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Ann-Charlotte Nedlund and Annika Taghizadeh Larsson

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To protect and to support: How citizenship and self-determination are legally constructed and managed in practice for people living with dementia in Sweden

Ann-Charlotte Nedlund and Annika Taghizadeh Larsson

CEDER—Center for Dementia Research, NISAL—The National Institute for the Study of Ageing and Later Life, Department of Social and Welfare Studies, Linköping university, Sweden

Abstract

Since living with dementia implies increasing difficulties in taking charge of rights due to cognitive as well as communicative impairments, many people with dementia are vulnerable and in need of support in order to realize full citizenship. In Sweden, all adults right to self-determination is strongly emphasized in law, regulations, and policies. Further, and in contrast to the situation in many other countries, people living with dementia cannot be declared as incompetent of making decisions concerning social care and their right to self-determination cannot legally be taken away. The article shows that in the Swedish welfare system, the focus is more on protecting the self-determination of citizens than on supporting people in making decisions and exercising citizenship. Subsequently, this causes legally constructed zones of inclusion and exclusion. This article examines and problematizes how different institutional contexts, legal constructions, norms, and practices in Sweden affect the management of issues concerning guardianship, supported decision-making and self-determination, and outline the implications for people living with dementia.

Keywords

Citizenship, self-determination, decision-making capacity, legal representative, Sweden

INTRODUCTION

An important part of claiming full citizenship is to be acknowledged as an independent individual with rights and as an actor in society. Pointing to the relevance of considering people with dementia as citizens and agents, and not just patients or care receivers, Kornfeld-Matte (2015)—the first UN Independent Expert on the enjoyment of all human rights by older persons—stressed that people with dementia are right-holders and that in all stages of the disease, “the voice and choice” of people with dementia should be heard. According to her, people with dementia have the right to live with autonomy and as independently as possible: this includes having access to “information and care in order to maintain and regain their wellbeing” and “to services to enhance their autonomy.” However, as living with dementia implies increasing difficulties due to cognitive as well as communicative impairments, people with dementia are vulnerable and in need of support in order to take charge of their rights and realize full citizenship. On an international level, this need is acknowledged in The United Nations Convention on the Rights of People with Disabilities, stating that all “parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (UN, 2006, article 12). This need for support is also recognized by Kornfeld-Matte (2015) stressing that people with dementia “must be able to receive adequate support to claim and exercise their rights” and that it is the responsibility of the welfare states and other stakeholders, who are the duty-bearers, to follow the obligations based on international human rights’ standards and principles.

Thus, as we will argue in this paper, to be regarded as an independent person with rights and also as an actor in society does not stand in contrast to being in need of support from the

welfare system. Instead, access to support from the welfare system can be considered as one of many ways of protecting each citizen.

However, the issue of supporting people with cognitive impairments in claiming and exercising their rights as citizens has different legal construction in different countries. In Sweden, people with dementia are, formally, to be considered as independent individuals with the same rights as other adult citizens and as actors in society. That is, all adults' right of self-determination is strongly emphasized in law, regulations, and policies. Further, adult citizens cannot be declared as incompetent of making decisions concerning social-care services or residential care and their right of self-determination regarding these issues cannot legally be taken away. Consequently, matters of supported decision-making are largely unregulated.

This means that Sweden differs from many other countries in how issues of supported decision-making and cognitive impairments are legally constructed. In other countries, such as England, Wales, Scotland, Northern Ireland, and Canada, capacity assessments are prescribed in law, and defining adult people who are assessed as lacking decision-making capacity as non-fully capable citizens, is considered a form of protection (see, for example Boyle, 2008; Davidson et al., 2015; Wilkinson, 2001). For example, the Mental Capacity Act (MCA) 2005 in England and Wales seeks to empower people as long as they maintain capacity and protect them when they lack the capacity to make a certain decision (Boyle, 2008, 2010; McDonald, 2010). According to the act, “a person's capacity must be assessed specifically in terms of their capacity to make a particular decision at the time it needs to be made” (Department for Constitutional Affairs, 2007, p. 40). In Swedish legislation, the challenges in allowing people with dementia the greatest possible freedom—while at the same time preventing them from being harmed—are subordinate to the issue of self-determination.

