, such as by attaching new meaning to the rights. In particular, the scenes that break with convention (one, three and eight) support the scenes that emphasize Goksøyr's life: the scenes that address the moment when Goksøyr realizes she is different and her difficulties following her dreams, wanting a relevant education, being an actor and having a job. These dreams have been established as human rights in the CRPD (UN, 2006). Especially significant to Goksøyr is the hostile public atmosphere that denies the differences she lives with and within. Conversely, as addressed by Article 3 of the CRPD, Goksøyr has the right to respect for her inherent dignity, individual autonomy – including the freedom to make her own choices – and independence as a person. Hildebrandt and Peter (2019, p. 5) describe this form of struggle to claim rights as "fake it till you make it", when one is claiming, enacting or presupposing a right that has yet to gain a legal apparatus. *I Answered a Dream* may be seen as an act of "fake it till you make it".

The drama *I Answered a Dream* may then be seen as attaching new meaning to CRPD rights, including the opportunity to develop and utilize creative and intellectual potential, not only for one's own benefit but also for the enrichment of society (Article 30). The enrichment in the drama may be those creative, rupturing acts that create processes of becoming within a difference-centred notion of citizenship. Finally, the acts of citizenship may be seen as affirming a standpoint epistemological approach. This is achieved within interdependent agency, formulating Goksøyr's new agency and broadening the opportunity for participation in deliberating upon and shaping common social norms (Hadley et al., 2019).

CONCLUSION

Isin and Nielsen state that acts of citizenship mean making the world your own (2008, p. 180). I have shown how Goksøyr and Eidsvold creatively enact and perform citizenship in the drama *I Answered a Dream*. In this way, the drama text may be a site for becoming, as well as resisting straightforward signification. In accordance with Donaldson and Kymlicka, *I Answered a Dream* draws on creative projection, which makes it possible to construct new spaces and places of citizenship that allow all members to have a say in the norms that govern our shared life (2017, pp. 853–854).

Hargrave argues that by reconfiguring the aesthetics at the centre of theatre of learning disability and non-disability, it is possible to dwell on what resists straightforward signification – the uncanny – which also delivers insights into the discourse about social justice (Hargrave, 2015, pp. 8, 13, 15, 17). In *I Answered a Dream*, disability is not reduced to a binary difference; rather, its appearance underscores the profound interconnectedness of all identity. Hargrave goes on to state that the possibility of following dreams is more complex than just material exclusions, and cannot be solved by resource redistribution or legislation alone. These cannot address the fundamental question of human companionship. In the drama text, as an author and an actor Goksøyr acquires her agency in relation to the audience and to Eidsvold and Siv, and in so doing she also disturbs the carer–cared binary. As Hargrave puts it, theatre creates a space in which human proximities can be negotiated and redefined.

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10. Materiality and the enactment of citizenship in assisted living facilities for young adults

Kristina Hoydal and Hilde Thygesen

Abstract Building on empirical data, this chapter explores the relationship between materiality and citizenship in assisted living facilities. The notion of *arrangements* is mobilized to show how different forms of citizenship are constituted through meal practices. The analysis revealed materialities as key actors of meal arrangements, having different roles related to their size and scope. Also, the complexity of materialities involved, and their roles in enacting different values, is revealed and discussed.

Keywords relational citizenship | materiality | technology | assisted living facilities | disability

INTRODUCTION

Enabling people with disabilities to live and participate in society is a core value of Norwegian policy development, in line with the UN Convention on Rights for People with Disabilities (CRPD) (Lid, 2015; UN, 2008). This is also a major theme within the field of disability studies (Kjellberg, 2002; Ursin & Lotherington, 2018). The understanding of persons with disabilities as autonomous and participating citizens underpins the organization of living arrangements and access to care and support services for this diverse group. In Norway, many disabled people in need of extensive care and/or support services live in co-located homes, with on-site staff (NOU 2016: 17; Tøssebro, 2019).

This chapter explores the relationship between materiality and citizenship in the context of such co-located homes, here referred to as "assisted living facilities" (ALFs). The chapter builds on empirical data from fieldwork and interviews in two ALFs for young adults with moderate to severe disabilities. The two ALFs have cer-

tain common features, such as private living areas for each individual resident, 24-hour on-site staff, as well as access to common areas with kitchen facilities. At the same time, they represent different material environments, both in shape and size, and are, as such, interesting empirical contexts for the study.

In our analysis, we draw on analytical resources from the multidisciplinary research field Science and Technology Studies (STS). This means that we base our analysis on a sociotechnical perspective where social, material and value relations are understood as an intertwined phenomenon rather than as isolated entities (Moser & Thygesen, 2019).

Specifically, the chapter address the question: how is citizenship constituted in the context of assisted living facilities, and what is the role of materialities and technologies in this process?

In order to explore these issues, we use a praxiographic approach (Mol, 2002). This means that citizenship (as reality) is understood as constituted in and through practices. Hence, detailed studies of everyday practices form the empirical basis of this chapter. The analysis is related to what we name *meal practices*. This was chosen as it was an important and everyday activity of the ALFs included in the study. Also, meal practices involve a number of materialities and technologies, and represent as such a fruitful approach to the analysis of the relations between materiality and citizenship.

Background

The notion of citizenship is widely used in disability policies (Halvorsen et al., 2018; Sépulchre, 2017). In Norwegian policy development, the notion of citizenship builds on the principle of all individuals as fullworthy members of the community, with an aim of ensuring equal status and opportunities for participation in all parts of society (Lid, 2017; NOU 2016: 17).

The notion of citizenship originates from a political science context and was initially understood as a contract between the state and the individual citizen (Marshall, 1950). However, the concept has become broader over the past decades (Bartlett, 2016; Kallio, Wood & Häkli, 2020) and now emphasizes citizenship to entail participation, belonging, self-determination and equality (Lister, 2007; Strømsnes, 2003). This brings about a shift from citizenship as strictly related to the individual's (passive) connections to the state, to a broader understanding which promotes an idea of people as active agents in their own lives and in society (Lister & Campling, 2017). Hence, the social and relational aspects of citizenship are emphasized.

The relational and social aspects of citizenship are the focus of a growing and diverse body of literature in the field (see for example Lid, 2017; Mol, 2008; Pols, 2006, 2016; Ursin, 2017). The underlying assumption is that we are all social beings living in relation to others and to the world, and that citizenship is enacted in and through these relations (Kallio et al., 2020; Pols, 2016). This necessitates an understanding of citizenship as *performative*, with an emphasis on how citizenship is lived and experienced, and on the set of relations through which it is constructed. Both the notions *lived citizenship* and *relational citizenship* encompass these dimensions of citizenship, not as something fixed or pre-defined, but as something that is made and re-made in a specific context (Kallio et al., 2020). Different parts of the literature put emphasis on different aspects of the relations that make up lived citizenship, including its material dimensions (Lee & Bartlett, 2021; Pols, 2016).

This chapter builds on this understanding of citizenship as relational and performative. Also, and in line with Ursin (2017), Ursin and Lotherington (2018), and Lee and Bartlett (2021), we put emphasis on the role of objects, technologies and materiality in the constitution of citizenship. This also entails an understanding of ability and disability as located neither within people nor society, but as a result of the interaction between humans and the surrounding society (Moser, 2006; Lid, 2020; UN, 2008[1]).

Despite a growing body of literature on living arrangements for people with disabilities, as well as on practices and socio-material relationships (see, for instance, Ivanova, Wallenburg, & Bal, 2016; Moser, 2006; Pols, 2016; Tøssebro, 2019), there seems to be a lack of studies focusing on young adults. And, according to Bøhler and Giannoumis (2018), Lee and Bartlett (2021), and Ursin (2017), more knowledge on the role of materiality and its relation to citizenship and disability is called for. In this chapter, we respond to this challenge.

THEORETICAL AND ANALYTICAL RESOURCES

As mentioned in the introduction, the chapter draws on theoretical and analytical recourses from the field of science, technology, and society studies (STS). This approach enables the study and analysis of the complex networks and relations between technology, materials, humans, society, and science (Moser & Thygesen, 2019).

Mol (2002) uses the notion of *enactment* to conceptualize the process of how reality is constituted in and through practices. Hence, citizenship practices are understood as being enacted – as being brought into being through a continuous

1 This aspect is emphasized in the UN CRPD in the preamble part e and Article 1.

process of production and re-production. In the words of John Law (2004, p. 56), "enactments and practice never stop, and realities depend on their continued crafting – perhaps by people, but more often (…) in a combination of people, texts, [and] architectural arrangements (…)."

Building on this understanding of reality as enacted, Pols (2007) and Mol (2008) argue for an empirical ethics, where values can be studied from inside practices. From this perspective, values are not defined beforehand or out of context, but are brought into being in and through different relations and practices. In our studies of meal practices at the ALFs, it means that it is not taken for granted that *citizenship*, in this context, is about the realization of values such as autonomy, independence and individual choice, as emphasized through policy.

In the analysis for this chapter, we mobilize the notion of *arrangements* in describing the meal practices (Moser & Thygesen, 2019; Thygesen, 2009). The notion of arrangement refers to the networks of relations that are enacted through practices and emphasize their socio-material composition. Citizenship practices at the ALFs are seen as involving different arrangements composed of entities such as humans, policy regulations, layout of buildings, wheelchairs, cutlery with thick handles and different forms of food – to mention a few. These are all elements of the same socio-material practices consisting of both human and material actors. It is important to note that it is the *particular* associations between the different elements of arrangements that makes certain kinds of health, care, or citizenship possible (Moser & Thygesen, 2019). As such, the arrangement defines the *conditions of possibility*. This means that the specific arrangements define and set the conditions for practices, for how and what kind of practices and realities that are enabled and made possible (Law, 2004; Thygesen, 2009). In this chapter, the notion of arrangement is used to trace the elements involved in meal practices and the values at stake (Moser & Thygesen, 2019).

APPROACH AND METHODS

Design

The empirical data for this chapter stems from a larger ethnographic study conducted by the first author, focusing on the role of materiality and technology in everyday activities in three ALFs.[2] Due to space limitations, this chapter builds on data from two of the ALFs included in the study.

2 Hoydal, K., Phd-project in process: Hverdagsliv i bofelleskap for unge voksne med funksjonsnedsettelse – fysisk utforming, teknologi og praksis.

Ethnographic fieldwork allowed the researcher to be present in day-to-day situations and offered opportunities to talk to informants and to observe their practices. Importantly, it also gave insight into the ideals and values embedded in these practices (Pols, Althoff, & Bransen, 2017).

The first author followed residents and carers over several weeks in each ALF, observing and participating in everyday activities, having informal conversations with residents, carers and next of kin, as well as conducting formal interviews with key actors. During the fieldwork, extensive fieldnotes were taken, including descriptions of activities, practices, conversations and reactions. In addition, the fieldwork material included sketches of rooms, situations and movement patterns within each building. Architectural floorplans and photographs of material details were also included in the fieldwork data.

Empirical context and participants

The two ALFs forming the empirical basis of this chapter are given the fictional names: "the Topaz" and "the Diamond". These are the homes of a total of 15 residents, of which most were between 18 and 30 years of age at the time of the fieldwork. All residents needed assistance with activities of daily living, due to physical and/or cognitive disabilities. However, their functioning-level and need for support services varied considerably. While most residents at the Topaz needed extensive care and assistance with most activities of daily living, including personal care and eating, most of the residents at the Diamond only needed verbal support or guidance with certain activities. Several residents were wheelchair users, and some used alternative or supported communication.

In both ALFs, the residents had their own private apartments. These were their legal homes. Carers – providing care and/or support services to the individual residents – were present on a 24/7 basis. Hence, staffrooms were a common feature. In addition, both ALFs had common areas which included a lounge and kitchen facilities.

The ALFs were also different in important ways. The buildings were of different ages and had different sizes and layouts. In addition, the integration and use of technologies differed. The ALFs represented as such two quite different sociomaterial environments.

Ethical considerations

As mentioned, the study included persons with moderate to severe disabilities, including some who used alternative communication and some with cognitive dis-

abilities. Although the research concentrated on materiality and everyday practices, and not on characteristics of individual residents, this called for extra attention on ethical issues (Sundet, 2010). Specifically, this involved a close dialogue with and supervision from the Norwegian Centre for Research Data (NSD) concerning the research design and the process of information-giving. Informed consent was first obtained from leaders and carers for the first author to be present in common and staff areas of the ALFs. Next, the residents and next of kin received information about the study in writing and in information meetings. Carers assisted the process of registering consents or reservations from the residents for the researcher to visit them in their private apartments.

To ensure anonymity, all names of persons and places in this chapter are fictitious. For the same reason, pictures and sketches used are only of material details and in black and white. Potential person-identifying details are removed or covered in the pictures.

Analysis

The analysis of the data can be described as a hermeneutical process, involving both authors. This meant going back and forth between the data and our understanding of it, continually gaining new insights and re-interpretations (Fangen, 2010). During our early readings of the material, we found meal practices as an emerging theme (Miles & Huberman, 1994). The analytical lens for this chapter was hence to focus on meal practices as a way to study the role of materiality in the constitution of citizenship. In this process, we made use of Nicolini's (2009) notion of *zooming in and out* as an analytical strategy – zooming in on the empirical data to identify the material actors and the embedded values of the different meal arrangements, and zooming out to find out how these actors formed the meal arrangements, and finally, how these arrangements constituted citizenship practices.

RESULTS

In the following, the results of the empirical analysis are presented. In doing so, we use excerpts from fieldnotes, interviews, and pictures from the Diamond and the Topaz. In the presentation, we zoom in on the role of materialities and technologies involved in the meal practices. It is important to note, however, that the strong emphasis on materialities does not mean that other actors, such as the carers, the residents or their disabilities, played insignificant roles in these arrangements. Through our focus on materiality and technology, our aim is, on the contrary, to

make visible that these are also important actors in the enactment of different forms of citizenship.

Materialities are key actors of all meal arrangements

The analysis revealed that materialities – in a broad sense – are key actors of all meal arrangements. Our data also shows that the materialities have different roles in the arrangements, related to their size and scope. Based on this, our descriptions of the materialities are divided into three main groups: large-scale materialities, smaller-scale technologies and seemingly trivial objects. The *large-scale* materialities include the layout and size of the buildings and individual apartments.

Figure 10.1: Apartment kitchen at the Topaz.

As described above, each resident had their own apartment, including kitchen facilities. Hence, individual meal-making arrangements were possible. However, the individual kitchen facilities varied considerably in size and layout. At the Topaz, the residents' kitchens were very small (Figure 10.1). The residents and carers therefore considered them as unsuitable for the preparation of hot meals. This was particularly the case for residents using a wheelchair, who were in need of assistance with meal preparation.

Due to this, hot meals at the Topaz were prepared and mostly eaten in the common rooms. These were open areas situated halfway along the internal corridors that connected the individual apartments. The common rooms were much-used meeting places for the residents. As most hot meals were prepared and eaten here, dinners were communal events, with each resident responsible for planning and preparation one day a week.

At the Diamond, the residents also had access to a common room with kitchen facilities. However, these facilities were placed behind a locked door, beside the staffrooms. For the residents to have access, carers had to unlock the door. Also, there was no internal passageway connecting the individual apartments to the common room. Instead, each apartment was designed as a separate "cell" with direct access to the outside carpark or stairway (Figure 10.2). This arrangement meant that the common room was rarely used for other than carer-initiated activities. Almost all meals were prepared and eaten in each individual apartment, with the carers providing necessary assistance.

