



Crafting citizen(ship) for people with dementia: How policy narratives at national level in Sweden informed politics of time from 1975 to 2013



Ann-Charlotte Nedlund*, Jonas Nordh

Center for Dementia Research (CEDER) & National Institute for the Study of Ageing and Later Life (NISAL), Department of Social and Welfare Studies, Linköping University, S-601 74 Norrköping, Sweden

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ABSTRACT

This article explores how policy narratives in national policy documents in Sweden inform associated politics on people with dementia. This is disentangled in terms of how people with dementia have been defined, what the problems and their imminent solutions have been, and if and how these have differed over time. Based on a textual analysis of policy documents at national level in Sweden, covering nearly 40 years the study shows how divergent policy narratives shape the construction of citizens with dementia as policy target groups. This study shows the temporal character of people with dementia as a political problem, the implications of policy narratives on people with dementia as a citizen group, and policy narratives as something being crafted rather than shaped by fixed pre-existing “facts”. Dementia, and further citizens living with dementia, does not have a once and for all stabilised meaning. Instead, the meanings behind the categories continue to evolve and to be crafted, which affects the construction of citizens living with dementia, the space in which to exercise their citizenship and further belonging to the society.

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Introduction

This article focuses on how policy narratives in national policy documents in Sweden inform associated politics and further the space within which people with dementia can exercise their citizenship. Utilising a citizenship perspective in order to study and problematize situations for people living with dementia, has received increasing attention during the last decade. Significant interest followed Bartlett & O'Connor's (2007) article, where they presented their ideas of using a “citizenship lens” to gain a more appropriate understanding into dementia research, by recognising a person living with dementia as an active agent with the right to be self-determinant, formulate their own goals and have power over their own lives. In dementia research, the citizenship lens is in contrast to the two dominant perspectives: the biomedical lens

(cf. Ballenger, 2006), where people with dementia are depicted as “sufferers” with substantial care needs, the solution to which is finding medical treatment in order to cure or ease the medical condition, and to the personhood lens, where dementia is regarded as a unique personal experience of living with dementia dependent on unique biopsychosocial factors (cf. Kitwood, 1997).

An increasing body of research problematize citizenship and social exclusion of people with dementia, due to an existing understanding within their surroundings that they are incapable of participating in social interactions (Baldwin, 2008; Behuniak, 2010, 2011; Gilmour & Brannelly, 2010; Brannelly, 2011; Kelly & Innes, 2013). Other studies shed light on citizenship from a legal perspective related to aspects of self-determination (Boyle, 2008; 2010; 2011; 2013). Another type of problematisation is how citizenship can be practised through self-help groups, the ombudsman and by people living with dementia as active co-researchers (Bartlett, 2012; Örvulv, 2012). Studies have also problematized the institutional meetings

* Corresponding author. Tel.: +46 70 085 06 06.
E-mail address: ann-charlotte.nedlund@liu.se (A.-C. Nedlund).

between care managers and people with dementia from a citizenship perspective (Österholm & Samuelsson, 2013; Österholm & Hydén, 2014; Taghizadeh Larsson & Österholm, 2014). However, there are still few studies that seek to problematize the role of national policies in order to increase the understanding of how policy narratives have constructed people with dementia as policy targets and service users, and the further implications on claiming citizenship. Baldwin (2013) touched upon it by analysing the narrative features of the UK's National Dementia Strategy (NDS) and its related documents. His analysis shows the persuading character of national policy documents with a dominant and univocal view of dementia within a narrative medical model, although the voices of several diverse stakeholders had been incorporated. As Baldwin concludes, "the NDS opened up space for stories to be told about certain aspects of dementia and closed down opportunities for other stories." (Baldwin, 2013:82).

Collective narratives are powerful, they can influence the "assumptive worlds" that service providers convey into their professional/occupational tasks (Wilson, 1991). Thus, by identifying dominant stories as well as excluded voices, the study of policy narratives gives us some information on how and whether people with dementia can practise their citizenship. The present article attempts to bridge this knowledge gap.