Comparing Sweden to other countries, these differences indicate that different legal system/jurisdiction encompasses different ideas and constructed “zones of inclusion and exclusion” and provide different directions as to how these should further be managed in practice. Consequently, zones of inclusion and exclusion can be constructed both legally and in practice and these zones do not necessarily correspond. It is noted however that in practice these intentions might be interpreted and become realized in ways that might differ from the legal intentions and this too requires further understanding.

Subsequently, the construction of citizens and the meaning of citizenship, in Sweden as in other countries, are constantly under negotiation and interpretation, and therefore undergoing change (Nedlund, 2016). Legislations are powerful means to influentially institutionalize, legitimize, and also change, social constructions of citizens and citizenship in a democratic context (Nedlund & Nordh, 2015; Schneider & Ingram, 1997; Stone, 2002). For example, one of the ideas with MCA was to constitute people with dementia as subjects ruled by a legal discourse and regulated by democratic principles. By that, people with dementia should not formally be dependent on discretion by, for example, professionals or care managers, but have rights that can hold decision-makers to account (McDonald, 2010). These matters do not only revolve under the formal realms of life but also outside the formal legal and political domain. Though, the legal constructions are powerful means in drawing lines between, for example, the public such as the responsibility by the welfare system and the civil society, a good citizen and a deviant (one), citizens and non-citizens, and further, to regulate, structure, and organize the society, and the welfare services based on these constructions.

International variations on how issues concerning self-determination, supported decision-making, and dementia are legally constructed are seldom acknowledged in the literature.

Research on decision-making practice in relation to dementia has so far mainly focused on formal aspects such as legal capacity assessments (O'Connor & Purves, 2009) or on informal decision-making among relatives of people with dementia preceding relocation to residential care. Furthermore, the formal and legal context of the informal assessments or decisions in question has seldom been acknowledged. Instead, most research in the area seems to be based on the assumption that this aspect is known to the reader and/or that the same legislative system and organizational structures apply in all countries (Taghizadeh & Österholm, 2014). Thus, knowledge is needed on how people with dementia are supported in exercising their citizenship in different parts of the world, and within varying forms of explicit, legally constructed zones of inclusion and exclusion.

Given the challenges embedded in supporting people with dementia in taking charge of their rights and realizing full citizenship, an important issue that needs further exploration is if and how existing variations concerning legislative intentions and formal forms of supported decision-making may be traced in the way people are actually supported—or not—in *practice*. This paper is to be seen as one step in this important endeavor.

The aim of this paper then is to examine and problematize how self-determination in cases of decision-making incapacity is legally constructed and managed in practice in Sweden. The paper describes legal intentions that are in play in the case of adults in need of support in making decisions in Sweden, and sheds light on the tensions between these intentions and how issues of decision-making incapacity, supported decision-making and autonomy are managed in different contexts and by different actors. Sweden serves as an interesting and appropriate case due to its relative uniqueness because of its fundamental lack of rules associated with decision-making incapacity. Based on the Swedish example, the purpose is to

foster (more) informed reflections and guidance on how to proceed in order to strengthen the content of citizenship for people with dementia. This paper also contributes to the theoretical debate concerning how constructions of citizenship shape people's decisions and situations in everyday life.

In the following, we will elaborate on the matter that arises with incapacity to make decisions. We will then outline the legislation in Sweden and how support in instances of decision-making incapacity is regulated in terms of forms of legal representatives, and substitute decision-making. Later sections will explore how the dilemma concerning self-determination and decision-making incapacity inherent in the Swedish system is handled in practice. Implications for people with dementia in situations of decision-making incapacity from a citizenship's perspective will then be outlined.

SELF-DETERMINATION AND DECISION-MAKING INCAPACITY

The right to self-determination is central in the Swedish democracy and welfare system and is protected and highly emphasized in Swedish legislation. The Swedish welfare system is based on an assumption of active citizens which presuppose that everyone, including people living with dementia, can take in information well enough to participate in public reasoning and formulate their voice when meeting with welfare-state institutions. This idea is clearly visible in the final report by the Government Commission on "A Sustainable Democracy" (SOU 2000:1) which states: "Every social group should be involved in [formulating] the politics, which should not be formed by a few while others are excluded" (p. 210). Self-determination is also clearly highlighted in the initial paragraph of the Social Services Act¹ (SSA) that states

¹ In Swedish: "Socialtjänstlagen".

that the work in social services “should be based on respect for people’s self-determination and integrity” (SFS 2001:453).