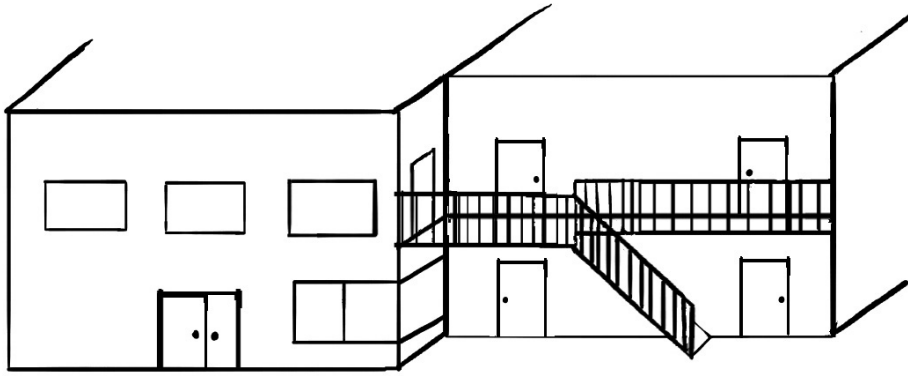

Figure 10.2: The Diamond. Staff and common rooms on the left, individual apartments on the right.

Another aspect of the larger-scale technologies was the design of the kitchens. Although many of the residents at the Topaz used wheelchairs, neither the common room kitchen nor many of the individual kitchens were wheelchair accessible.

The above descriptions show how large-scale materialities, such as the size and design of the kitchens, as well as the placement and availability of common area kitchens, were key actors in meal arrangements at the ALFs. And, in addition, that these larger-scale structures constituted the main conditions of possibility as they laid important premises for what kinds of meal arrangements and citizenship practices were possible at the ALFs.

However, the analysis revealed that also other forms of materialities and technologies were important actors, and that their roles differed from each other. While the larger-scale materialities constituted the main conditions of possibilities, the smaller-scale technologies were important for supporting individual needs.

What we have termed *smaller-scale* technologies included a whole range of solutions, ranging from assistive technologies compensating for functional impairments or providing safety and security, to plates and everyday household devices such as hobs, mobile phones and tablets.

The following excerpts from fieldwork notes illustrate how smaller-scale technologies were part of the meal arrangements:

> It's dinner time at the Topaz, and the residents and carers are seated at the table in the common room kitchen. Most of the residents sit in their wheelchairs while eating. Some have plastic support rings attached to their plates, and cutlery with thick handles.
>
> ---
>
> Fia, a resident at the Diamond, has chopped vegetables and finished the preparations for cooking her dinner. She uses her mobile phone to text carer Hannah to remind her of their appointment. Every day Fia gets guidance and support from a carer while using her cookertop hob, which has a touch panel.

In both excerpts, smaller-scale technologies were important actors. At the Topaz, the residents' wheelchairs took up a lot of room around the table. But at the same time, the wheelchairs supported the residents' posture, enabling them to sit upright for the meal. This story also points at the importance of small assistive technologies. The plastic rings attached to plates and cutlery with thick handles made it possible for some residents to eat independently, despite poor motor control.

On the other hand, the story from the Diamond shows how ordinary household equipment, such as a hob and a mobile phone were important actors for Fia's dinner arrangements (Figure 10.3). Fia felt insecure using the hob's touch controls and needed a carer to be present while using the hob. In this way, the hob made her dependent on assistance.

Figure 10.3: Hob at the Diamond.

The story of Fia also make visible the important role of another small-scale technology of the meal arrangements at the Diamond: the mobile phone. As the Diamond consisted of individual apartments without any connecting corridor, much of the everyday communication between the residents and carers took place by using mobile phones, for texts or calls. In the above story, the mobile phone made it possible for Fia to reach and communicate with her carer without leaving her apartment.

A third category of materialities with a role in the meal arrangements were solutions that we name *seemingly trivial objects*. These objects were important in the sense that they provided necessary structure, cognitive support, and creativity to the meal arrangements:

> Every Thursday at the Topaz, during dinnertime, the residents have their weekly house-meeting. At the meeting next week's dinner menu is planned. Previous menus are stored in a ring binder, which also include recipes. Carer Bodil opens the ring binder and browses through the papers to find a blank menu-sheet. Bodil writes down all the menu suggestions on the menu-sheet.

In this arrangement, the ring binder and menu-sheets played a central role. The ring binder held an overview of who is responsible for dinner each day of the week. It also included the dinner menu for the present and previous weeks. The residents could use the previous menus as sources of inspiration for their choice for the coming week's menu. The menus also offered an overview of recipes and ingredients needed. In this way, the ring binder and menu-sheets provided ideas for meals, as well as necessary structure and cognitive support for the residents to take on responsibilities related to dinner preparations.

Another example of how seemingly trivial objects affected meal arrangements was the use of creative solutions to support individual needs. The below excerpt describes one such solution:

> Carer Bodil attaches a liquid bag to a coat hanger (Figure 10.4) and uses its long handle to push up a loose ceiling tile to position it high. The liquid bag connects to resident Thomas, providing him with liquid food while joining in on the common dinner.

Here, the liquid bag attached to the coat hanger combined with loose ceiling tiles over the dinner table made it possible for Thomas to participate in the common meal, despite there being no space for a floor stand.

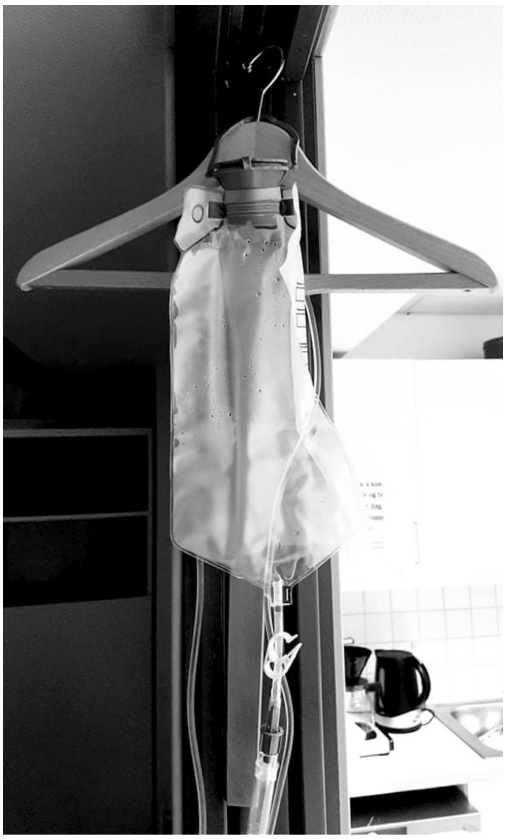

Figure 10.4: A liquid bag attached to a coat hanger with a long handle.

In this way, the coat hanger helped to overcome challenges (in kitchen design and body) and supported Thomas' needs for participation and belonging.

The meal arrangements have a degree of flexibility

A common feature of the meal arrangements was that they had a degree of flexibility. This was important as it provided agility in the day-to-day meal activities. The flexibility acknowledged that there were individuals with different needs and preferences living at the ALFs, as well as persons with different physical and cognitive capacities.

The analysis showed that the smaller-scale technologies and trivial objects played a particularly central role in enabling such flexibility in the meal arrangements. The wheelchairs, plastic support-rings, cutlery with thick handles, and the coat hanger with liquid food exemplify technologies that provided necessary support according to the residents' bodily preconditions. These materialities also offered flexibility in how and how much the residents were enabled to participate in and/or take responsibility for the preparations and meal situations.

In both ALFs, the availability of common rooms with kitchen facilities offered flexibility in relation to where the food was prepared, making both individual and common meals possible. In this way, also the larger-scale technologies can be seen to provide some flexibility. For example, at the Topaz, the residents could choose whether they wanted to eat dinner in the common room, or independently in their own apartment. As expressed by a resident, this flexibility – to be able to withdraw from the common room dinners – was important as "you don't always feel like being with or seen by others".

The meal arrangements enact different values

The meal arrangements of the ALFs enacted different values. These values varied according to different parameters related to the socio-material relations between individual residents and their capacities, carers and material components.

At the Topaz, the routines of common dinners enabled values of sociability and community. These values were enacted, partly through the specificities of the large-scale technologies, such as an open and easily accessible common area with kitchen facilities, but also through smaller-scale technologies and trivial objects like assistive technologies for mobility, menu-sheets, ring binders and coat hangers. In addition, these common dinners enacted values of responsibility and participation, as each resident was responsible for planning one dinner each week.

This meant that the residents had to engage themselves in the meal arrangements in order to fulfil their obligations. As the residents had different levels of capacity, these arrangements were flexible and individually tailored, allowing for necessary support from the carers.

The meal arrangements of both ALFs also enacted values of individuality and choice. For example, by having kitchen and dining facilities in all apartments. Hence, some elements of individual food preparation and eating were possible at both ALFs. Also, individual preferences were enabled. At the Diamond, each resident decided for themselves what to make and when to eat. However, also at the Topaz, choices and individual preferences were, to some degree, catered for. For example, residents could choose to eat the dinner prepared in the common rooms in their own apartment. Also, individual preferences and tastes were catered for in preparations of common meals. As one carer pointed out: "For Celine, we made a part of this pizza without cheese".

As already noted, the role of the carers was not the main focus in our analysis. It is, however, important to emphasize that the carers played a key role in most meal arrangements, for example in ensuring that food was prepared and served, and in facilitating and guiding the residents in their material environment. The analysis revealed the importance of the carers' role in creating flexibility and creativity using smaller-scale technology and seemingly trivial objects, by adjusting different situations to the resident's needs, and by reducing potential barriers caused by the larger-scale materialities. In this way, the carers supported the residents' opportunities to participate in and to take on responsibilities in meal situations.

In highlighting the normativities enacted through the meal arrangements, the many (more or less) implicit values embedded in the lived citizenships at the ALFs is brought out into the open and may be contested.

In the following, we will briefly discuss the implications of these findings in relation to current policy and literature on citizenship.

DISCUSSION

The discussion is divided into two main parts. First, we will discuss the significance of materiality in the constitution of *lived citizenship* through everyday practices, and its implications for policy. The second part relate to issues of normativity; to our findings that many (partly conflicting) values are enacted in and through everyday lived citizenship, and how these values coincide with the normativities and the understanding of citizenship which is embedded in policy and literature in the field.

The significance of materiality in the constitution of citizenship

Through our detailed analysis of meal practices, we have shown that materialities are integrated actors in the arrangements and relations that compose everyday life, and hence lived citizenship at the two ALFs included in the study. More specifically, our findings show that the material relations set the premise for the kinds of meal practices and arrangements that are possible at the ALFs. Hence, materials are not merely backdrops in people's lives (Ivanova et al., 2016; Moser, 2006), and material relations not just integral to everyday practices and lived citizenship, but contribute to set the conditions of possibility as to what kind of practices can arise and what kind of citizenship is possible. As demonstrated, this means that the material environments both increase and constrain the possibilities for action and activity in different settings (Bøhler & Giannoumis, 2018), and that flexibility is of vital importance (Ursin & Lotherington, 2018). For instance, we found "one size fits all" solutions – like the kitchen designs and Fia's hob were challenging as they make some residents dependent upon assistance. On the other hand, carers were sometimes able to enhance flexibility by using smaller-scale and seemingly trivial objects to adjust to barriers in the larger-scale materiality – like in the example with the coat hanger. This insight calls for a greater awareness of the need for flexibility in design, layout and possibilities for adjustments to common solutions, to meet differences and changes in individual needs, and as prerequisites for enabling a life according to their own preferences and abilities.

In conceptualizing the notion of lived citizenship, Kallio et al. (2020) suggest a framing consisting of four dimensions: spatial, intersubjective, performed and affective, where the spatial dimension can be seen to relate to the material context, while the others are seen as entirely human enterprises. In the spatial dimension, the importance of context is emphasized, and an understanding that "citizenship plays out within the messiness of daily living" (Kallio et al., 2020, p. 717). Kallio et al.'s (2020) notion of lived citizenship is useful as it draws attention to citizenship as something that is performed (or enacted) through practices of everyday life, and with a spatial dimension. Our study contributes towards expanding this spatial dimension to include materiality in understanding citizenship as enacted in and through socio-material relations; it also seeks to highlight the broad spectre of materiality, technology and objects which have different roles in these relations.

The importance of assistive technology and universely designed buildings, spaces, and mainstream technology in supporting the individual is known from different research literature and policy documents (Bøhler & Giannoumis, 2018; Lid, 2020; NOU 2016:17; Ravneberg & Söderström, 2017). Our analysis also points to the importance of other small-scale technologies and everyday objects which

are easily overlooked and have so far been given less attention in citizenship research (Lee & Bartlett, 2021). Our findings therefore both confirm and expand on research from other care settings (Lee & Bartlett, 2021; Pols, 2016; Ursin, 2017; Ursin & Lotherington, 2018), adding to an emerging body of literature foregrounding the role and importance of materiality in understanding citizenship.

Values embedded in lived citizenship

This second part of the discussion relates to the issues of normativity and the multitude of partly opposing values we found enacted in and through lived citizenship.

The overarching goal of current policy on disability (UN, 2008) builds on an understanding of citizenship mainly as a capacity of the individual, related to values such as equality, autonomy, independence, privacy and participation in society (Pols, 2006, 2016). The design of the ALFs, with individual apartments and access to care and support services, are examples of structures and materials supporting these values.

In line with political goals, our analysis revealed that materialities like wheelchairs, special cutlery, ringbinders, and menu-sheets contributed to support and reinforce the residents' capacities and competences (Moser, 2006) as well as to provide agency by recognizing the individual residents' needs, enabling them to act, to participate, to make choices and to take on responsibilities (Lee & Bartlett, 2021; Nedlund, Bartlett & Clarke, 2019).

However, our analysis of meal arrangements also highlighted other, partly opposing values enacted in the socio-material relations, which did not necessarily correspond to those embedded in policy. For instance, the large material structures at the Topaz enacted values of sociability, community and participation, but also (to some extent) values of privacy, individuality and choice. We found several structures and materials enacting values of privacy, responsibility and independence (private apartments, individual assistive technology, ring binders), but also other forms of materiality contributing to dependence and needs for assistance (inaccessible kitchens, Fia's hob).

This shows that the values at stake in lived citizenship are not given but need to be understood in context. Policy development needs to take into account how different material relations set different premises for the conditions of possibilities, and to recognize different values – such as participation or independency, as outcomes or results of different practices in the specific relations involved in different arrangements.

Studying materiality, including architecture, design, technology and objects, as an important dimension of lived citizenship can therefore be particularly relevant

in care settings and in relation to people with disabilities, as their activities and opportunities in everyday life are at risk of being curtailed through socio-material relations and practices (Lee & Bartlett, 2021).

CONCLUSION

Using a praxiographic approach and the notion of arrangements has enabled us to explore citizenship as enacted from inside everyday life practices in the context of assisted living facilities for young adults with disabilities.

The main contributions of this chapter relate, on the one hand, to foregrounding the socio-material nature of relations in everyday activities, emphasizing the important roles of different materialities in the constitution of different forms of lived citizenship. On the other hand, the chapter contributes towards highlighting the many (partly conflicting) values that are enacted at the ALFs, and how the socio-material relations define and set the conditions for which values are made possible. As materialities and technologies are key actors in the constitution of lived citizenship, more studies exploring different contexts and their implications are called for, both within the disability field and elsewhere.