The purpose of the present paper is to explore how policy narratives in national policy documents in Sweden inform associated politics on people with dementia. This is disentangled in terms of how people with dementia have been defined, what the problems and their imminent solutions have been, and if and how these have differed over time. The study is based on a textual analysis of policy documents at national level in Sweden, covering nearly 40 years. The study contributes to the theoretical debate on the dynamic process and the temporal character in handling a political problem, the implications of policy narratives, and further how the ambivalent framing affects the construction of citizens, the citizenship content and space within which people with dementia can exercise their citizenship.

Understanding citizenship as shaped by policy narratives

Citizenship is commonly referred to as an agreement between the citizens and welfare authorities that typically include civil, political and social citizenship rights, as well as duties (Marshall & Bottomore, 1950/1992). However this view has been contested where citizenship also encompasses dimensions, such as how people experience themselves in collective and cultural terms, and highlights dimensions such as identity, solidarity with others, social membership, belonging, the politics of recognition and by being a political actor in a community (Bosniak, 2006; Lister, 2003; Kymlicka, 2001; Isin & Turner, 2002; Yuval-Davies & Werbner, 1999). In this way, citizenship concerns not only the relationship between the state and the citizen, the relationship between citizens, but also the meaning of belonging and the practice of political enactment in claiming rights in society, including its various policy areas.

The meaning of citizenship and the construction of citizens are constantly under negotiation and interpretation, and therefore undergoing change. Public policies are primarily means whereby government can influentially institutionalise, legitimise and change social constructions of citizenship and

citizens (Hajer, 1993; Schneider & Ingram, 1993a,b, 1997). The policy process relates to the construction of political problems where the construction of policy areas, targeted groups, goals and appropriate solutions do not come into being until they are recognised as political problems. Policies are not mirrors of reality; rather they create meaning and give a specific question a particular value (Bacchi, 2009). The process in which problems and their imminent solutions become recognised and thereby legitimate, is a struggle over ideas and interests where various actors compete (Stone, 2002).

An important element in this process is policy narrative. Policy narrative is a powerful tool used to shape beliefs and actions (Roe, 1992; 1994; Jones & McBeth, 2010; Jones et al, 2014). Policy narratives rest on particular understandings of causes, dynamics and knowledge claims about problems, and a means to present reality in such a way that it becomes a more coherent whole than is possible in practice. What can be considered a problem will depend on the narrative in which the problem is debated. Hence, narratives drastically simplify the phenomenon they are seeking to steer (Boswell et al, 2011). The presentation of narratives is often in order to see problems as facts, as originating from natural forces even though they do not need to be factual to a full extent, or at all. By doing so, the problem and its solution are more likely to be accepted and thereby close the debate. They contain "causal stories" which construct causality portraying the evolution and causes of the problem, including its imminent solution, in ways that are comprehensive and convincing (Stone, 1989). In this way narratives offer reasons for requisite acting in certain situations and serve to legitimise a particular political course of action (Hajer, 1993; Roe, 1992; 1994; Waagenar, 2011). The narrative in which a problem is presented will also draw on former or existing solutions to similar problems (Hajer, 1993; Atkinson, 2000). In that sense, policy narratives are underwriting and stabilising the assumptions in the policy process (Roe, 1994). A story is dominating when it directs policies, institutional action and important policy actors (Stone, 1989; Hajer, 1993; Boswell et al, 2011). Commonly, there can be several competing policy narratives for understanding, in which many actors vie for control. Policy narratives are not a uniform whole; they can encompass various persuasive arguments and elements of discourse and take place on many different levels and localities, but are held together by a similar conceptualisation of the world (Hajer, 1993). According to Schön & Rein (1994) these underlying structures of belief, perception and appreciation that construct policy problems and preferred solutions, can be understood as problem frames. In ambiguous and complex situations, actors create narratives of social reality through a complementary process of framing. Usually the identification and framing of social issues in public policies and practices are related to which actors claim, or are claimed to have knowledge (Schneider & Ingram, 1993a,b; Stone, 2002; Colebatch, 2009; Fischer, 2009).

Policies and their narratives can be regarded as "political persuasions" (Atkinson, 2000); they are dynamic instruments where the state gives signals and legitimises how citizen groups are valued and regarded by other citizens, which attitudes and courses of action are regarded as appropriate and what services they can expect from welfare organisations (Schneider & Ingram, 1993b; Stone, 2002). Welfare-state organisations can either support or undermine established images of various citizen

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