In practice, self-determination and decision-making cover matters related to our life-style choices including where we want to live and with whom, what medicines we want to take, and how we want to spend our money. That does not imply that the decision we make is always the best. On the contrary, many times decisions might, in hindsight or in the view of others, appear ill-considered and unwise. There is however a general understanding that we have the right to make mistakes, and make “wrong,” “bad,” or unpopular decisions: such mistakes and wrong decisions do not necessary imply that one is regarded as having an incapacity to make one’s own decision. Decision-making incapacity implies that someone is lacking capacity “to understand, to take a standpoint on and make decisions concerning important matters in their daily lives” (Klemme Nielsen, 2012). In our view, decision-making incapacity is also about lacking capacity in understanding, reasoning, and planning so that one cannot protect one’s own interests well enough being responsible for one’s decisions; getting an overview of one’s decisions in relation to what one wants to do and to ones values; and further, to act based on all these considerations.

While the phenomenon of decision-making incapacity is clearly and explicitly acknowledged in some countries, for example in the UK through the MCA, even to use the concept of decision-making incapacity is controversial in a Swedish context where the state so strongly emphasizes the freedom to be self-determinant that no criteria for decision- making incapacity even exists in the Swedish legislation. To use the concept of decision- making incapacity means to explicitly acknowledge that there are situations when people cannot or should not be allowed to make a decision by themselves in a specific matter since they are lacking the

capacity to do so—this runs counter to values underpinning Swedish legislation (or lack thereof).

One could, on the one hand, argue that using the concept of decision-making incapacity and acknowledging that not everyone has equal conditions to make a decision automatically weakens some citizens' positions and prospect of having influence. But, on the other hand, if the point of departure is that every citizens' interests are always best considered if they are allowed to speak for themselves, and if one too narrowly and too firmly distances from the idea of representation and guardianship and substitution in all its various grades, it could imply that no one could speak for those particular citizens and/or of those social groups in cases when they cannot do it for themselves. In a similar argument, it has been described as a paradox that in some situations and for some social groups in Swedish society, there is a need for stronger protection and paternalism in order to increase the autonomy of these people (Lewin, 1998). Commonly, the relation between these two ethical principles, autonomy (self-determination) and protection, is described as a fundamental tension (Moye & Marson, 2007). It also creates a tension between the assumption of capacity and the normative idea of active citizenship, that everyone is presumed competent and having capacity to be active, and on the fundamental idea of a welfare system—and a view of society as a safety net if its citizens fall.

It is of importance to have in mind that for a person living with dementia, this incapacity is not necessarily global—rather it pertains to specific decisions—and it can vary over time. In other words, people living with dementia may still be able to make some decisions, with or without support, dependent on the complexity of the matter, the situation, and the context (see e.g. O'Connor & Kelson, 2009; Wilkinson, 2001). Furthermore, it is important to emphasize that the criteria for assessing and judging whether someone has the capacity to make decisions

and therefore should have the right to self-determine, versus having decision-making incapacity and therefore being in need of someone to assist, represent and guard the person's interests or substitute in the sense of taking over the person's self-determination (cf. O'Connor, 2010), are not simple or once and for all defined. But still judgments of decision-making incapacity, based on interpretations of what is understood as reasonable in the specific case, are constantly made in practice by, for example, professionals such as care-managers. Accordingly, what we can see here it is an ambiguity inherent between *how to protect* and *how to support* people with decision-making incapacity in order to enhance their citizenship — complicated matters found in both legal regulations and in practice.

THE LEGAL AND ORGANIZATIONAL STRUCTURE IN SWEDEN

In Sweden, in law and regulations, people with dementia have the same right to self-determination as other citizens and cannot be declared as incompetent of making decisions. In other words, unlike many other countries, there are no legal processes available to overturn an adult person's right to self-determination. The Swedish democracy and welfare model is based on the strong normative idea of active citizenship that assumes everyone, including people who are frail and having a disability, can participate in public debate and make their case in meetings with welfare institutions. But in practice, in actual situations, when a person cannot or should not be allowed to make decisions on a particular issue, someone has to step in and make decisions for this individual; that is, step in and represent or substitute for her or him in the sense of taking over the person's self-determination. The question is how the issues of decision-making incapacity, supported decision-making, and autonomy on a more detail level are regulated and legally constructed in Sweden, and indeed whether these issues are acknowledged in laws and regulations at all.