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11. Citizenship for persons with profound intellectual disabilities – everyday living within professional care practices

Anita Gjermestad and Synne N. Skarsaune

Abstract People with profound intellectual disabilities challenge common ideas of citizenship and participation. The chapter puts the spotlight on the matter through practice research involving four persons with profound intellectual disability, their family and staff. The evidence suggests several conditions for participation. In dialogue with the theory on lived citizenship, these put forward the complexities embedded in how citizenship is intersubjectively lived and how the different conditions interact.

Keywords profound intellectual disability | participation | lived citizenship | practice research

INTRODUCTION

A young man is seated in his wheelchair at the kitchen table. His left hand is tightly holding the end of the sling that is wrapped behind him in his chair. The professional carer approaches him, and asks: "Are you ready for breakfast?". She has already prepared half a slice of bread with melted cheese, and now she prepares another half with liver paste. She moves the bread with the liver paste up towards his mouth and nose. He closes his mouth, and his eyes are shut. She puts the bread down, leaves it down for a couple of seconds, and then leads the bread up to mouth and nose again. His mouth and eyes are still closed. "Don't you want liver paste today?" she asks while putting the slice of bread on the table. She takes the bread with the melted cheese up towards his mouth and nose. His mouth is still closed. Then he smells, opening his eyes and mouth. The firm grip on the sling eases up. The carer moves the bread into his mouth,

> which is now wide open, receiving the bread and chewing. "So you had a bigger fancy for cheese today", she says, recognizing that he is now chewing joyfully on the slice of bread.

This anonymized story was written after a visit to this young person's house. We were there in order to get to know the person and the staff as part of the CHAPAR[1] research project, putting the lens on participation when autonomy is restricted. The story can serve as an example of the challenges relating to communication and participation in caring practices together with people with profound intellectual disability, who communicate by other means than verbal words.

Morris (2005) engages the concept of participation as one of the key points to secure disabled peoples' opportunities for citizenship, understood as the right to be included in society and participate in family, community and national life. To be a citizen involves the right to participate, influence and make decisions in life – rights that are rooted in the Universal Declaration of Human Rights (UN, 1948), stating that all have the right to freedom.

People with profound intellectual disabilities are challenging common ideas of being a citizen through participation (Talman, Wilder, Stier, & Gustafsson, 2019) and some claim that reduced psychological capacity lowers a person's moral status (McMahan, 2010). This can be linked to notions in Western culture that emphasize independence in efforts towards freedom such as making choices and having influence over one's own life, a notion that excludes persons with profound intellectual disability (Dowling, Williams, Webb, Gall, & Worrall, 2019). Furthermore, due to this exclusionary terminology, the perspectives of people with disabilities are missing from these debates on citizenship (Morris, 2005), and any inquiry into the matter should start with their ways of being citizens.

Drawing on an understanding of lived citizenship (Kallio, Wood, & Häkli, 2020; Lister, 2007), we will put forward an understanding on how citizenship through participation for persons with profound support needs can be understood. This theoretical framework argues that citizenship must be understood as a lived experience that cannot be divorced from its context (Lister, 2007), and that citizenship unfolds through interactions with others in the course of daily life (Kallio et al.,

1 The CHAPAR project (www.chapar.no) is financed by the Norwegian Research Council (NFR) and involves researchers from several research groups. The overarching research question in the CHAPAR project, to be studied in and across the case studies, is: *What are the conditions for effective participation when service users' autonomy is challenged and/or restricted?* The research project is designed as practice research (Uggerhøj, 2012) involving different user groups, different professions, user organisations, researchers, and students.

2020). This latter is in line with the CRPD (UN, 2006) which draws on the relational theory of disability and defines disability as a natural part of human diversity, that human beings are interdependent, and that rights are achieved through supportive relations (Skarstad, 2018). All people, regardless of cognitive and communicative capacity, need to be supported to participate and make decisions in all aspects of everyday life (Aarstein-Kerslake, Watson, Browning, Martinis, & Blanck, 2017; Skarstad, 2018).

Health and social care workers need to acknowledge, protect and find ways to facilitate and mediate practices which support citizenship and participation for people with profound intellectual disability. But how is this done or practised within the Norwegian health and welfare services, and what are the related challenges?

These are the questions at stake in this chapter; they will be extensively discussed on the basis of data from an ongoing study.

Person with profound intellectual disability

Persons with profound intellectual disabilities are a highly heterogeneous group. Their health and functioning are hampered by reduced cognitive and bodily functions, but also by social, institutional and cultural barriers that restrict engagement and participation. According to the ICD-11 (WHO, 2018), the cognitive function and intelligence quotients for people with profound intellectual disabilities are below 20. Reduced cognitive function also affects ability to use conventional language. People with profound intellectual disability communicate through nonverbal expressions and body language, which means that their communication is highly unique, individual, and idiosyncratic (Horgen, Slåtta, & Gjermestad, 2021). This means that each deploys their unique communication, which needs to be interpreted in light of the actual context, and this is where historical knowledge of the person's expressions and utterances is important. Together, these factors imply that people with profound intellectual disabilities face limitations in both understanding and in being understood in everyday care practices, and that they require lifelong care.

The voices of people with profound intellectual disability are often left out of research because they are considered as vulnerable (Liamputtong, 2007). Building on feministic perspectives, like Liamputtong (2007) we argue for the need to advance the lived experiences of marginalized groups, and hopefully this chapter will be a contribution towards this. In order to highlight the lived experiences of people with profound intellectual disability, it needs to build on the voices of fam-

ily members and staff close to these individuals (Mietola, et al., 2017; Simmons & Watson, 2015; Calveley, 2012).

Citizenship

Critical studies of citizenship over recent decades have taught that what is important is not only that citizenship is a legal status, but that it involves practices of making citizens (Isin, 2008). The concept *lived citizenship* is derived from several theoretical origins and takes as its point of departure in people's daily, mundane lives, which aims to account for its meaning in real life-contexts (Kallio et al., 2020). This is also the context of this study; we seek to illuminate citizenship through participation in the mundanity of life for people with profound intellectual disabilities. Kallio et al. (2020) propose four dimensions of lived citizenship and argue that these might help provide the term with content. The four dimensions are *spatiality*, *intersubjectivity*, *performed* and *affective experiences*. The spatial dimension points to the significance space plays, and in this understanding highlights that attention must be drawn to the mundane spatio-temporalities of everyday life (Kallio et al., 2020). Terminology must thus expand the terrain from a nation-state view and embrace the intimate and domestic perspective as well, underlining that citizenship is contextual (Lister, 2007). It must further be understood as lived and shaped interpersonally, not carved out in an isolated endeavour, thus pointing to the dimension of intersubjectivity (Kallio et al., 2020). Citizenship is unfolded within our different relational experiences. The performed dimension points to the different acts and practices that constitute lived citizenship (Kallio et al., 2020) and can be understood as the moments when subjects constitute themselves as agents through acts of citizenship (Isin, 2008). The fourth dimension is related to the affective experiences entailed in citizenship, arguing the importance of not overlooking the emotional aspects involved in feelings of being a citizen, of belonging or not belonging (Kallio et al., 2020).

In this study, these perspectives will be used as an interpretative lens to discuss the findings, focusing on citizenship as understood to unfold in the mundane, lived life (Kallio et al., 2020). Furthermore, it points to the relational agency, by recognizing the deeply varied experiences of being a citizen, providing space for the inclusion of those traditionally excluded (Kallio et al., 2020). Both Morris (2005) and Lister (2007) point to the importance of including the somewhat neglected perspective of people with disabilities in order to realize the potential of inclusive citizenship. Through the four dimensions, the focus will be on the experiences of being a citizen and acting as agents through everyday living, focusing on the affective, relational

interactions with others. These viewpoints build on relational perspectives which are put forward within feministic research/theory as critiques of individual understanding of citizenship as well as understandings that exclude people.

Recent research has provided some knowledge about the conditions for participation (Talman, et al., 2019) for people with profound intellectual disabilities. This study will provide knowledge about how conditions for participation can be understood in terms of lived citizenship for people with profound intellectual disabilities.

The following research question will guide this section: *What are the crucial conditions for participation when service user's autonomy is challenged, and what does it tell us about the lived citizenship of people with profound intellectual disabilities*?

METHOD

The chapter builds on data from the ongoing CHAPAR project (chapar.no) exploring user participation in different contexts when services users' autonomy is restricted. In this chapter, we will report from a case study involving persons with profound intellectual disability which is one example of such a user group. The overall project's methodology is designed as practice research (Uggerhøj, 2012) in order to emphasize embodied empathy and phenomenological reflections about the research (Finlay, 2006), this latter involving the researchers to project themselves into participants' experiences, and thus trying to build an understanding of what their perspective might be. Knowledge production concerning vulnerable groups like those with profound intellectual disabilities calls for sensitive research, which aims to amplifying the voices of highly marginalized people. This demands *sensitivity* and *polyphony* (Liamputtong, 2007, p. 19). Our intention is to include multiple voices: Both those of the individuals in question and the interpretations and understanding of the individuals by other people (Liamputtong, 2007). Like Calveley (2012), Mietola et al. (2017), and Simmons and Watson (2016) the methodological design of this study acknowledges family and staff as proxies, who can provide important knowledge about the persons in question. This is a promising approach, though we need to be aware of the challenges of using proxies in studies like this; these include the risk of misunderstandings, overestimating, underestimating or being influenced by your own expectations, and the fact that a proxy can never truly know another person's first perspective (Calveley, 2012; Mietola et al., 2017; Simmons & Watson, 2015).

Inspired by other similar studies (Mietola et al., 2017; Simmons & Watson, 2015), an ethnographically inspired approach was adapted to create knowledge and explore how participation was supported in the mundane lives of four adults with

profound intellectual disability. Researchers and bachelor students who took part in the project carried out the initial observations of the persons' everyday lives, at home or in school. This was done in order to get first-hand knowledge of the person. When the person in question does not primarily communicate with words, all these other ways of existing should be focused upon in order to do justice to the person's unique way of being, and therefore a sensitivity towards embodied ways of communication were vital. The focus of the observation was open but with an emphasis on becoming familiar with the unique communication and utterances of the person with profound disability, as well as their communication and interactions with staff. This would further assist the researchers when in dialogue with the proxies.

Inspired by Watson (2016), dialogue meetings in addition to participant observations were carried out with the family and staff who knew the person well. The dialogue meetings focused on the significant other's understanding of the person's unique communication and utterances, their likes/dislikes, and their ways of participating in everyday life activities.

The last method used was interviews with family/parents and staff. Parents/family was interviewed individually, either one parent or both together. Staff interviews were carried out in groups. The groups consisted of four to six staff who knew the person well, either at home or at school. Altogether the data consists of the view of six family members and 21 staff from four residential housings and one upper secondary school, in addition to observations of the four young adults with profound intellectual disability. The project was approved by the NSD (project number 103943).

Table 11.1

Contexts and materials			
Person 1	Staff: residential housing: 4 and school: 5 Family: 2	Initial observations in school and at the residential housing	Focus group interview with staff at residential housing and one focus group interview with staff at school Individual interviews with family
Person 2	Staff: residential housing: 5 Family: 1	Initial observation at the residential housing	Focus group interview with staff at residential housing Individual interview with family
Person 3	Staff: residential housing: 4 Family: 2	Initial observation at the residential housing	Focus group interview with staff at residential housing Individual interview with family
Person 4	Staff: residential housing: 3 Family:1	Initial observation at the residential housing	Focus group interview with staff at residential housing Individual interview with family

Research ethics

Involving a vulnerable group of citizens, who are considered not to be able to give consent, requires certain ethical reflections and sensitivity from the researchers involved (NESH, 2016). One important aspect is to adapt the consent process (Calveley, 2012) and to be constantly assessing for signs of discomfort or distress as a result of the observations taking place. These adaptions were done both individually by the researchers and together with staff or family who know the person well. Undertaking research where understanding of the person must be obtained through proxy respondents and their interpretations leads to concerns about the research's validity (Boxall & Ralph, 2009). These challenges have been met by including multiple voices and through the use of dialogue meetings where several perspectives and interpretations have been discussed.

Analysis

Based on the research question, the data was analysed as a whole by emphasizing patterns of similarities and differences (Thagaard, 2018) regarding how participation was talked about and practised, aiming to identify crucial conditions. Both authors analysed the data in several settings. The first reading was naive and was carried out individually. The second reading was done together by comparing tentative themes and patterns. In line with practice research (Uggerhøij, 2012), staff and family members were involved in the initial analysing process. This was done through dialogue meetings where the tentative findings were discussed with staff, family members and students in order to bring in multiple voices and get their views of the findings. The contributions from these meetings were further analysed by the researchers and authors of this chapter, while the other stakeholders did not participate in the writing of this publication.[2] The following six characteristics of conditions for participation were identified and will be presented:

a. See the possibilities in relational, mundane moments
b. It's all about communication
c. To balance fundamental needs
d. Trusting and sensitive relationship
e. Individualized and fleeting competence/expertise
f. Shift-rotations govern all

2 Some of the participants contributed as co-authors in developing local guidelines for the municipality in the project (Gjermestad et al., 2021).

FINDINGS

The overall impression from the observations, dialogue meetings and interviews are that participation relating to this group is challenging. Both staff and family state that there is a great need for reflecting upon and discussing user participation, and it is felt that there is a great need for specific knowledge directed towards this groups' needs.

a) See the possibilities in relational, mundane moments

In the interviews with family and staff, varying thoughts on how to understand participation for the persons in question are given. In some of the interviews, the respondents start out with a reflection that there is little the person can decide on, like staff in IS1 who initially state "there isn't much she can participate in" or staff in IS2[3] stating that "I can't think of any settings where she can be self-determined, where she can choose activity freely". However, when the dialogue continues, several examples of small moments that illustrate participation are given, linked to how the caregivers interpret and meet the person's communication. Examples might include the person pointing at something they want to eat or opening their mouth when served what they wanted, to look at the glass of lemonade, signalling that they want to watch TV by taking the remote control, or lifting one's head on the changing table when clothes are to be removed. All the examples involve the interaction between the person and the professional. Likewise, they give examples of how the person might show disagreement, for instance, by turning their head away, closing their mouth when presented with food they do not want, or trying to stop the wheelchair from going in an unwanted direction by placing their hands on the wheel. And the professional adjusts their actions to meet the person's communication. These interactions and adjustments pinpoint the participation and communication as conditioned by their relationships to others.

When being present as researchers, observing different glimpse into the person's mundane life we sensed both how difficult it is for staff to capture and be attentive of all the possible moments of participation that might arise in the relationship, and we sensed what might be experienced as challenges for the person with a profound disability regarding being understood on needs and will, and be overlooked/ignored. For instance, during mealtimes the staff must prepare the food and at the same time pay attention to the person's small gestures. On occasions we observed that the person might have been communicating, but staff had their backs turned to them.

3 IS1, abbreviation for – Interview Staff 1 and IS2, IS3, IS4.

b) It's all about communication

The factor that is most strongly emphasized across cases in order to facilitate the person's participation is communication. This requires that someone is able to interpret and understand the person's unique way of signalling their wants and needs. As staff in IS1 describe it: "she shows it all with her body language". This has also been a recurring theme in all the dialogue meetings between staff and family – the importance of all involved knowing and understanding their unique communication.

