

Ageing in Place for Persons with Dementia -- Autonomy, Capability and Social care

Location: G2

Chair: Titti Mattsson, Sweden

Session Type: Symposia

This symposium will provide an interdisciplinary analysis (law, social work, ethics) of the inter-relationships between autonomy, capacity and social care for ageing in place for persons with dementia in Sweden. In specific, the symposium will include five different presentations as follows:

The first presentation will describe and analyze the various representatives and care supporters that Swedish legislation offers to persons with dementia in different family and social welfare legislation.

The second presentation will address a new legal instrument of future decision-making in Swedish law, a durable power of attorney, and its possibilities and limitations for use to plan the personal ageing situation and to increase the individual's autonomy and capacity.

The third presentation will present a study of interviews with persons with dementia, describing their experience of ageing in place with social welfare support, as well as a study of interviews with social services professionals working with persons with dementia and their views of dilemmas of autonomy and capability in everyday life for persons with dementia.

The fourth presentation will discuss a review of interventions for economic security of persons with dementia ageing at place, counteracting financial abuse such as foreclosure and theft, from a capability approach.

The fifth presentation will address the normative issue of where to draw the line between appropriate decision-making support and undue influence in the context of ageing in place for persons with dementia, and the challenge of ensuring that representatives do not cross that line.

Older People with Dementia who are Ageing In Place and Autonomy - Lessons from Qualitative Interviews with People with Dementia and Professionals in Social Services and Social Care in Sweden

Lottie Giertz [Växjö, Sweden]¹

Linnaeus University¹

This presentation discusses dilemmas of autonomy of older people with dementia ageing in place from the view of themselves and the view of professionals working in four municipalities with dementia care. The aim of this study is to describe and analyze significance for older people with dementia to speak for themselves and/or to have a representative. Another research question is; How do different professionals deal with the individual's autonomy in their daily work in municipality dementia care and social services? Preliminary findings are presented from qualitative interviews with people with dementia and for example with managers of social services and social care, dementia nurses and legal guardians. In the interviews with people with dementia, they express a strong desire to manage as long as possible without municipal support in their own homes. On the other hand, they are aware of that this approach requires a lot of support from family members. In the interviews with professionals there is a correspondence between the different groups of staff to support the individual's autonomy as far as possible but they all emphasize many dilemmas they have to deal with according to the aging-in-place principle and especially dementia. Dementia is characterized by progressive deterioration of cognitive abilities, general capability and in the capacity for decision-making and independent living. The Swedish legislation of social services stresses individual autonomy but many people with dementia are depending on others to take care of their demands and legal rights.

Interventions against Financial Abuse among Older People with Dementia who are Ageing In Place - Lessons from Qualitative Interviews with Staff in Social Services and Social Care in Sweden

Angelika Thelin [Sweden]¹, Marie Eriksson [Sweden]¹

Linnaeus University¹

This presentation discusses interventions for economic security of older people with dementia ageing in place, counteracting financial abuse such as fraud and theft, from a capability approach. Research questions are: How do social services and social care practitioners handle the problem? Who is doing or is supposed to do what, where and when in order to prevent or act on financial abuse? What are the characteristics, causes and consequences of financial abuse against older people, according to these actual or potential interventions? How are interventions against financial abuse assigned, documented and evaluated? Preliminary findings are presented from qualitative interviews with managers of social services and social care, formal caregivers and employees who work specifically with preventing and taking action on violence in two municipalities in Sweden. Theoretically, the study takes its starting point in Sen's capability approach and the emphasis on the value of peoples' freedom to engage in economic transactions to achieve outcomes that they value or have reason to value. Of special interest is how identified interventions, or the lack of them, support or hinder this specific substantial freedom: financial security and well-being. Dilemmas in relation to the specific substantial freedom and interventions for people with impaired cognitive ability are also discussed. Conclusions are drawn with reference to further need of additional research, need of development of existing interventions and ideas for innovations.

The Durable Power of Attorney -- what can this legal instrument add to the planning of ageing in place in Sweden?

Titti Mattsson [Lund,Sweden]¹

Lund University ¹

Among the various representatives and care supporters that Swedish legislation offers to persons with dementia in different family and social welfare legislation is the durable power of attorney the newest. A power of attorney enables a trusted person, for example a family member or a good friend, to handle a person's affairs if that person becomes mentally incapable later on in life. The authority to act on the person's behalf has different variations in different national legislations. In Sweden such legislation became reality first in July 2017. Before, it was not possible to decide who was entitled to handle a person's legal, financial and personal affairs in the future if this person would end up in a position when he or she would lose the decision-making ability.

This presentation will address this new legal instrument of future decision-making in Swedish law and its possibilities and limitations to plan the personal ageing situation and to increase the individual's autonomy and capacity. The legislative framework is focusing legal and financial affairs and restrictive when it comes to personal matters, such as housing conditions, social care and healthcare. The question arises to what extent this legal instrument is useful for future decision-making concerning issues having to do with such personal matters. The presentation will discuss the possibilities and limits in this regard.

Competing or Complementary Support? A Legal Comparative Analysis of Different Kinds of Personal Support for Persons With Dementia in Swedish Law

Therése Fridström Montoya [Uppsala, Sweden]¹

Uppsala University¹

Persons with dementia might benefit from a fairly large number of different kinds of personal support within the Swedish legal system. These different kinds of personal support vary in purpose and also in legal context; support is in some cases regulated as part of the system of welfare law, in other cases viewed and regulated as private legal matters. Depending on a persons' needs, some kinds of support are more suitable than others. However, legal analyses that stretches over different areas of Law are scarce in Swedish Law. Depending on this fact, and on the fact that different kinds of personal support can be found within both public and private law, there has been few comparative legal analyses of personal support within the Swedish system. Even fewer - if any - of these analyses have taken the interests of persons with dementia as their starting point. Questions to be addressed in such an analysis are, for instance, if persons with dementia can claim a right to all of the different kinds of support; if the legal conditions that certain kinds of support are applicable under prevents persons with dementia from benefitting from them; what kind/s of support a person with dementia needs in order for his or her human rights to be fulfilled; and if a person could benefit from several kinds of support at the same time or if they mutually exclude one another? Legally speaking it might be argued that some of the kinds of personal support are competing phenomena, whilst others are complementary.

Undue Influence in the Context of Supported Decision-Making for Persons with Dementia

Linus Broström [Lund, Sweden]¹

Lund University¹

Supported decision-making for persons with dementia may consist in legal representatives making decisions on the former's behalf, but may also consist in aiding such persons in making their own decisions, through empowerment, the provision of information in an accessible format, clarification of situations and options, etc. The latter kinds of support for the exercise of legal capacity raise the normative issue of how they should and should not be done. In particular, a line needs to be drawn between the kinds of support that are acceptable and the kinds of support that amount to undue influence (where, for example, the person with dementia is inappropriately "nudged", or where the decision made more reflects the outlook of the support person than that of the person supported). Where to draw that line, it will be argued, is not self-evident. The regulatory and other challenges of ensuring that those offering support do not cross it also need to be understood. This presentation addresses these general issues about undue influence, mainly from an ethical perspective, but also in the light of the UN Convention on the Rights of Persons with Disabilities, in the context of ageing in place for persons with dementia.