To understand what this looks like, several aspects of Swedish law will be examined. The provision of social care (e.g. special housing and home assistance) and the provision of health care for people with dementia are primarily regulated in the SSA and in the Health and Medical Services Act² (HMSA, SFS 1982:763). The Act concerning Support and Services for Persons with Certain Functional Impairments³ (SFS 1993:387) is a so-called special law that complements the SSA. SSA and HMSA are different in their character but are both framework laws, meaning that general obligations and principles are stated but the regional and local governing authorities have the discretion to enact further legislation and other specific measures as may be required. The SSA embraces the individual's rights to care and services as well as the responsibilities of the care principals. The HMSA, on the other hand, does not include regulations concerning the rights of the individual but only the responsibilities of the health-care principals. Both laws are based on the free will of the individual to receive care and support, thus consent is always needed by the individual in concern.

The SSA which is the law that covers social care for people with dementia states that “one who cannot provide for one's own needs or have them provided in any other way is entitled to assistance from the social welfare authority for one's maintenance (income support)” and “one's way of life in general” to ensure a “reasonable standard of living” (SFS 2001:453, Section 4, §1). Furthermore, the authorities responsible for social services must ensure that older people in need receive adequate housing, support and home assistance, and other “easily accessible” services—the latter means that the social service must be organized so that the elderly really receive the service they are in need of. In the Swedish welfare system, it is the municipalities who are the principals responsible for arranging special housing and

² In Swedish: ”Hälso- och sjukvårdslagen”.

³ In Swedish: “Lag om stöd och service till vissa funktionshindrade”.

social care for older people in need of support. While individuals are entitled to assistance, SSA rests strongly on the basic idea that no compulsion or force should occur within the provision of social services (cf. Section 3, §5). Instead, activities covered by the SSA should be characterized with respect for an individual's self-determination and integrity. Also, according to SSA, the individual has to apply for care and support personally. This means that an older person shall as far as possible be able to choose when and how — or even if — support and assistance will be provided.

While adult persons, in this case people with dementia, cannot be declared as incompetent of making decisions, there are unique cases where some compulsion for over-riding of self-determination is possible. Three pieces of legislation apply here: The Code of Penalty⁴ (SFS 1962:700), the Patient Act⁵ (SFS 2014:821), and the Compulsory Mental Care Act⁶ (SFS 1991:1128). The Code of Penalty (SFS 1962:700) has a paragraph of necessity that can be used and interpreted in cases of compulsion and force concerning care, which in some areas is complemented by governmental regulations and guidelines. In exceptional cases and in situations when it is completely out of question to communicate with the person in question to receive their opinion on a treatment, paragraphs of necessity may be used as a legal basis for effectuating forced medical treatment such as in the case of an emergency and if the treatment may be considered justified (Government Committee Directive 2012:72; SOU, 2015:80).

However, it is noted that the paragraphs of necessity in The Code of Penalty permit inadmissible acts only when life or health is threatened. The intention with the paragraphs of necessity, as the term also indicates, is that they should only be applied in case of emergency, and only for as long as the emergency lasts. Because of these conditions, these paragraphs are

⁴ In Swedish: "Brottsbalken".

⁵ In Swedish: "Patientlagen".

⁶ In Swedish: "Lag om psykiatrisk tvångsvård".

difficult to apply in situations of dementia, at least in a long-term perspective and particularly when it comes to social care (Government Committee Directive 2012:72; SOU, 2015:80).

A second piece, the Patient Act (SFS 2014:821), allows in Section 4, §4, an exception of the main principle of consent, to give health-care treatment to a person who is not capable to give consent in case of an emergency. This passage however is not valid when the situation is no any longer an emergency even if the patient is still not capable to express her/his will.

Therefore this passage cannot be applicable to continuously provide health care to a person who has enduringly decision-making incapacity that is not of emergent character (SOU, 2015:80).