There are examples of how 'the other' can be both an important facilitator and also a hindrance to the person's participation. "If there is staff new to her, not familiar with her signals, then she would not be able to decide anything" (from IS1). This underlines how knowing someone's unique communication demands specialized knowledge. This is illustrated when two of the participating staff start discussing how they interpret her facial gestures and how one of them realizes that she as a carer lacks the knowledge and skills to interpret that the other member of staff has, saying to the other one: "yes, but you have known her much longer than me". Another one says: "I can see it a bit better now (with reference to understanding the person's facial expressions) than I did a few years back, but I have spent a long time getting there". There are also examples of how the use of augmentative forms of communication is a hindrance when the devices are out of service, leaving the persons without the tools to communicate.

In situations when we as researchers are together with the person with profound intellectual disability and staff, we sense and experience the difficulty of being understood in the right ways. We have sensed that non-verbal utterances and expressions are ignored or overlooked and initiatives are not answered. We have also seen several examples of the opposite – namely that the staff have responded to the person's expressions, for instance in one of the cases where the person suddenly started to sulk and moved her arm towards her head. The member of staff asks her "What is wrong, might you be thirsty?". The member of staff, with her eyes on the person, starts to move towards the kitchen, and when she opens the fridge, she can see a big smile on the person's face. "Aha", she replies, "you wanted to get me up to fix you something to drink". The person responds with laughter.

c) Balancing fundamental needs

It becomes very clear that situations occur where different needs collide; for instance, there are several descriptions of how the person's need to have self-deter-

mination might be endangered by the staff's obligation to give services that ensure the necessary healthcare. If the doctor has prescribed medication, then the personnel are obliged to ensure that the medicine is taken. Staff reflect upon this and provide illustrations of how they try to get the person to take the medication voluntarily, without the use of force. "But it isn't really any dilemma, because she has to take them. The dilemma might be on whether we should force her or not, but we do not have a choice not to take the medication" (from IS1). The same story is told in different cases; sometimes there are issues concerning health that reduce the person's possibilities to make their own decisions. One staff member points to the fact that sometimes the person does training programmes in order to improve physical health, but when it comes to participation the same is not the case; "She has training programs for her muscles, but when it comes to these more abstract things, then it gets more difficult". (IS1). There are suggestions that one should have more focus on supporting and improving the person's participation in the same way that one enhances their physical health.

There are examples of fears that if the person were to decide totally, this would lead to a life where no-one ensured their other needs were fulfilled. For instance, one person might choose to exclusively watch TV, an activity that is regarded as something he loves but might also make him a bit uneasy. This fear has led to a practice where the staff try in different ways to regulate his TV-watching and also try to motivate him to do more varied activities. And this might lead to challenging situations: "He really shows with all his being that he does not care for the activities at the day centre, but yet you have to give it a go, it might suddenly be something he might like" (from IS5). This balancing of needs is challenging both on a practical and ethical level, and the staff say that it is difficult to know how to handle such issues. It is a trait found across cases – the importance of collaborating and talking together, and in all of the dialogue meetings different forms of collaborative endeavours have been discussed as one important way of ensuring the person's participation.

Our observations expand these understandings regarding the difficulties experienced by staff in balancing fundamental needs. For instance, some of the adults had to use special equipment like belts in wheelchairs, or shins on arms/legs, which were unpleasant and uncomfortable but were a means of preventing harm. One such example was a person who had to wear a shin on his arm for the whole day in order to prevent self-injury. He also had to use it during meals while eating. When he did not have the shin on, he could use his arm to hold a cup by himself and drink, and he also managed to drink by himself.

d) Trusting and sensitive relationships

Both staff and family members point to the importance of having close and intimate knowledge of the person in order to manage to support participation. They talk about knowing the person with profound intellectual disability well, their routines, emotions, unique communication, and likes or dislikes. This kind of knowledge and sensitivity towards another person takes time to establish. As one of staff tells us "She is dependent on people who know her (…) but it takes time to get to know her and her communication" (from SI1).

Staff also highlight that when you know the person well you become more sensitive towards the person and you manage to "see and manage to find out for instance what is wrong" (SI5). One of the staff (SI5) states: "Yes, he calms down, for example when he seems sad and we are together with him and trying to understand him, and when he turns happy, I don't know exactly how to explain it but it is about the feeling/sensitivity, it's hard to describe, and you can try as much as you can to describe, but you have to experience having this contact together with him and experience that he seems safe together with you" (SI5).

This need for sensitivity also represents a threat when staff haven't had the opportunity to build trust over time. There are several examples of misunderstandings or cases where the person's wishes or preferences are overlooked or violated. As one staff member stated: "You see the difference when he is together with staff who know him well and staff who don't know him. It's a big difference for him, you can see if he is more tense or relaxed – more calm in a way" (SI5).

In order to build trust and sensitivity, family and staff stress the importance of collaborating and building knowledge together. Cooperation with family members is especially emphasized (SI5, p. 110): "I think it's important to find an agreement/unity within the group of staff. In order to work ethically, it is also important to listen to the parent's opinions and thoughts" (SI5). Family members also request more cooperation and dialogue with staff: "We could have had closer co-operation with staff, it would have been better for both them (staff) and us if we had met more regularly, and not just at the yearly meeting" (IF2).

As researchers, it has been challenging to observe and gain knowledge of the vulnerabilities that the participants with profound intellectual disability experience regarding the sometimes large numbers of staff from whom they receive support in the residential housing. We often sensed a feeling of resignation and helplessness not only from the person in question but also from family members and staff trying to do their jobs.

e) Individualized and fleeting competence/expertise

In all the interviews and dialogue meetings, knowledge about the person in question is highlighted as key to understanding of that person's unique communication; how to support their participation is a highly individualized decision. Even though all of the participants with profound intellectual disability are surrounded by a core group of staff who know the person, their unique communication and life history well, the staff and family express their concern that the person in question often has to be supported by staff who don't know them well.

The knowledge is personalized by staff and is not always properly documented in journal systems used by the health and welfare services. It is stated that there is a need to enhance this: "It's important that information is written down, this would make it easier for new staff to read and to get to know NN" (IS4). Another says: "I do think a bit about co-operation, that we tend to operate a bit like *we* are one unit, housing is one unit, family is one unit. I think that these co-operative arenas we are all participating in now (with reference to the ongoing dialogue meetings in the project) are very helpful" (IS2).

Knowledge and expertise of the person's significant and unique communication, their ways of participating, and how to support decision-making is developed over time and is highly individual due to a lack of adequate and systematic documentation. When significant staff, who know the person and family well, leave work, essential and crucial knowledge also disappears. In discussion during observations and interviews, both staff and family member express their concerns about this, but say they feel powerless and don't know how to handle this challenge.

f) Shifts rotations governs all

All the persons with profound intellectual disability in this case study live in residential housing together with other people with a variety of needs and disabilities. The residential housing is fully staffed 24 hours a day working in shift rotations. Both staff and family say that a lot of considerations are made in order to decide who is supporting who, balancing the different and individual needs of all the residents.

In the residential housing, there are approximately 30–50 different staff. Both staff and family express their concern about the huge number of staff who are supporting the particular individual. They are concerned about the fact that this person receives support from people who don't know them well, and they are especially worried about conditions for supporting decision-making when receiving support from strangers. Especially during weekends, due to shift rotations, the person with profound intellectual disability receives support from staff who don't

know them "well". A consequence of that is that it threatens the conditions for supporting participation: "Every fourth weekend there are only vicars/temporary staff who don't know our child. And that means that every fourth weekend our child has very poor conditions for participation" (IF2).

Although both staff and family understand that it's hard to receive support from people who don't know the particular individual, they struggle to find more appropriate solutions to the problem. For family members, it can be difficult to make suggestions or criticize the staff or the care the individual receives.

During our observations, we sometimes saw four different staff supporting one person during our visits. Thus, this was contrary to the institution's aim of reducing the number of staff together with the person in question. With one incident, we, as visitors, had sensed and observed one individual's utterances of pain and discomfort due to poor posture in his wheelchair. We had to inform the staff about this because a result of their shifts they had not had a chance to notice.

Summarized findings

These findings address two essential conditions for participation, which can be categorized as relational and organizational. The first, relational conditions, involves the interaction or relationship between the individual in care and staff and family. The second, the organizational/structural conditions, is embedded in the institutional settings and work practices in the residential housing in which these people live, putting the spotlight on how both shift rotations and personalized competence within institutional settings are crucial conditions for the lived and enacted citizenship and agency of people with profound intellectual disabilities in their everyday lives.

DISCUSSION

This study elaborates on how persons living with profound intellectual disabilities are citizens and agents communicating, interacting, contributing and participating in everyday life practices with significant others in their homes and in school. Through dialogues with family, staff and through observations, the individual with profound intellectual disability has supplied a significant and essential glimpse into their lived citizenship and agency in everyday life (Kallio et al., 2020). These significant moments or acts of citizenship and agency are both intersubjective and embodied. In addition, these moments indicate how citizenship for people with profound intellectual disabilities is enacted through practice with others and

is a narrative and dialogical practice which is co-authored by staff or family (Fjetland & Gjermestad, 2018).

The relational conditions pinpoint that citizenship for this group is facilitated through small moments of caring practices in mundane everyday life (Kallio et al., 2020). For acts of citizenship to be realized, this study also indicates the importance of sensitivity and trusting relationships where knowing the person, their significant ways of communicating desires and preferences is critical and functions as an anchor. This means that, if this sensitive and trusting relationship is missing/absent, people with profound intellectual disabilities are at great risk of experiencing violation; this therefore highlights the intersubjective as well as the affective dimension of citizenship (Kallio et al., 2020). For persons who are profoundly dependent, the recognition of how citizenship is being constituted and mediated together with significant others is crucial. Experiencing, for instance, professionals who facilitate one's preferred way of communicating and being understood might necessarily enable a feeling of belonging, and therefore underlining the feelings associated with being met as a citizen. It also highlights the importance of acknowledging people with profound intellectual disability as agents. Agents capable of informing others about their desires, preferences, and wishes in everyday life, and acknowledged as having *a voice*, represent the performed dimension (Kallio et al., 2020).

The organizational/structural conditions for participation are embedded in the institutional settings and work practices in the residential housing in which people with profound intellectual disability live. These conditions shine a spotlight on how, through mundane practices, the institutional settings have an implicit impact on conditions for participation and citizenship as co-creating process in everyday life of people with profound intellectual disabilities. Shift rotations and large numbers of staff jeopardize supportive structures which underpin participation. According to Tøssebro (2019), this can be viewed as an ongoing conflict between the lifeworld of the residents and system world of the employed staff, where the system world tends to dominate. This underlines Kallio et al.'s (2020) understanding that citizenship is something that exists in daily life, involving all the messiness embedded in this life that combines both the individual and the institutional. The professional, relational competencies are interwoven with economic and political structures.

CONCLUDING REMARKS

Both the relational and organizational conditions for participation and citizenship put forward the complexities embedded in how citizenship is *lived* and also intertwined by the professional practices in residential housing in which people with profound intellectual disability live (Kallio et al., 2020). Through the mundane lives of four persons with profound intellectual disabilities, their staff and families, the meaning of citizenship has been sought. In addition to the relational and organizational conditions, it is important to be aware of the power imbalance embedded in care relations and the inherent power structures in the organization between the user, the professional (Juritzen & Heggen, 2009), and the services involved in lived citizenship (Kallio et al., 2020).

In a relational perspective, lived citizenship calls for an understanding which highlights interdependence and support structures for realizing citizenship in everyday living (Skarstad, 2018). In this study, these support structures are both relational and organizational/institutional and also interact and amplify each other.

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12. Trauma-conscious understanding: A contribution to quality in professional relations and citizenship in environmental work

Hanne Line Wærness, Oliva Teigland and Anita Gjermestad

Abstract People with intellectual disabilities are more exposed to potential trauma than the general population. However, there is little research on people with intellectual disabilities and their potential expressions of trauma, and how this can be accommodated in environmental work. In this chapter, trauma-conscious understanding (TCU) is described as a fruitful model which can be used in caring encounters. TCU recognizes residents' expressions, which are one central dimension of lived citizenship.

Keywords trauma-conscious understanding (TCU) | intellectual disabilities | quality of relationships | lived citizenship | environmental work

INTRODUCTION

In this chapter, we highlight TCU[1] as a promising approach in environmental work with adult people with intellectual disabilities living in residential housing. These

1 The concept of trauma awareness used in this chapter is based on an integration of trauma psychology and developmental psychology (Nordanger & Braarud, 2017), emphasizing trauma as being caused by more than big, violent events; it is also the damage that is wrought when repeated, overwhelming events occur over time. In a trauma-conscious context, trauma can arise from inadequate care relationships in adolescence, or situations where one does not have the cognitive capacity to adapt one's impressions. Moreover, developmental trauma is understood as leading to challenges in functioning optimally in one's own life (Nordanger & Braarud, 2017; Bath, 2015; Kirkengen & Næss, 2015).

residents are more exposed to potential trauma than the general population (Kildahl, Helverschou, Bakken, & Oddli, 2020; Kildahl & Bakken, 2020). People with intellectual disabilities have an innate emotional and psychological vulnerability due to their intellectual and communicative challenges. This makes them more exposed to stress in life, as cognitive impairment makes it especially challenging for them to interpret and adapt in social situations and events in their environment (Kildahl & Bakken, 2020). Moreover, the intellectual and communicative challenges faced by people with intellectual disabilities may complicate their ability to verbalize and express their thoughts and feelings (NOU 2016: 17; Kildahl & Bakken, 2020).

There are a number of challenges associated with capturing trauma or other mental health problems in the lives of people with intellectual disabilities: for example, diagnostic overshadowing can occur, in which the intellectual disability becomes the main explanation for all of their behavioural expressions (Bath, 2017; Kildahl et al., 2020; Kildahl & Bakken, 2020; Bakken & Sageng, 2016).

Following the de-institutional process in Norway, knowledge production regarding empowering approaches in professionals working with people with intellectual disabilities has been scarce (Tøssebro, 2019). However, recent years have seen a growing body of knowledge on relational approaches in caring encounters with people with intellectual disabilities (Lorentzen, Pettersen, & Myhrer-Næss, 2018; Mansell & Beadle-Brown, 2012). Lorentzen et al. (2018) have developed a *relational approach* as a model of understanding in environmental work with persons with disabilities; this model shows the importance of developing knowledge about the value of dialogic understanding and the quality of relationships in environmental therapeutic work (Lorentzen et al., 2018).

A trauma-conscious approach is a useful conceptual framework for understanding all individuals (Nordanger & Braarud, 2017), including those with intellectual disabilities. As TCU in professional care work is fundamentally relational, it is in line with Lorentzen et al.'s approach (2018). Moreover, TCU places emphasis on emotions and the caregivers' regulation of emotional expressions (Nordanger & Braarud, 2017). As a model of understanding, it also challenges the caregiver to have a dual perspective concerning both the interaction in the relationship and the emotional expressions of the other, which is in line with affective and intersubjective dimensions of lived citizenships (Kallio, Wood, & Häkli, 2020).

To be able to see reactions in the other as potentially reflecting trauma, staff must be theoretically informed (Kildahl & Bakken, 2020; Kildahl et al., 2020). A trauma-informed perception enables them to see and acknowledge the other's reactions and thus provides opportunities to meet the other's emotions. Kildahl

and Bakken (2020) point out that little research has been done on the mental health of people with intellectual disabilities, and on the mapping and understanding of behavioural expressions that may be due to trauma.