A third piece of compulsory care legislation is found in the Compulsory Mental Care Act (SFS 1991:1128) and this allows people with serious mental illness to be taken into care against their will in cases where there is a risk to the individual's own life or health or for the safety, physical or mental health of others. As such, the Compulsory Mental Care Act does not apply to people living with dementia except in cases where the individual is considered to have a serious mental illness (SOU, 2004:112; SOU, 2006:110; SOU, 2015:80).

Different forms of legal representation and substitute decision-making in Sweden

So, aside from these three legislation pieces, where over-riding self-determination was possible in emergencies, are there any laws and regulations on how to respond to the actual need of adult people in need of social services or residential care in situations of decision-making incapacity, such as people who are living with dementia who are in need of support and protection in order to exercise their legal capacity and rights as citizens? In other words, what are the legal arrangements available for people in need of support and protection without over-riding their self-determination?

In Sweden, there is a system of representatives available with the task to protect vulnerable adult citizens. These are Special Representative⁷ and the Legal Administrator⁸. Another legal institution that can be used is the Power of Attorney^{9, 10}. However, as we will see, the role of these representatives is advocated on behalf of the citizens in concern and should not act on the representative's own judgment or discretion (SOU, 2015:80). By that, they cannot overturn someone's right to self-determination.

A Special Representative can assist the person in making decisions and in protecting rights and interests, concerning issues such as private finances and ensuring that she or he gets adequate care. With the intention to represent without depriving the person of their autonomy and right to self-determination, the Special Representative is a unique arrangement internationally and is based on the idea that every adult citizen should have equal rights, regardless of her/his decision-making incapacity (SALAR, 2011). In order to be appointed a Special Representative, it is required that the person (with dementia), legally called *the principal*, has a medical condition that entails a need for support, for example to assist with the payment of bills and take care of things that she or he owns. In principle, there should be consent, but if there is a medical record in the patient journal, consent is not, in practice, always necessary. Another form, so-called *Full Special Representative*, comprises three areas managing the property owned by the person in need, protecting his or her rights, and providing for him or her as a person. The arrangement of a Special Representative is based on the principle of the least intrusive measure, which means that a Special Representative should be appointed *only* if the person's needs cannot be met in any other way (SALAR, 2011).

⁷ In Swedish: "Godmanskap" and/or "God man".

⁸ In Swedish: "Förvaltarskap" and/or "Förvaltare".

⁹ In Swedish: "Fullmakt".

¹⁰ The English terminology is taken from the Swedish National Courts Administration.

The same is true for a *Legal Administrator*. However, the Legal Administrator is a coercive measure by society and can, unlike the Special Representative, be enforced by the district court against the person's will. Whoever gets a Legal Administrator loses all rights to act in "what the administration encompasses" (cf. SALAR, 2011). A person who has a Legal Administrator must have the consent of the administrator to conclude contracts, and the Legal Administrator has sole control of the property subject to the administration. Thus, a Legal Administrator can be regarded as a formal form of substitute decision-maker covering financial and property matters. Important to note is that neither the Special Representatives nor the Legal Administrators have the right in law to decide on social-care services or residential care nor the majority of issues concerning health care (SOU, 2015:80). The explicit references here to the person in concern (in this case, the person with dementia) as "principals" bear an implicitly "contractual" notion to a person as agent that refers to "actorness" and autonomy of an individual.

Several actors are involved in legally securing these different forms of representative. The authority of social services is not allowed to represent people but is obliged to notify the *Municipal Board of Chief Guardians*¹¹ if they consider that the person is in need of a Special Representative or Legal Administrator (SALAR, 2011). The *District Court*¹² appoints the Special Representative and Legal Administrator, but it is the role of the Municipal Board of Chief Guardians to investigate the need for a Special Representative or Legal Administrator. As a rule, the Municipal Board of Chief Guardians turns to the responsible unit of social services for details on the principal's needs. The Municipal Board of Chief Guardians is also responsible for the supervision of the Special Representative and Legal Administrator. The

¹¹ In Swedish: "Överförmyndarenheten".

¹² In Swedish: "Tingsrätt".

*County Administrative Boards*¹³ have a supervising role for the Municipal Board of Chief Guardians and also support Chief Guardians in promoting the law (SOU, 2013:27). All these actors have the task to monitor and guarantee that the principal's right to self-determination is not over-ridden.

Power of Attorney (SFS 1915:218)¹⁴ is another form of legal institution that can be used when making decisions on behalf of someone. However, Power of Attorney is only legally applicable in cases when individuals retain their capacity to decide and consequently does not—legally speaking—apply in situations of decision-making incapacity or in cases where a person's decision-making is considered inadequate or if the person loose capacity (Rynning, 1994; SOU, 2004:112; SOU, 2015:80).

Furthermore, in Sweden, family members, next of kin or friends have no legal authority to act as surrogates or to consent to health care, social care, and long-term care against the will of the individual, independently if they have legal representation or not (Ministry of Health and Social Affairs, 2012). The authorities' role of social services is also limited. According to SSA, HMSA, Act concerning Support and Service, support and services may be granted upon request and according to needs, but shall not be provided against the person's will. Also, the formal application must come from the person in need of support, no one else can apply for social services without the person's consent.

Thus, in the Swedish welfare system, there are a number of legal arrangements, which to varying degrees compensate for the vulnerability of people, and support people in situations of decision-making incapacity. However, there is no arrangement that gives someone the right

¹³ In Swedish: "Länsstyrelsen".

¹⁴ Regulated in the Contracts Act, in Swedish: "Lag om avtal och andra rättshandlingar på förmögenhetsrättens område".

over the long term to decide for a person living with dementia, concerning health care and/or social-care services or residential care. Self-determination can only be over-ridden in the context of an emergency.

TO REPRESENT AND SUPPORT IN PRACTICE

What becomes even more difficult in practice is that there are no specific rules or guidelines, apart from the rules covering financial management, on *how* an appointed Special Representative or Legal Administrator should reason or act in situations when they have consent to make decisions for or support a person with decision-making incapacity. Some guidance is provided by the Children and Parents Code¹⁵ which states that a Special Representative or a Legal Administrator shall always act in the "best interest of the individual" (SFS 1949:381, section 12, §3). However, comments or clarifications regarding the meaning of this formulation are lacking in the legal preparatory work and in the statute comment (Government bill. 1993/94:251, p.211; Walin & Vängby, 2010). Moreover there are questions as to whether this applies to a citizen who is an adult and of legal age. Furthermore, existing handbooks for Special Representatives and Legal Administrators do not discuss how the person who steps in and substitutes should reason when she or he makes a decision for a person who lacks decision-making capacity (c.f. Dahlstedt & Björnfeldt-Rex, 2007, Sehlin 2005). To sum up, how Special Representatives and Legal Administrators should act in relation to decision-making is not accounted for, nor is their direction regarding how "the best interest of the individual" should be interpreted. Moreover, the formulation "the best interest of the individual" implies an additional challenge, except the drift between law and practices, which concern the expectations and the role of the representatives intended in law. Hence, it seems like there is also ambivalence regarding what mandate the different arrangements of

¹⁵ In Swedish: "Föräldrabalken".

legal representatives should have when acting in “the best interest of the individual”. This can be compared with other countries, for example, the MCA (2005) in England and Wales, where, similar to Sweden, the best interests of people with decision-making incapacity is stated as the so-called decision norm, but where it is also stated in detail what sort of information and which considerations the representative, guardian or substitute should, and should not, take into consideration in their decision making.

Those who have to deal with this problematic situation in practice are those people living with dementia and their relatives, public servants (working at different levels in the public administration and with various professional backgrounds), Special Representatives, and Legal Administrators, among others. These actors have to consider and handle different kinds of pressures to follow the law and rules, to be loyal to superiors and others in the organization, to consider their professional knowledge, and to respect the citizen (Lundquist, 1998; Nedlund, 2012). Daily, they are handling concrete situations, meeting people with various conditions where they have to handle these pressures and judge what to do in this ethical dilemma: how extensive their judgements and actions are is dependent on professional discretion which, in practice, can be more extensive than is formally regulated (Lipsky, 2010; Nedlund, 2012; Wagenaar, 2011). These types of pressures and role-conflicts can also be identified, not only in the actors closest to the citizens, as street-level bureaucrats, but also in politicians and senior administrators who have to balance these when they are implementing law into local policy documents and guidelines (Nedlund, 2012). Doing this involves handling tensions, concerning supported and substitute decision-making, and self-determination, which are incorporated in the Swedish welfare state, the legislation, and the practice.