Adult people with intellectual disabilities living in residential housing are exposed to many different staff members and are therefore particularly vulnerable to trauma. This vulnerability requires a conscious professional approach on the part of the staff members, in order to facilitate the residents' citizenship and participation in their own life.

The following research question will be highlighted in this chapter: *How can staff members' trauma-conscious understanding enhance quality in professional relationships and citizenship when working with people with intellectual disabilities?*

In this chapter, we explore this question by presenting a pilot study carried out in residential housing. The pilot study was a cooperation between staff at a residential housing unit and the two first authors, who were researchers at VID Specialized University. We sought to highlight how trauma-informed knowledge in environmental work can provide a pedagogical perspective on and a shared understanding of concepts that enhance quality in professional relationships and citizenship.

THEORETICAL GROUNDING

Trauma awareness

A trauma-conscious understanding in this chapter is based on knowledge of the three-part brain, the window of tolerance and emotion regulation – core concepts in recent trauma understanding and developmental psychology (Nordanger & Braarud, 2017).

A trauma-conscious perspective in caring encounters with people with intellectual disabilities focuses on the *relationship* between the service provider and the service recipient as central, and on how to compensate for a lack of regulatory experience. TCU strengthens knowledge about development-promoting relationships, and an awareness about the importance of previous relationship experiences in the here and now. Security, relationship, and regulation are key concepts for creating a good therapeutic environment for people vulnerable to trauma (Bath, 2015), and are also basic pillars of quality care.

TCU is not a method but an *understanding framework* in which environmental work in itself becomes the intervention. Environmental work can be understood as well-being, learning and change work in the resident's environment at all times. A dynamic understanding of environmental work recognizes residents as an inde-

pendent contributing part of the whole and highlights relationships as central to this work (Nordlund, Thronsen, & Linde, 2015; Bath, 2015). As noted earlier, TCU is fundamentally relational: the service provider's informed gaze sees the person, interprets what is being expressed – and makes a professionally qualified choice regarding interaction. This places TCU within a phenomenological perspective (Thomessen & Neumann, 2019), which is in turn supported by a relational approach to environmental work (Lorentzen et al., 2018). In other words, it is *the relationship itself* that matters most with regard to whether a resident benefits from the environmental work. It also highlights how the lived citizenship of people with intellectual disability is shaped and formed interpersonally in the mundane interactions with professionals (Kallio et al., 2020).

One criticism of TCU is that the very concept of trauma is unclear and inadequately delimited. There is also a tendency for TCU to be promoted as the answer to all relational challenges (Bath, 2017). However, TCU is not a method with clear manuals for intervention, and it can be a challenge in environmental work. Moreover, as Bath (2017) points out, TCU is also criticized for not being sufficiently research-based.

Citizenship

Citizenship is a human right and related to all aspects of people life: identity, trust, belonging and participation. It centres around making one's own choices and thus having an influence on one's own life (Lid, 2020; Skarstad, 2019). History shows that human rights do not necessarily apply to everyone; people with disabilities have long been exposed to serious human rights violations. Many people with intellectual disabilities are, in practice, deprived of the right to make decisions about their own lives (Skarstad, 2019). Compared to the majority of the population, people with intellectual disabilities often do not experience being acknowledged as citizens (Lid, 2017).

This pinpoints citizenship as a relational phenomenon, indicating that citizenship is both *lived* and *practised* together with others through relationships and community (Kallio et al., 2020). In addition, citizenship is related to agency and being acknowledged as an agent – an agent with emotional and bodily expressions that need to be met and acknowledged in caring encounters (Kallio et al., 2020). As people with intellectual disabilities experience challenges in communicating conventionally, their emotional and bodily expressions – their narrative citizenship – must be interpreted and facilitated by others if they are to be acknowledged as agents and active citizens with lived citizenship (Fjetland & Gjermestad, 2018; Kallio et al., 2020).

Services for people with intellectual disabilities living in residential housing are often organized in ways that can be described as paternalistic (Lid, 2020). Due to their dependence on support from staff in residential housing, this can be expressed through institutionalized and instrumental practices with a lack of individualized support (Tøssebro, 2019; Helsetilsynet, 2017). Such institutional practices also illuminate the relational aspects of the everyday – and lived – citizenship (Nedlund, Bartlett, & Clarke, 2019; Kallio et al., 2020) of people with intellectual disabilities, and how this is highly dependent on and intertwined with the staff's competence, skills and ability to support and enhance the residents' citizenship. Lid (2017) points to the way services are organized for people with intellectual disabilities as being especially critical for promoting citizenship.

In professional practices with people with intellectual disabilities, staff have a significant role as a key in the realization of the citizenship of people with intellectual disabilities. Living life and receiving support in residential housings highlights the significant spatial dimensions of lived citizenship of people with intellectual disabilities, pointing at the intersection between the private and the public, as well as how the individual and institutional are intertwined (Kallio et al., 2020, p. 5). Living an everyday life in residential housing highlights the dependency and vulnerability to which people with intellectual disabilities are exposed, and which can trigger or cause trauma: this in turn can contribute to developing trauma reactions (Kildahl & Bakken, 2020). As residents often display symptoms – emotional expressions – after potential trauma in other ways than usual (Kildahl & Bakken, 2020), staff must have relevant knowledge and competence which enables them to observe and understand these expressions as meaningful, so they can be seen and understood.

Indeed, it is the service provider's theoretical lens which guides what they see, interpret, act on, and contribute to a co-creation of meaning in the relationship, thereby giving people with intellectual disabilities the opportunity to make choices for themselves in their lives (Lid, 2020). Here, the staff's theoretical perspectives and their sensitivity toward the residents' non-verbal expressions are particularly important. This highlights how people with intellectual disabilities are at risk of being excluded as fellow citizens due to the inability of other citizens to understand and interpret the forms of expression that people with developmental disabilities may have (Fjetland and Gjermestad, 2018).

METHODOLOGICAL APPROACH

Methods in the project

This project was inspired by action research aiming to improve practice together with those involved, and to document and study the process in order to identify the development of new knowledge (McNiff, 2017). Such a methodological approach builds on Kallio et al. (2020) who called for research to be carried out with a closeness to where people's citizenship unfolds, in order to illuminate their lived citizenship.

Staff from the residential housing initiated the project, aiming to change their own practices in order to enhance the quality of caring encounters between staff and residents. To enhance quality and make changes, staff were inspired by TCU and sought to implement this approach – the understanding of which was necessarily phenomenological, as humans are fundamentally relational (Thommesen & Neumann, 2019; Bath, 2015). The project was therefore designed as a close collaboration between researchers and co-researchers throughout the entire process and was, in this way, also inspired by action research. It has been found that collaborative action research can contribute to the improvement of professional practices for both academics and staff with regard to residential housing (McNiff, 2017).

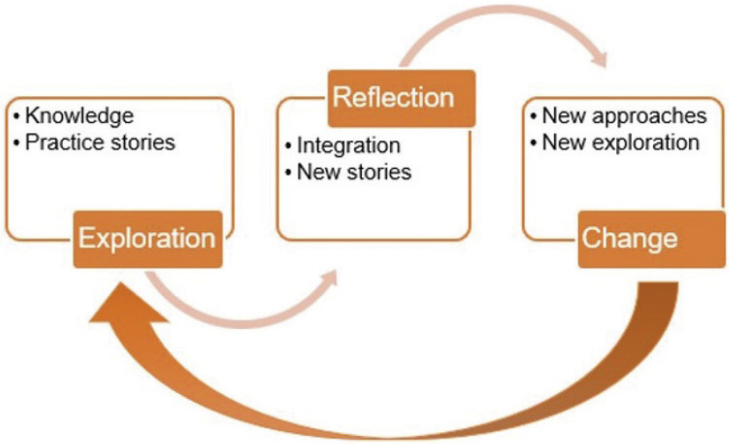
Methods in the study

The design of the pilot project centred around two actions. The first action focused on providing staff with new theoretical understandings of TCU (carried out via subject days highlighting the core concepts of TCU) and was followed up by the second action, which was meetings in reflection sessions groups. Sharing experiences from and applying new theoretical lenses to their professional practices was the focus of the reflection groups. During the project, data were collected via transcripts, reports/minutes from meetings and subject days, and the researchers' logs. The table below provides an overview of the study participants, actions and empirical material.

Table 12.1: Participants, actions and empirical material

Participants	Actions	Empirical material
• Staff in reflection sessions (on average 10 people every time); some of the staff had higher education, while others had no formal education • Project group (2 researchers from VID, 2 students, 2 employees from the residential housing facility)	• 1 introduction day presenting key concepts • 2 subject days (start and end) • 5 reflection sessions • Project group meetings (leading the project) • Implementation of 3 thematic points: o *The three-part brain* o *The window of tolerance* o *Regulation of emotion*	• Transcripts from 5 reflection sessions • Reports and logs from 2 subject days (approx. 80 participants) • Reports from project group meetings • Reports and notes from introductory analysis seminar • Researchers' own logs

The project was also developed through circular phases based on the core elements of action research: observation, reflection, action, and evaluation (McNiff, 2017). Throughout the project, we developed a model that describes the circular phases and how the staff's application of TCU in practice – via reflection on new concepts – provided new approaches in environmental work; the model thus became a separate action in the project.



Model 12.1: Reflection model.

The model highlights how the staff's exploration and reflection on their individual everyday work in the reflection session is based on *both* collaborative research *and* a phenomenological approach to studying and communicating with people as fundamentally relational. It can contribute to improving knowledge, competence and quality in practice highlighting the importance of emotions in professional relationships.

Ethical considerations and challenges

It is an ethical challenge to initiate processes that can change the care framework for residents in residential housing. This research project aimed to increase the quality of environmental work through changes in knowledge and skills development among staff. There was a shared motivation among the various parties in the project to develop practice through cooperation and participation; this was in keeping with a central tenet of collaborative research, which is that all involved have a common understanding of the project's objectives (Dyhr-Nielsen, 2013).

In the reflection groups, the focus was on the staff and their role in relational interactions. Nevertheless, residents were sometimes mentioned: as the reflections thus occasionally contain indirect information about third parties, anonymity, and confidentiality have been emphasized. Moreover, privacy and confidentiality have been safeguarded through obtaining the consent of all parties involved. The project was approved by the Norwegian Centre for Research Data (NSD – project number 398099).

A possible critique of this project is the absence of the residents' voices regarding how the project impacted them. To mitigate this, the staff maintained a heightened focus on the residents throughout the project. Moreover, in line with common action research challenges (McNiff, 2017), we are aware of the risk that positive changes from the project may not be continued after the project's completion.

The project's validity was strengthened through systematic documentation of the process (Ulvik et al., 2016). Analysis and sorting of the data were conducted jointly between the project group members, with clarification rounds throughout the process.

Analysis

The data were analysed by researchers and the project group leading the project. The analysis was guided by the aim of the project as well as the research question noted earlier. The objectives of the TCU project informed the analysis, and it was through these lenses that we began to read the material – or the "travel logs", to draw on Kvale, Brinkmann, Anderssen and Rygge's metaphor (2015). One topic in the TCU project was to facilitate changes in approach through the implementation of key concepts: the three-part brain, the window of tolerance and emotion regulation. The empirical material was analysed and interpreted using a phenomenological approach (Bengtsson, 2006); we asked, *What emerges for us as readers with a professional eye? How can we understand the staff's understandings, as revealed in their stories*? In the readings and analysis, some connections were identified in the

texts, and a preliminary picture was developed around staff's understandings through their reflection on their own practice. To clarify this picture, the following analytical questions were asked of the data: 1) What changes in understandings and insights were expressed by staff throughout the project; and 2) How can these changes and insights be understood within a lived citizenship perspective? The "answers" to the first analytical question are presented directly below, while the answer to the second is presented and discussed at the end of the chapter.

We captured the staff's changes in understandings and insights during the project by organizing them into the following thematic categories:

1. Conflicts and rules
2. Voices toward awareness
3. Courage toward quality
4. Recognition of the resident's emotional and physical expression

These themes capture some of what emerged from staff when they were focused – and reflected – on their own practice.

FINDINGS

Conflicts and rules

At the beginning of the project, the staff's reflections were largely focused on the way in which they were instructed to interact with the residents – particularly after situations where conflicts or "deviations" had arisen in the interaction. The staff described an everyday life that was characterized by complying with certain rules in their interactions with residents, as violation of these rules could result in the residents' acting out or engaging in verbal violence. This was described as challenging for both staff and residents, an example of which can be seen from the first reflection session. The staff were sharing some experiences from the weekend, and it was pointed out that these were not unusual incidents and situations. The conflicts between staff and residents were described as largely about rules and agreements, and different understandings of how these agreements should be interpreted. One staff said:

> I think the staff's boundaries toward the residents are very bad. We do not make demands toward them – say they have to wait a bit. Everyone pleases them to avoid an outburst, and it hurts the other users. Maybe it's a habit they have with them from home?

The staff articulated their own experiences and understanding. At the beginning of the project, in particular, there was a great deal of discussion around how the staff should relate to the residents. Several of the staff described how agreements, frameworks and rules in residential housing governed and dominated their communication with the residents. One staff member asked: "Can't we just make an agreement on how they should behave? What applies in just this specific situation? In their head the case is they always want an apology – it is something they have with them". Their understanding seemed to be that the rules themselves governed the interaction. Moreover, the staff described how the residents needed control and predictability – and that the agreements and rules became a way to meet the residents' needs in this respect. The staff talked about the fact that they had to agree on common rules and frameworks as, in order to create a predictable, secure environment, it was important that the staff acted the same.

The attitude amongst the staff seemed largely to centre around their loyalty toward the rules. They noted that the most important thing was to keep the rules and agreements in mind and not break any of them. As noted above, violations of rule could trigger verbal violence, acting out or self-harm among the residents. To prevent these incidents, there was a strong focus on the framework: thus, there was more focus on the *technical* action in the interaction than on the content itself.

Voices toward awareness

At the beginning, as we just saw, the focus of the staff's stories was characterized by making and abiding by agreements, rules and frameworks – and this, in turn, influenced their approach. However, some of the staff began talking about how they used themselves in the everyday encounters with the residents. These stories led to new questions and wonderings from others in the group discussions: some recognized themselves in the stories, while others raised questions. The voices of the latter – few, but clear – highlighted their own experiences in their encounters with residents. They asked questions like, "Think about whether it is actually like that for them", and "Maybe we must dare to be in the relation". These voices created movement in the staff group, which was maintained throughout the project. Expressing sensitivity in this way toward the residents' perspective sparked curiosity – and thus reflection – in the staff group regarding increasing sensitivity in their own interactions with residents.

As the project continued, the staff's reflections gradually changed and their stories reflected an increased awareness of their role and how they influenced the content of their interactions with residents. The staff discussed and reflected on

the three-part brain and emotion regulation, and what significance this could have for their understanding of the residents. Several in the staff group used terms from the project to describe their own experiences. The stories changed from "describing behavioural agreements" to "how can we interact with them in the relationship?" The relating of incidents involving the residents also began being described differently: for example, as one staff member said, "Yes, they have a behaviour that is challenging, yes, it is demanding, but it is not often I hear, 'They are so difficult'. There's an understanding behind it that says 'Okay, now it's going to be like that – then it's going to be like that – then it's going to be a dispute, but okay'. It is important to go from being difficult, to having it difficult".