To illustrate these tensions we present a quote from an ongoing project exploring the care-managers' dilemmas and strategies encountering people living with dementia (c.f. Nedlund et al, 2016; Nordh & Nedlund, forthcoming). In this borderland of ideas and practice the various actors have to find creative solutions for handling these tensions.

... sometimes we give support even if the person explicitly says 'no', we do that since there is some kind of paragraph of necessity...I think, I don't know where exactly, but ..but if it's obvious that the person does not eat, for example, and that you see that that's the case, it could be that we make an order to the home services to leave a food box on the door, and if it is gone the next day or so, one could interpret that it's some kind of consent. (Care-manager Karin)

The quote here — which should not be read as a finding of this article but simply as an illustration — shows that it can sometimes be ethically challenging for professionals to know *how* things should be done. It is a tough task to balance the different pressures that might be in conflict, such as respecting self-determination rights and consent versus considering the person's situation and provide protection. For these various actors, in legally vague situations, it is especially unclear how to act which risks creating a practice that differs between individual professionals as well as local authorities. How people should be treated in situations of decision-making incapacity within a welfare system that is responsible for protecting its citizens and that, at the same time, is based on an idea that every citizen should participate and give their voice, is without doubt an unclear, ambiguous, and fuzzy situation (see Nedlund et al., 2016; Nordh & Nedlund, forthcoming).

An implication of this is that there is great variation in scope in what is actually happening in the meeting between people with dementia and representatives of the welfare-state institution. Apart from separate reports (as Magnusson, 2013), and studies that are in progress at the moment at CEDER — Center of Dementia Research (e.g. Nedlund et al., 2016; Nedlund &

Taghizadeh Larsson, 2016; Nordh & Nedlund, forthcoming; Österholm et al., 2015), there is a knowledge gap — we know very little about the practice of public servants and other actors in supported decision-making and dementia in Sweden. This is also the case for possible variations between and within various authorities. Furthermore, since the legal systems differ in different countries (Boyle, 2010; Sokolowski, 2010), we cannot infer from individual studies on one context “how things are” in another one. We need more country specific studies as well as comparative ones.

THE GREY AREAS OF SELF-DETERMINATION AND SUPPORTED DECISION- MAKING

This paper has explored the matter of how self-determination and supported decision-making is legally constructed and managed in practice for people living with dementia in situations of decision-making incapacity. Specifically, it is about matters that become clearly visible in vital choices from large decisions such as who should decide about a move to a residential home, to daily and iterative decisions. An important point of departure for this paper has been to shed light on the individual’s exposure on legally constructed zones of inclusion and exclusion and explain how these constructions further regulate, structure, and organize the practice.

As we have shown, no-one, including Special Representatives, Legal Administrators, health-care professionals, social-care staff or relatives, are allowed to act against the will of a person living with dementia since an adult person living with dementia is regarded as a full legal agent. In other words, in Sweden, there is currently no formal arrangement that gives someone else the legal right to decide, even for an adult in situations of decision-making incapacity, on interventions in health care or social care, except in cases of necessity in

emergency situations. Thus, there is a discrepancy between what is legally allowed concerning restrictions of someone's right to self-determination and the actual needs of many people with dementia who may require someone who can support, represent, or substitute for her or him in making these decisions. Another way of viewing this discrepancy is that in Sweden, the idea of the individual's right to self-determination is considered as particularly important but risks being over-ridden since there are no further regulations or guidance on how to support or how to protect in situations that could well correspond to a person living with dementia. As an example, the need of social care by a person living with dementia risks being totally overlooked since no one else has the right to step in to support or protect the person and apply for social care. Therefore, the legal intention is to protect citizens by laws emphasizing individual autonomy, and which refrain from restrictions on people's privacy and reduce the risk that decisions are taken against a person's will. The focus is more on protecting the citizens' right to self-determination than to support people in making decisions and exercise citizenship.

What is paradoxical is that in Sweden, legally constructed zones of inclusion imply that various actors encountering people who are living with dementia, in practice, have to act in ways that are incompatible to the Swedish legal premises. The legislation does not acknowledge or give enough guidance to situations where people with dementia, or others with similar conditions, cannot live up to the idea that every citizen should be involved in the public reasoning and give voice in their meetings with the welfare-state institution. Hence, the problem remains hidden and needs to be handled in practice in ways that may create tensions and dilemmas. Moreover, this discrepancy paves the way for the emergence of gray areas where professionals and family members may be acting under arbitrary and uncontrolled conditions and, where individuals are not protected by

law. The law is also clear that family members, relatives, or actors from the civil society do not have legal authority to act as surrogates or to consent to health care, social care, and long-term care against the will of the individual. Also, the intention is clear in the sense that the person's capacity should always be in focus. However, the wide scope for practical adaptation that the legislative construction entails carries the risk of variations that may threaten the governing ideas of equality and the individual's right to protection. But the scope also provides flexibility for staff to adjust to the person's individual needs and the particular circumstance concerned: it gives professional discretion to assess the person's need and create appropriate solutions based on professional expertise.

This means that people who are involved in the various parts of the everyday life of the person living with dementia are in different ways in search of and finding consent, either verbally or by the actions of the person living with dementia (see also Nedlund et al., 2016; Nordh & Nedlund, forthcoming). In this, consent becomes the important key to bridge and overcome the gray area between the legal intentions and the practice.

In summary, and as the Swedish case illustrates, it is complicated not only to limit but also to refrain from limiting the autonomy and self-determination of adults by legislation. Embedded in current and internationally varying legally constructed zones of exclusion and inclusion are various considerations, such as the balance between freedom and security, the welfare system's responsibility, and obligation to protect vulnerable individuals and social groups versus limiting autonomy and self-determination, and between consent and constraint. But also between having general and flexible rules or more rigid rules with the former giving scope for individually

designed support and for taking into account the person's circumstances and capacity to make decisions, to take charge of their rights and consider their interests while the latter seeks to provide concrete guidelines and reduce the ambiguity on how to act. Clearly, we can see that there are challenges inherent in how to protect but also how to support people living with dementia in order to enhance their citizenship—these matters we can find both in legal regulations as well as in practice. Also, these legal constructions related to the right to (or the limitation of) self-determinations are akin independently if the support is organized based on the notion of citizenship or from a human rights-based approach. Legal constructions are powerful means to influentially institutionalize, legitimize, and also change, social constructions of citizens and citizenship in a democratic context and further in shaping people's decisions and actual situations in everyday life. To have power to participate and to influence in shaping the construction of citizenship and the actual citizenship content, or to have support in having voice and realizing this, are necessary in order to be acknowledged as an agent in a welfare system and further as a citizen living with dementia in a democratic society.

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Author Biographies

Ann-Charlotte Nedlund is a lecturer of Politics and Policy Analysis in Aging and Later Life at NISAL (National Institute for the Study of Ageing and Later Life) and CEDER (Centre for Dementia Research), Department of Social and Welfare Studies at Linköping University, Sweden. She is also affiliated to the Division of Health Care Analysis and to Medical Education-Interprofessional Learning, both at Linköping university. She has initiated and is a coordinator of the International Research Network on Citizenship and Dementia. At CEDER she is a coordinator of the research group Citizenship and Dementia. Her research primarily concerns issues related to citizenship, legitimacy, democracy and the welfare system. Special interest comprises how the conditions for citizens with dementia to practise their citizenship are regarded and realised, and further, how various institutional settings, norms and values, different ways of organising, practising and participating construct what becomes the citizenship content for people living with dementia.

Annika Taghizadeh Larsson is senior lecturer in Ageing and Later Life at NISAL (National Institute for the Study of Ageing and Later Life) at Linköping University, which is an interdisciplinary research institute focusing on the interplay among the cultural, social, health, and technical aspects of ageing in a changing society. She is also linked to CEDER (Center for dementia research), which is a large six-year programme with the ambition to conduct social scientific and humanistic research around persons living with dementia diseases.

Annika Taghizadeh Larsson's research comprises questions and issues at the intersection of social gerontology and disability studies. At CEDER she is part of a research group focusing on how the conditions for citizens with dementia to practise their citizenship is regarded and realised.