We see that, as the professional understanding changed and increased, the staff changed their professional view: from a focus on frameworks and agreements to a focus on the relationship itself. Several of the staff started exploring and reflecting on the residents' previous relationship experiences. They were curious about understanding the residents, their life history and possible incidents that could aid in understanding the resident in new ways. This was reflected on during the project, and this opened a different understanding of the residents' reactions and interactions with staff. Staff started to discuss and reflect on whether the residents had been in care environments that lacked stimuli, pointing out that there could have been broken relationships and few opportunities for connection. One of the staff members wondered about one resident, "What is her attachment behaviour?" In their reflections and conversations, the staff members thus began showing a recognition of the residents' previous lives, and how these could be expressed in everyday situations. In other words, they began using elements from TCU.

Courage toward quality

We found that the staff had the professional courage to dare to be in the challenging relationship – without all the rules and agreements. The reflections in the group changed from what the *residents* should and could do, to what the *staff* could do. As one staff member noted, "We are probably more aware of what we do. I think we think more about – how we go in. I remember in the beginning we interpreted this behaviour in a different way. Now there is more understanding of why the behaviour is there. That we do not automatically think that it is aggression, directed at us, but that it is more frustration". The staff also pointed out that it is the relationship itself that had changed – they had become better acquainted with the residents, and could be present in the relationship in a different way than before. Another staff member commented: "Maybe it has something to do with our atti-

tudes? That we as staff have changed when we are with her?" Several in the staff group described how they now reassured the residents by reading their body language – and meeting the residents by confirming what they were seeing.

During the project, the staff members expressed a new understanding of the residents; we interpret this as a change in their ability to see emotional, not just behavioural, expressions. The staff shared experiences in the reflection group concerning new ways of meeting the residents. They described taking a different approach to their environmental work: "We as staff carry out our environmental work in a different way – now we are able to solve the challenges because we think a little differently".

Courage toward quality is also evident in their new understanding that it was *they themselves* who were the very condition for the interaction – and thus it was they, rather than the rules and agreements, who could ensure quality in the relationship and interaction:

> But we see a change in the way she expresses herself. We have a greater understanding of why the behaviour is there, that she has experiences that are unstable. We have gone from saying that she is difficult – to that she has had a difficult time. Now it is more so that she is our teacher in her own everyday life, and we build a bridge between reaction and emotion.

Recognition of the residents' emotional and physical expressions

As the project continued, the reflections amongst the staff developed further. At the beginning of the project, the staff were already describing the bodily expressions of the residents in a very pictorial way: "You see in her whole body language that this is going to be completely wrong. She turns completely black in the eyes and white in the face. What is her body saying?" In their reflections, staff described their own experiences and observations of their relationship interactions with the residents. Some noted bodily expressions, as mentioned above, or actions that were interpreted as expressions that a resident was not feeling well: "Because I see that something is happening to her. You see the frustration. When she dips and trips, there is frustration coming from her side".

We encouraged the use of professional concepts in the reflections, especially the understanding of the window of tolerance among both staff and residents. When one of the staff asked what the body of the resident was saying, this was explored in the staff group: How could they understand this "story of the body"? The staff's reflections reveal a recognition that the residents had lost a great deal of security

when they moved into the housing community, and that they were now encountering different reactions than before. Moreover, the staff were also affected by the residents' very clear body language; some of them told stories about residents acting out and self-harming when the residents were far beyond their tolerance window, and how this was clearly expressed in the body: "That she – it looks like she wants to crawl out of her skin. Because you just saw her whole… she just crawled".

Several of the staff emphasized that they were not afraid or angry in these situations, but that they could clearly see that it did something to the resident. Through discussion and reflection on these experiences, it emerged that several staff members did react with frustration to these clear bodily expressions and did not have the concepts to explain what was happening. As one explained: "But sometimes you get a little annoyed or frustrated even then because you think that she must understand that I cannot help with this or I just cannot do this, but maybe I cannot think that she actually does not understand it because she might not do that, she jumps straight in… she skips the whole mindset and goes straight to anger".

We interpret the change in the staff as indicating that, through reflection and experience-sharing, they had developed a trauma-informed gaze. New words and concepts were being used to describe what was happening: "It's clear when they see that we are safe in it, then she does not often come out of it so often – the comfort zone I should say, I mean that window". In the reflections on the residents' bodily expressions, the extremes of the tolerance window were discussed: for example, the difference between being hyper and hypo-activated, and how this may appear. As one staff member reflected, "I think there is a lot of wordlessness in her, too. It's not everything she can put into words—of feelings, losses that she has had. She does not cope by shouting and getting angry! I think it's in her body". Several of the staff members described situations of relationship breakdown for the residents – both when the residents were growing up, but also in the housing community. The exploration of the residents' previous relationship experiences enabled the staff to reflect on regulation – or the lack thereof: "The fact that you are dependent on help from others means that there are a lot of broken relationships, which means that the safe connection – the safe base that will build it – is constantly broken".

Summary of findings

The findings highlight two promising changes due to the project. First, staff's understandings and insights gradually changed throughout reflections in the project regarding their interactions with the residents. Second, the findings also illu-

minate staff's process of movement in their care work, meaning moving from rules and regulations, via awareness and courage, to quality in relations and recognition of emotions and physical expressions. In other words, staff used the practice stories during the project, in that they recognized the residents' body expression as communication. In their reflections, the staff members also highlighted the importance of their role in securing good relationships and interactions: "We must give them lots of care, scoop on love – meet their feelings, and endure some chaos". In terms of lived citizenship, these findings elaborate and enrich our knowledge about how lived citizenship of people with intellectual disabilities unfolds, is supported or hampered within professional relations in residential housings. Affective and intersubjective dimensions of lived citizenship are especially illuminated (Kallio et al., 2020).

DISCUSSION

This study explores how the development of TCU amongst staff might contribute towards enhancing quality in care relations, new insights and understandings of people with intellectual disabilities living in residential housing. We will now discuss how the staff's acquisition of new theoretical understanding, followed by reflections, seemed crucial for securing quality in their caring relationships with the residents, as well as essential for promoting residents' lived citizenship (Kallio et al., 2020). Moreover, we emphasize how the staff's new insights and understandings can be understood in terms of a relational citizenship, meaning how the staff's theoretical lenses are significant elements of the supportive structures which mediates citizenship in professional relations (Lid, 2017), as well as in line with various dimensions of lived citizenship (Kallio et al., 2020). In line with Kallio et al. (2020), we also argue for the importance of small-scale action projects like this, in order to build knowledge about how the significant lived citizenship of people with intellectual disabilities unfold and are enacted.

TCU as a promising framework for enlightening and enhancing lived citizenship in residential housing

This study explored how the acquisition of TCU amongst staff seemed to contribute to new insights and understandings of the residents with intellectual disabilities, meaning developing their awareness and sensitivity towards the residents' non-verbal and bodily expressions. Awareness and sensitivity towards the residents' bodily relational experiences means acknowledging their unique ways of being, and

respecting the residents' lives as lived and experienced in both previous and present relations. Such awareness and sensitivity are, according to Kallio et al. (2020), fundamental aspects of the affective and intersubjective dimension of lived citizenship.

In addition, this study illuminates how the staff's practices gradually changed as they became more sensitive toward seeing the resident as subjects, which was anchored in relational experiences and the residents' history. The staff changed in practice towards the resident's unique perspectives and values and focussed less on institutional rules or personal values. On this basis we argue that, throughout the project, by using the trauma-conscious lens, language and perspective, the staff changed and developed new ways of seeing, relating to and understanding the residents. Such changes in practice enrich our understanding of the relational nature of citizenship of people with intellectual disabilities living in residential housing, and how staff are essential supporting structures for this citizenship to unfold (Lid, 2017). This also put the spotlight on how the lived citizenship of people with intellectual disabilities are unfolded and situated within professional practices, as also highlighted by Ursin (2017).

This also illuminates how the staff's theoretical knowledge, attitude and willingness to achieve reflective competence is a crucial condition for quality of care and for realizing the residents' lived citizenship. In addition, this study enriches how intersubjective, affective, and performed dimensions of lived citizenship of people with intellectual disability are mediated and intertwined within contexts of residential housing and caring encounters in such (Kallio et al., 2020).

The value of small-scale, participatory action-based research in residential housing

In line with our findings, we argue that this pilot project illuminates both the value and potential of small-scale, action-based research carried out in residential housing, and how such collaboration in knowledge production can contribute towards enriching our understanding of the lived citizenship (Kallio et al., 2020) of people with intellectual disabilities. We find this methodological approach promising in action-based research, due to its closeness to the performed and affective actions of the residents. In particular, the two main actions carried out in the project – increased theoretical knowledge and reflection groups – seemed to be of great value. They contribute towards recognizing the embodied, relational and lived experience of being a citizen. However, we are also aware of the fragility of such action-based research and its dependency on both dedicated leadership, and staff engagement and willingness to invest in change (Gotvassli, 2020).

We also argue that the reported changes amongst staff can be understood in terms of broader cultural changes (Hamran, 2018), which might challenge institutional and paternalistic practices toward residents with intellectual disabilities in residential housing. Such challenges toward institutional and paternalistic practices might help create new opportunities for residents to exercise their everyday citizenship, explained through the concepts of lived citizenship (Kallio et al., 2020). This underscores the importance and value of small-scale participatory action research projects carried out within institutional practices where people with intellectual disabilities live their lives.

Finally, we argue that this study enriches the understanding of both social and material circumstances of the lived citizenship of people with intellectual disabilities living and receiving support in residential housing. In addition, this study also especially highlights the importance of staff's theoretical lens and relational knowledge as an interwoven aspect of the affective and intersubjective dimension of lived citizenship of people with intellectual disabilities living in residential housing.

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13. Self-determination and citizenship

Kirsten Jæger Fjetland and Peter Paluga

Abstract The chapter explores how self-determination is described and justified in bachelor theses of social education students. This knowledge is crucial for the quality of social education to facilitate the competence needed to support citizenship in professional practice. The analysis shows students' focus on: small vs significant choices; level of function; power and coercion; experience, training and learning. The results indicate that students have both a conditional and a universal understanding of citizenship.

Keywords self-determination | lived citizenship | social education | intellectual disability

INTRODUCTION

The equal right to make decisions and to control our own lives is fundamental to realizing human rights (Skarstad, 2018). Autonomy as a human condition presupposes participation and influence as qualities for understanding citizenship as universal for all citizens. These phenomena is based on humanistic values implying the acknowledgement of human beings as social, relational as well as autonomous (Jonassen & Barbosa da Silva, 2018).

Service users' participation, involvement, and self-determination are overarching objectives in welfare policy (Askheim, 2014; Meld. St. nr 29 (2012–2013)). Understanding and facilitating self-determination in care encounters is a key challenge when evaluating the well-being, quality of life, and living conditions of people with intellectual disabilities (Gjermestad, Luteberget, Midjo, & Witsø, 2017; Guddingsmo, 2019; NOU 2016:17; Söderström & Tøssebro, 2011).

The administration of self-determination in practical environmental therapy includes ethical considerations and judgement. The professional ethical guidelines of social educators emphasizes: *Respect for the individual's values and desire for con-*

trol over one's own life is fundamental in health and social work (FO, 2017a; 2019, p. 6; Forskrift om nasjonal retningslinje for vernepleierutdanningen, 2019). Social educators' understanding of environmental therapy includes, however, different basic pedagogical views with different views of human nature, knowledge, and pedagogical practice influencing how they facilitate and support self-determination in environmental therapy (Steinsholt & Løvlie, 2004). Knowledge and insight about how to facilitate self-determination in caring encounters is therefore a key competence in the social educator's education[1] in Norway (FO, 2017a, 2019; Forskrift om nasjonal retningslinje for vernepleierutdanningen, 2019).

To our knowledge, no studies have been conducted exploring students' understanding of self-determination in Norwegian social education. The purpose of this study is to enlighten teaching for the Bachelor of Social educator about students' understanding of self-determination. Based on the significance and complexity associated with interpreting and practising self-determination in social education, we will explore the issue: *How is self-determination described and justified in bachelor theses of social education students?*

THEORETICAL BACKGROUND

When presenting theoretical perspectives of the phenomena of self-determination and citizenship, we will have a main focus on relational perspectives. In order to reflect the students' framework of understanding as it shows itself in the bachelor theses in this study, we will, however, also shortly present self-determination based on rights, the theory of psychological human needs and on learning theories.

Perspectives on self-determination

Wehmeyer, Abery and Mithaug (2003, p. 177) define self-determination as "acting as the primary causal agent in one's life and making choices and decisions regarding ones quality of life free from undue external influence or interference". Self-determination represents a valued outcome in the disability field and refers to making or causing things happen in one's own life (Shogren, Wehmeyer, Martinis, & Blanck, 2018, pp. 8 & 22).

1 "Vernepleier" is a unique Norwegian profession where healthcare and social work competence is combined. People with intellectual disabilities are an important group of citizens receiving professional care from "vernepleiere". In this study, we use the English term social educator.

The theoretical understanding of self-determination is not static (Shogren et al., 2015). As a result of the Convention of Rights for People with Disabilities (UN, 2003) and the growing emphasis on promoting self-determination, supported decision-making models are emerging and replacing, or supplementing, traditional models of guardianship (Shogren et al., 2018, p. 101). All citizens as their own decision-maker represents a shift of paradigm involving a relational understanding of citizenship that includes diversity.

Autonomy must be inclusive, meaning it can be applied in the lives of everyone (Stefansdottir, Bjornsdottir, & Stefansdottir, 2018, p. 163). If autonomy and self-determination are understood as well-defined phenomena, the agency and competence of people with disabilities might not be acknowledged (Fjetland & Gjermestad, 2018; Wyller, 2011). Theories of supported decision-making points to self-determination as personal autonomy, relational and social, as well as contextual (Dinerstein, 2012; Shogren et al., 2018; Stefansdottir et al., 2018).

In professional practice, interventions must be based on every citizen's opportunity to participate and influence decisions concerning their everyday life (Lid, 2017). In this way, self-determination represents an expression of participation and self-agency that contributes to diversity and democracy. Lorentzen (2007, p. 96) describes self-determination as: "(…) an expression of a need to say and do something from a specific point of view, a position and a unique perspective in the social community". Self-determination based on an understanding of relational autonomy is fundamental to the understanding of citizenship.

A rights perspective in self-determination is based on the premise that self-determination is a universal phenomenon, including all inhabitants as citizens constituted by the Convention on the Human Rights of Persons with Disabilities, CRPD (Skarstad, 2019; UN, 2003). Acknowledging the right to self-determination is a basic quality of agency and equality for all citizens, and represents values and goals in health, care, and welfare services (Meld. St. nr.10 (2012–2013)). Self-determination in professional practices for people with intellectual disabilities often takes place in everyday life at home, a particularly challenging context in social educators' professional practice (Ellingsen, Berge, & Johnsen, 2005).

Self-determination is further communicated as a basic human psychological need and fundamental for the experience of autonomy and freedom (Bollingmo, Ellingsen, & Selboe, 2005). Self-determination involves a focus on citizen resources contributing to empowerment, motivation, mastery, self-confidence, and security (Manger & Wormnes, 2015). Practising self-determination presupposes acknowledgement, social support, and communicative competence in service providers (Fjetland & Gjermestad, 2018).

Self-determination is also described as a skill promoted by practising, fundamental for learning and personal development (Nordlund, Thronsen, & Linde, 2015). Wehmeyer (2005) describes self-determination as conscious acts of will that make a person a significant agent, showing how self-determination is promoted using multiple interventions. However, a skills perspective might also include an understanding of learning that has a focus on the citizen's cognitive limits rather than competences and rights. A skills perspective on self-determination can include a paternalistic perspective in professional practice, including a normative ideal of citizenship where citizens are expected to learn certain standards of behaviour to access self-determination. Paternalistic practices will challenge a universal perspective in citizenship, potentially excluding groups of citizens.

Self-determination and citizenship

Self-determination is often connected to user participation, which includes a service perspective on the phenomenon as opposed to self-determination as a universal phenomenon for all citizens based on their inherent dignity and autonomy (Arstein-Kerslake, Watson, Browning, Martinis, & Blanck, 2017). Citizenship is shaped through the practice of democracy, supported by human rights (UN, 2003). Different welfare ideologies represent understandings of citizenship with differing perception of the individual's rights and society's duties (Askheim, 2017; Boje, 2017). A universal perspective on citizenship involves self-determination because it involves *civil rights* such as freedom of expression, the right to decide over private property, and personal choices; it concerns *political citizenship* through the right to be represented, to vote in elections, and to contribute to democracy; and it concerns *social citizenship* in the sense of acknowledgement and relationships with other citizens, belonging and connection to persons and local communities with the opportunity to choose participation in work and leisure (Fraser, 2009; Kymlicka, 2002; Lid, 2017; Marshall, 1950).

The understanding and practising of citizens' rights as self-determination concern the experience of lived citizenship. The way lived citizenship of people with intellectual disabilities unfolds and is performed in everyday life concerns the experience of autonomy, security, as well as influence (Halvorsen et al., 2017). Kallio, Wood, and Häkli (2020) points to the interdependent dimensions of performed, intersubjective, affective and spatial citizenship. Lived citizenship for people with intellectual disabilities dependent on professional support thus concerns social educators' understanding of professional relationship as well as the materiality of everyday life for people receiving public services.

Research questions

Based on the basic significance and complexity of self-determination and citizenship in social education and practice in the everyday lives of people with intellectual disabilities, this study explores these questions:

- *How is self-determination described and justified in bachelor theses of social education students?*
- *What characterizes the understanding of citizenship as interpreted from students' bachelor theses?*

METHOD

To explore the variations in students, understanding of self-determination, we chose the qualitative method as described by Silverman (2021) with narrative text analysis of students' bachelor theses. The students' presentation of discussion was chosen because this part of a thesis encompasses students' descriptions and judgements concerning the phenomenon of self-determination as both theory and practice, which is the focus of this study. This study is based on a selection of students' bachelor theses, exploring self-determination in different settings. Thus, we understand our data as empirical texts and stories. Narratives as empirical data provide insight into the way narrators put together a story with descriptions and interpretation (Riessman, 2008). The students have made active choices of literature and examples, giving the reader insight into their understanding and production of meaning.

Systematic searches were carried out to identify bachelor theses exploring self-determination, inspired by a review design. Our study is inspired by openness characterized by a general framework of narrative reviews (Ferrari, 2015, p. 232).

Search terms and selection of bachelor theses

Relevant databases for searching for student / bachelor theses are Brage and Oria. We used the search terms "vernepleie" (social education) and "studentoppgaver" (student assignments). All bachelor theses in social education in Brage and Oria are marked with text: Bachelor in social education.

The synonyms used when it came to self-determination were *autonomy*, *participation, user cooperation, empowerment* and *mandate*; they were chosen

because they are repeated in theoretical texts relating to self-determination and social education (Askheim, 2014; Nordlund et al., 2015). The title and subject were used in order to achieve the most adequate number of hits. Search history is shown in Figure 13.1.

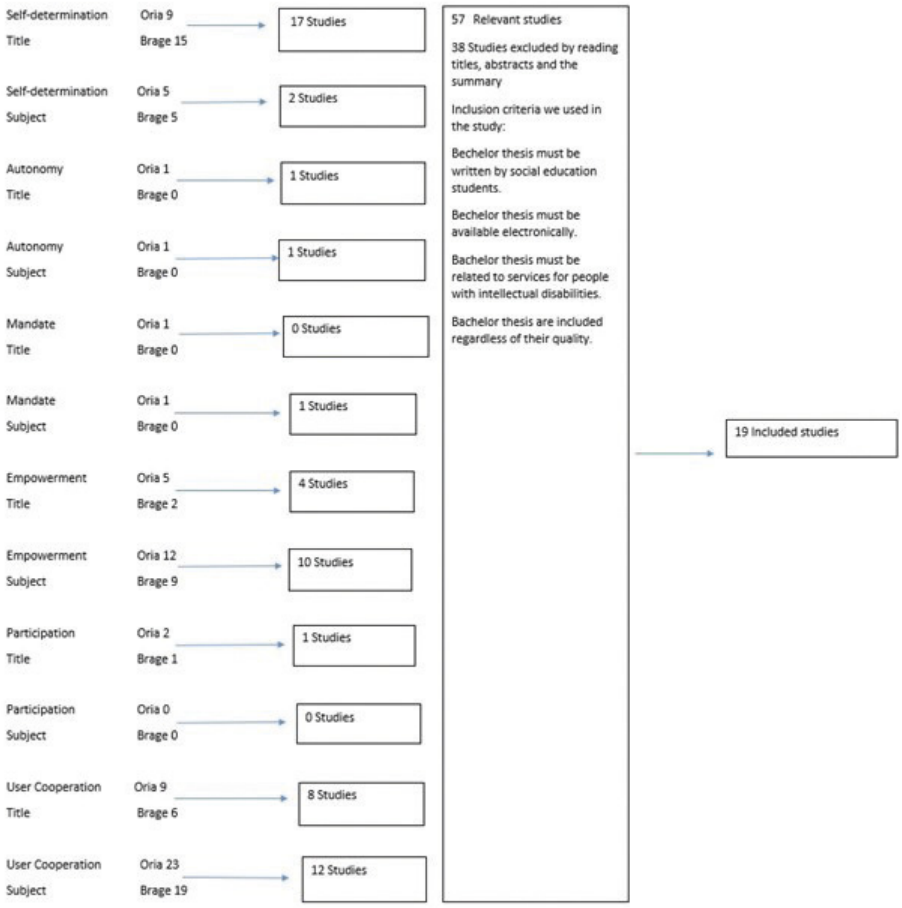

Figure 13.1

After the first searches with excluded duplicates, 57 bachelor theses remained for reading the summary of the assignments. Using the inclusion and exclusion criteria described below, further processing resulted in 19 texts, including the assignments' discussion chapter, 156 pages.

Inclusion criteria

The following inclusion criteria were used:

- The Bachelor theses had to be written by social education students.
- Libraries' lending practices meant that the assignments had to be available electronically.
- The Bachelor theses had to be related to services for people with intellectual disabilities because self-determination is particularly challenging in services for people with intellectual disabilities and 55.6 % of social educators work in this field (FO, 2017b, p. 9).
- Passed assignments are included regardless of quality to provide insight into students' knowledge at various levels.

Analysis

The data material was analysed using narrative thematic analysis inspired by Riessman (2008) and Fjetland (2015). This involves four readings where, based on the research questions, we asked different questions of the text. Narrative thematic analysis is suitable for gaining insight into the connection between description, interpretation and understanding (Fjetland, 2015). The first reading implied a naive reading to produce knowledge of the general characteristics of the data. The second reading addressed the participants' thematic descriptions of self-determination. The third reading focused on justifications due to values, choices, and interpretations in the students' texts, and the fourth reading implied an interpretation of meaning of how self-determination concerns citizenship. See schematic presentation of the analysis below in Table 13.1.

Table 13.1: Schematic presentation of the analysis

Analysis	1. Naive reading	2. Thematic reading	3. Reading	4. Reading
Analytical questions	What are the overarching characteristics of the texts?	What topics are described and highlighted in the texts?	What assessments, choices and values are presented as justifications?	What characterizes understanding of citizenship?
Result	Diversity of theories of self-determination are assessed against challenges in social education practice	Four repeated topics 1. small and significant choices 2. level of function 3. power and coercion 4. experience, training and learning	Different and complex reasons: focus on the person's function and needs, self-determination as a human right, importance of the professional relationships, situations and contexts	Conditional vs unconditional citizenship

Ethics and reliability

The bachelor theses that represented the empirical data in this study are electronically published and available via the databases Oria and Brage and thus already subject to provision of informed consent for publication. The assessments do not contain confidential information. However, they are of varying quality. In order to take into account the students' learning process and recognize the student's search for understanding regardless of assessment results (NESH, 2016, pkt. B), we chose to anonymize the authors by numbering the assignments rather than stating candidate names. We have further emphasized being descriptive in our presentation of results and avoiding assessment of students' work.

At the same time, we intend to keep descriptions of search and analysis processes transparent, open and documentable, to ensure that the search we conducted can be repeated with similar result (Silverman, 2021). This was a dilemma when we also chose to anonymize the student assignments, which represents an ethically justified limitation in this study.

RESULTS

The results described below respond to our first research question: *How is self-determination described and justified in bachelor theses of social education students?* Our thematic analysis of the students' discussion resulted in the identification of four recurring themes.

Self-determination in small vs. significant choices

The student assignments are generally based on the importance of small everyday choices and mastery of everyday challenges. Significant choices in an existential and /or life course perspective are mentioned by many as dependent on the cognitive function of the person with intellectual disabilities and therefore too difficult to manage. Small everyday activities mentioned are choosing drinks, a bread spread, or daily activities. The service recipient's self-determination and feeling of mastery, increased freedom and reduced need for help are the reasons referred to. One thesis mentioned:

> (…) emphasis on self-determination in the thousand everyday situations that may be most important for people with intellectual disability and their experience of having a real influence in their own lives.

Other students, however, emphasize different contexts for self-determination: "To be participatory in my own life, I would say, is to make both big and small choices". In this thesis, it is stated that small choices are the most important in everyday life. The student underscores that big choices can be difficult for everyone, and everybody may want someone else to choose for them:

> (…) it is not always right to transfer the responsibility to persons with intellectual disability when it comes to making big and significant choices. As Vatne (2003) writes, participation must be adapted to the individual user's competence, resources and condition.

One thesis links small everyday choices as a starting point for practical training in self-determination as a skill. Another one points to both everyday and significant choices. "Self-determination is also about more difficult choices such as where you want to live, career choices or who to vote for in a parliamentary election".

In summary, the theme *self-determination in small vs. significant choices* shows that the intention to highlight small everyday choices as important for practising self-determination is described as making visible opportunities for impact and influence in one's own life, regardless of function and situation. The intention refers to pedagogically based mandates in professional work and shows that understandings of self-determination can be interpreted in an instrumentalizing way and limited to established everyday activities in professional practice. In this way, the intention to promote self-determination in professional services can also contribute towards limiting opportunities for citizens' social participation and can be perceived as something more than a recipient of welfare services.

Self-determination and level of function

The theme *self-determination and level of function* refers to the fact that the bachelor theses in this study generally underline that people with intellectual disabilities may have difficulty seeing alternatives and understanding the consequences of choices due to self-determination. The person's need for support should determine how much self-determination they can manage. However, some candidates also emphasize that the need for support can cause abilities or functional levels to be underestimated.

Lack of involvement of the citizen in planning the activities of everyday life is justified in the service user's failing ability or desire for influence: "To be able to see the consequences of one's own choices and actions, presupposes that one has a cer-

tain cognitive ability". This candidate justifies the absence of self-determination in the sense of safeguarding the user's health and safety. Persons with a greater need for support have less self-determination than those with less need for support. This thesis represents assignments that also emphasizes the rights perspective in self-determination: "One goal that the service provider must strive for is for the service recipient to be able to practice his or her right to self-determination regardless of functional level".

Several theses, however, mention examples of how functional level can be underestimated.

> It is not certain that a person can see the consequences of all the choices that are made, but one can ask the question if all of us always can see the consequences of the choices we make?

Several students also focus on the skills and attitudes of the environment: "The opportunities for self-determination are often very limited not only due to disability but in the way others have related to them".

In summary, the theme of *self-determination and level of function* indicates that students both emphasize the importance of self-determination as a cognitive practice, while at the same time working for the protection of self-determination as a human right for all. The texts show both paternalistic practices, implying protecting persons with intellectual disabilities against their own "imperfect" choices – and describing opposition to paternalistic practice.

Self-determination, power and coercion

Ethical challenges and dilemmas related to self-determination are central to the student assignments. Students discuss the right to self-determination in professional practice being linked to the person's level of cognitive function and motivation, the service provider's knowledge, values, attitudes and experiences, the desire to protect the citizen, and organizational culture.

Discussions of the importance of power and coercion linked to the service provider's mandate is central in several students' interpretation of self-determination. Power is elucidated both in a relational and a legal perspective and students point out that care can also be used to manipulate the service user to choose what the service provider wants. "It will be important to be aware that there is power in being the 'significant one' for another". This thesis points out that self-determination of people with intellectual disabilities often depends on how much their envi-

ronment allows, and that resistance and "disobedience" among users is modified by consequences that are justified in theories of social education.

Students also emphasize that the service users' choices depend on the approach the service provider chooses, thus referring to a relational understanding of self-determination.

Several students also emphasize that self-determination practices can be influenced by attitudes, competence and organizational culture. One student emphasizes that well-organized practices can represent a violation of integrity and self-determination if the social workers and management organize environmental therapy on rule-based principles. One student wrote: "What kind of approach is used depends on the service provider's attitudes, perception/understanding of self-determination and the service recipient's ability to make choices". This critical reflection in the understanding of self-determination is also evident in other candidates who point out that the right to self-determination is enshrined in laws and conventions. Prejudice, discrimination, lack of respect and desire to protect the citizen denies people with intellectual disabilities their right to be an independent agent in their own lives, mentioned in another two theses.

In summary, the theme *self-determination; power and coercion* shows that student assignments have a complex and contextual perspective on self-determination, referring to challenges and dilemmas in professional practice. Students who mainly refer to their own practice are generally concerned with justifying the importance of influence, paternalistic leadership, power and coercion in their mandate in professional practice.

Self-determination through experience, training and learning

This theme is based on results that show that the student assignments generally emphasize that experiences with the making of choices and their consequences contribute to learning and development in managing choices, thus contributing to mastery and independence. Students emphasize that the service provider's task is to make this possible through training.

In a learning perspective on self-determination, the importance of learning from consequences is a central argument in several theses. One states: "(…) being able to make mistakes and see the consequences of the choices is a learning opportunity and being able to develop in making choices based on one's own values".

According to the student assignments, facilitation and support are basic qualities in practical environmental therapy. Facilitation is described as structure and simplification, helping to create coherence and development for persons. One stu-

dent discusses that exercising choice-making that does not have dramatic consequences can be a part of facilitating. Students further emphasize the importance of the service providers' knowledge about the person's interests and needs so that they "know them and interpret their signals correctly".

Other candidates point to the learning potential of

> (…) positive reinforcement in attempts to exercise personal control, promote participation and inclusion, develop the availability of role models to follow, and use individualized plans and support (Wong & Wong, 2008).

The danger of underestimating the abilities of others and thus the opportunities to practice self-determination is emphasized, as well as the importance of including people with severe intellectual disabilities in learning and practising self-determination.

In summary, the theme of *self-determination through experience, training and learning*, indicates that students emphasize self-determination in a pedagogical perspective. This perspective is based on the social educator's professional mandate and care for the citizens' unique point of view, their values and personal development. In some texts, the learning perspective is used to control and shape the service user to adapt to valued norms in society, representing a paternalistic understanding of professional practice.

DISCUSSION

The results show both a paternalistic position and describe opposition to a paternalistic position when it comes to self-determination in professional practice. The discussion will answer the second research question: *What characterizes the understanding of citizenship as interpreted from students' bachelor theses?*

Self-determination as universal vs. conditional citizenship

The student assignments are generally based on a universal human rights perspective of professional practice characteristic of a universal understanding of citizenship, although students also consistently give arguments for the relevance of a conditional citizenship related to cognitive function and social behaviour. The transition from recognizing all citizens as unique and with irreplaceable individuality and rights (UN, 2003; Wyller, 2011) – and preserving this perspective as a mandate in professional practice, appears to be challenging for students, and

would – based on this study – be in need of more attention during social education.

The students' challenge is due to the history of professional practice as well as of citizenship. Traditionally, healthcare professionals decided what treatment service users should receive (Jonassen & Barbosa da Silva, 2018) and this represents expert-based and paternalistic perspectives in professional practice. "All professional care moves in the tension between considering the person as a category and as a person" (Leenderts, 2014, p. 55). Further the understanding of citizenship has changed from including categorized, privileged groups of citizens (Marshall, 1950) to representing a phenomenon that challenges categorization based on status and function (Fjetland & Gjermestad, 2018; Lid, 2017).

However, the student assignments generally focus on the tension and ethical and moral challenge between the universal citizenship related to all citizens and the conditional citizenship related to a person's position, role and function. The challenge and tension associated with these two understandings of citizenship is shown by the fact that the assignments have a strong focus on the importance of awareness of power in the professional role; *to be aware that there is power in being the "significant" for the other*. The students here refer to a lived citizenship perspective including a relational understanding of their professional mandate, as Lid (2017) and Fjetland & Gjermestad (2018) emphasize.

The student assignments underscore awareness on asymmetrical power relations in daily life. Relational power in social education practice concerns the acknowledgement of the intersubjective and affective dimensions of citizenship, as Kallio et al. (2020) underscore. The students' rejection of a person's cognitive function as a gatekeeper for agency refers to citizenship in the sense of autonomy and acknowledgement, resistance and redistribution of influence and resources (Fraser, 2009). This is supported in the Rights Convention's specification emphasizing the right to access of necessary support to be able to exercise legal capacity, as stated in Article 12 of CRPD (UN, 2003).

According to Sly & Tindall (2014), lived citizenship is experienced and performed by being an agent in various specific areas of life (Duffy & Perez, 2014). A universal understanding of citizenship is emphasized as the student assignments point to the importance of self-determination, including both everyday practical choices and fundamental choices such as work affiliation, housing choices and financial independence. This refers to citizenship as experienced and lived, mediated by access to spaces and everyday activities as well as social relationships (Kallio et al., 2020).

The student assignments focus on specific everyday choices, referring, however, both to a universal understanding of citizenship, and to a limited understanding of

citizenship where small decisions in everyday life is used as an alibi for self-determination, participation and citizenship. The basic mandate of social educators is, however, described as strengthening a contextual perception of practice through the service user's opportunity for community participation in all arenas in society (FO, 2017a). In the assignments, we see that a universal understanding of citizenship as a right and value supporting autonomy, security as well as influence (Halvorsen et al., 2017) is preserved in the students' argumentation when it is linked to humanistic values and a relational and contextual understanding of social education practice. A universal understanding of citizenship mediates a focus on the citizen's agency supporting lived citizenship. The results of this study, showing students' justifications of individual everyday choices as the most important example of autonomy and self-determination, are challenged by a perspective of diversity and social participation in lived citizenship. The students' understanding might promote a normative and individualized as opposed to a community-based understanding of citizenship.

The students' work regarding their attitudes through ethical reflection and competence development related to self-determination as supported decision-making are examples that refer to a perspective of lived citizenship in the citizen's everyday life. This is shown in the results represented by the students emphasizing self-determination through experience, training and learning. Supported decision-making can contribute to promoting equality through our "choosing forms of cooperation and working conditions that provide the opportunity for full participation" (Werner, 2019, p. 166). Choice and freedom of action are characterized by an interplay between functional level and external conditions (Jonassen & Barbosa da Silva, 2018), and can impact possibilities of learning and the experience of lived citizenship. A universal understanding of citizenship then links the right of self-determination and level of function together rather than creating conditions, contrasts and contradictions between these phenomena. A focus on lived citizenship is based on a relational understanding of self-determination promoting social diversity and participation (Kallio et al., 2020) and can – based on the results of this study – contribute to avoiding an instrumental understanding of self-determination and learning as shown in some theses.

Contextual conditions are, however, used in the student assignments both to justify limitations as well as the facilitation of self-determination in social education practice. Citizenship as an unconditional, universal and relational phenomenon mediating influence versus a conditioned and paternalistic phenomenon mediating security, also appears here. Kittelsaa (2019) concretizes several external, environmental factors that contribute to the quality of everyday life in supported

housing for people with intellectual disabilities. The service provider's knowledge, attitudes and values, motivation, desire to protect, as well as the framework and culture in the organization in addition to socio-materiality, are in focus. These contextual factors are a focus in the results of this study as well. The level of function interacts with external conditions in a socio-ecological context preventing decision-making practices (Melbøe, Fylling, Gjertsen, & Fedreheim, 2020). According to Halvorsen et al. (2017), citizenship presupposes considerations of *both* security and influence.

Knowledge concerning legislation, ethics, human views and human rights are the framework for argumentation in the empirical texts of this study. However, there are also assignments based on random argumentation. Pragmatic analysis characterized by a paternalistic perspective on professional role and lack of theoretical references represents a basis for arguing for limits to self-determination and thus a conditional, paternalistic understanding of citizenship. The importance of highlighting challenges with paternalistic views regarding self-determination in social education can be supported by this study.

Managing the extra need for support to make decisions to be an agent in one's own life when one has an intellectual disability is challenging (Tøssebro, 2019). Acknowledging equality implies adapting to citizens' common vulnerability, dependence, and unique way of communicating: "we need a concept of the human that emphasizes vulnerability as a basic human condition" (Lid, 2015, p. 1564). These values are complex and require professional judgement to ensure lived citizenship as according to (Halvorsen et al., 2017) concerns both citizens' autonomy security, and influence in their own everyday lives and in society.

SUMMARY, CONCLUSION AND IMPLICATIONS

The aim of this study was to inform social education about students' understanding of self-determination as well as the relevance of citizenship in promoting the understanding of self-determination. The results of this study show that students' descriptions and interpretations of self-determination refer to citizenship as both a universal and unconditional phenomenon – rooted in fundamental rights and equality between all citizens – and a conditional phenomenon – related to a service user's functional level, as well as resources and limitations in the context and environment of professional practices. Students, who do not present the functional perspective as a pedagogically, environmentally, and therapeutically relevant phenomenon referring to academic and knowledge-based theories ensuring a focus

on the lived and experienced citizenship, are more likely to put forward arbitrary reasons for reducing self-determination.

Professional development in a citizenship perspective is based on democratic and dialogical values and methods where students' experienced-based knowledge from practice represents resources for learning and development. The student assignments as a genre show that it is theoretical as well as ethical and practical knowledge from social educational curriculum that can contribute to ethical practices and focus on citizenship in the professional interaction. This concerns the use of phronesis; judgement and professional judgement as basic foci in social education (Ellingsen, 2014; Owren, 2020). Professional judgement can then be understood as an expression of practical wisdom growing from reflected experience (Ellingsen, 2014; Folkestad, 2014). Through reflection on students' own practice, it is possible to develop critical judgement to explore challenges that self-determination raises (Ellingsen, Halvorsen, & Aadland, 2020; Fjetland et al., 2019). As Wyller (2011) underscores, promoting citizenship in the education of professional practitioners presupposes ethical reflection that acknowledges and includes the voices of the citizens in question.

Although this study is based on a small numbers of bachelor theses and a particular Norwegian context, it can be argued that social education would benefit from strengthening ethical reflection connected to practical, professionally justified management of self-determination that promotes an understanding of universal citizenship. It can further be argued that a universal understanding of citizenship with a focus on the person's lived citizenship will promote the practical performance of citizenship for people with intellectual disabilities who depend on professional practices of welfare.

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A postscript by Ruth Bartlett

This anthology takes us into the sea of citizenship. Each chapter and every story in this collection is awash with currents of being, belonging and becoming a responsible member of society – an everyday citizen. To take the metaphor still further, it is as if each chapter serves as an anchor for understanding or affixing a different aspect of lived citizenship, which might otherwise be considered unremarkable. Reflect, for example, on the chapters which bring to the fore the agency, creativity and hopes of older citizens, citizens with chronic conditions, including dementia and persons with intellectual disabilities. For me, these are the pearls of this anthology. Not only do they bring to the surface the wisdom of people with disabilities, they advance understanding of how persons with disabilities *are living* citizenship, and the strength and assistance they need to do so on a day-by-day, hour-by-hour, minute-by-minute basis. The whole anthology serves as a welcome wave in the sea of citizenship, elevating scholarship by integrating the lived citizenship of persons with intellectual disability and people with dementia.

Very few (if any) pieces of work in the fields of citizenship, disability and dementia studies combine the experiences of older citizens, citizens with chronic conditions including dementia, and persons with intellectual disabilities in the way this collection does. There is some work in dementia studies on the experiences of people with intellectual disability who develop dementia, and some disability scholars might consider both groups when discussing topics like cognitive accessibility and attitudinal barriers, but overall, persons with intellectual disability and people with dementia are considered two separate groups in academic debate. Yet, as has been shown in this anthology, a lot can be learned and shared about the nature of lived citizenship when the experiences of older citizens, citizens with chronic diseases and dementia and persons with intellectual disabilities are integrated.

One advantage of including work about different citizens in a single collection is that those of us working in the often separated areas of disability and dementia studies have the chance to learn about ideas used elsewhere. Usually, one must look outside one's primary area of study – whether that is dementia, disability or citizenship studies – to discover new concepts, but here, with this anthology, it is possible to find them in one place. For example, the idea of "trauma-conscious understanding" was new to me but is perhaps a familiar one to those working with people with intellectual disabilities in Nordic countries. I valued learning about

this framework and how it is used in caring encounters with persons with intellectual disabilities, and immediately started to think about its transference potential to dementia studies. Maybe other readers will do the same, either in relation to this concept or one of the many others in this theoretically grounded text.

Reading this text reminds me of the joy that can come with discovering a philosopher. Having studied politics and cultural politics, I know of some influential political philosophers like John Locke, Thomas Hobbes, Luce Irigaray, and Hannah Arendt, but I am less familiar with philosophical works related to hermeneutics and phenomenology. In fact, it was not until I started to work in Norway, with the contributors of this collection, that I learnt about the significance of Paul Ricoeur on disability studies. It is clear from engaging with this work that Ricoeur has had a profound impact on understandings of the human experience and relationships. Unquestionably, this is one of the strengths of this collection: its embracement of philosophical ideas and concern with the meaning and practice of being human.

Because of this, a strong current in this collection is its attention to the existential. As one of the authors says, a focus on the existential is about understanding the core "aspects of humanness" – such as surviving and touch (p. 162). Reading about this deeply philosophical idea in relation to both persons with intellectual disability *and* people with dementia was welcome and refreshing because it took us to a place in citizenship that radical social model of disability scholars (i.e. those who focus on dismantling disabling barriers) do not tend to go. That place is individual identity. Take, for example, the photographs of the technologies that people used daily (such as a clothes hanger). These images and the related text helped the reader to understand not only the materiality of citizenship but also a person's identity and the nature of identity work. Further, it was possible to gain from these images, and the whole collection, the essence of being a person with a disability, and the things that people do to help them stay and feel alive.

Another important current in this collection is the value of stories and narratives. Virtually all the chapters in this text include an authentic account of life with a disability. Again, philosophical ideas are drawn upon here, in this case, the idea of "poetic instants" (p. 35) and they serve to extend understanding of the experience of disability. However, what I value most about the inclusion of these stories is the researcher's response to them, as they show our own citizenship and humanity. Here is an illustration. In Chapter 3, the author reflects on his experiences as a young man of working in a care home with older people with dementia and recalls an encounter with a resident that has stayed with him over the years, because it "opened up something in me and made me responsible". In my view,

such personal reflections highlight why so many of us are interested in lived citizenship for persons in vulnerable situations: it makes us question our own choices and essence.

Reading these personal reflections reminded me of the encounters I have had with people in a vulnerable situation over the course of my career. People with dementia have said or created things which have made me stop and question the choices I have made, or what I know – my article on "Visualizing Dementia Activism" published in *Qualitative Research* describes one such encounter. But going back to this collection, I think the encounters described in this work raise some important questions for disability/dementia/citizenship studies scholars, such as: why are some meetings so memorable and pertinent to us? What *is* it about the encounter that lingers for so long – only the words, or the feelings as well? What changes because of the encounter, for the person and the researcher? Anything? And perhaps most importantly, how can we harness this power that persons in a vulnerable situation seemingly have?

Power dynamics are an important current in this anthology, as they should be, it is after all a text on lived citizenship. What is noteworthy is how the text covers dimensions of power between not only people but also paradigms, ideas and disciplines. As the editors state at the start, the anthology seeks to provide a "dialogical perspective on citizenship" (p. 4) and it achieves this by including and bridging a wide range of perspectives, from Aristotle to theatre studies, from existentialism to science and technology studies, from poetry to enablement. As such, the collection has the potential to shape the future of citizenship studies by bringing to the fore the lived experiences of older citizens, citizens with chronic diseases and dementia, and persons with intellectual disability. Further, by referring to the work of well-known philosophers, such as Aristotle, as well as philosophical ideas, which are perhaps less familiar to citizenship scholars, such as "poetic instant", the anthology opens new avenues of research for the field.

As I said at the start of this postscript, this anthology takes us into the sea of citizenship. In a way, I think it provides a beacon of humanity in the voyage of discovery we are on as scholars working with persons in vulnerable situations. By delving into both the theories and practices of lived citizenship, the authors of this book have shown us the power and value of listening to those with something to say about the nature of human existence, whether those people are renowned philosophers or simply ordinary citizens with profound insights to share. Their thoughts and experiences are important to draw upon if we want a future that offers a meaningful existence for us all, including older citizens, citizens with chronic diseases and dementia, and persons with intellectual disabilities.

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The need for care and welfare services puts elderly and persons with intellectual disabilities, chronic conditions and dementia in vulnerable situations. How are they recognized as citizens with rights and duties? In this book, the challenges and resources for persons in vulnerable life situations are made visible through a relational and rights-based perspective of citizenship.

The chapters are based on the authors' studies of lived citizenship in different contexts within professional health and welfare practices and the everyday life of citizens in vulnerable life situations in Norway.

This edited book is the result of contributions from the interdisciplinary research group 'Citizenship', hosted at the Faculty of Health Studies at VID Specialized University. The aim of the research group is exploring and enhancing citizenship through theoretical as well as empirical studies. The book brings contributions to scholars and researchers in the broad field of interdisciplinary disability and citizenship studies, as well as graduate students.

This book is also available open access at Idunn.

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