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Independence as a stigmatizing Value for older People considering Relocation to a Residential Home

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Abstract

Based on older people’s perspective, the aim of this article is to reveal how the culture of independence influences the decision-making process preceding relocation to a residential home. Since there is a predominant ideology of ageing in place in Sweden like in many other welfare states, the focus is on how a continued life in ordinary housing is justified versus how relocation to a residential home is excused. 21 older people have been included in open semi-structured interviews and in follow-up contacts. The findings show that the value of independence, originally intended to protect the position of older people, in practice lead to stigmatizing processes. In order to bridge the gap between values and declining capacities; expectations and actions, the older people develop individual-oriented, family-oriented, and public-oriented justifications and excuses, so called ‘accounts’.

Key words: older people, relocation, residential home, independence, stigma

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Introduction

This article deals with the time when older people consider relocation to a residential home, and it focuses on how the culture of independence has stigmatizing effects. Ever since being an infant, there is a life-long driving-force to stand out as capable, which is reinforced by predominating cultural values and political guidelines. International policy principles for older people approved in the United Nations General Assembly in 1991 emphasize the importance of independence, participation, care, self-fulfilment, and dignity (UN 1991). In line with these principles, the objective of the Swedish elderly policy emphasizes that older people will be able to live active lives, to have influence on the society and on their own everyday lives, and to retain their independence (Government Bill 1997/98:113). In Swedish policy documents in general, older people’s right to self-determination, autonomy, integrity, and freedom of choice hold a predominant position (Trydegård 2000). Influenced by this policy direction, a Swedish parliamentary committee called Senior 2005 devotes their report to the urgent request of tearing down age related barriers, instead launching older people as active agents in recreational activities as well as in the potential of prolonged working lives (SOU 2003:91). There is a culture of independence reflected in these policy principles approved by a great deal of the nations in the world. But if older people cannot alone provide for their needs or get them provided for in any other way, what happens? The global trends point to preventing premature institution as a major public health and social care goal (Ashton 2001). In Europe there is an ambition to strengthen the long-term care in the home and to serve ‘the right people at the right time with the right means’ (WHO 2008, p. 33). So ideologically, there are official guiding
principles guarding older people´s independence, participation, care, self-fulfilment, and dignity (cf. UN 1991, Government Bill 2009/10:116), but when relocation to a residential home comes to the fore these principles are exchanged by the argumentation of professionals in charge of preventing premature institution. The intention with the article is to highlight how older people on the one hand handle declining capacities and on the other the value of independence, but also how they reason when they consider relocation to a residential home quite contrary to prevailing policies.

Older people of today have been socialized into valuing independence and activity, and relocation from ordinary housing to a residential home brings those matters to a head (Bland 1999). Older people’s relocations from ordinary housing embrace relocations to care retirement communities, independent and assisted living facilities (in the United States), co-housing and assisted housing (in Europe), as well as facilities specially designed for older people with dementia (Oswald & Rowles 2007). Within the research area, there is a special interest in older people’s experienced conditions before and/or after the relocation (Armer 1996, Lee et al. 2002, Nay 1995, Svidén et al. 2002, Tracy & DeYong 2004). Over the years researchers have claimed that relocation could increase morbidity, while others have failed to substantiate these findings (Castle 2001). The influences of different characteristics of older people, the degree of voluntariness and environmental change have been emphasized in this context (Lawton & Nahemow 1973, Peace et al. 2011). Later studies conclude that relocation effects are largely dependent upon available support systems (Chenitz 1983, Coffman 1981). Special attention has been paid to the potential relationship between the decision-making process and the relocation adjustment (Johnson et al. 1994, Reinardy 1995), as well as between the planning phase and the
relocation adjustment (Rehfeldt et al. 2001, Thorson & Davis 2000, Wilson 1997). The research field includes studies on the interplay between older people and family members (Davies & Nolan 2003, Sandberg 2001, Sandberg et al. 2002), as well as between older people and service providers (Schneider & Sar 1998). Few studies have been devoted to the prevalence of stigmatizing processes related to the relocation. Fisher (1990) has found that residents at the residential homes feel stigmatized by those outside who pity and patronize them and within the facility residents in more regimented sections feel stigmatized by healthier residents (Fisher 1987, 1990). Except for that, research about older people and stigma is to a great extent about mental illness or mental disorder (De Mendonça Lima et al. 2003, Depla et al. 2005), sometimes related to specific minority groups (Marwaha & Livingston 2002).

This article is based on data collected within the research-project ‘Changing Place of Living in Old Age’ conducted in a medium-sized municipality in the southern part of Sweden. The aim of the project in its entirety is to explore the course of events related to a potential relocation to a residential home from the perspectives of older people considering relocation, their family members, and professionals influencing the process. Based exclusively on the older people’s perspective, the aim of this article is to reveal how the culture of independence influences the decision-making process preceding the relocation to a residential home; and since there is a predominant ideology of ageing in place, how a continued life in ordinary housing is justified versus how relocation to a residential home is excused. The research questions read:

- How are older people affected by their desire to remain independent, and how is their reasoning when declining capacities bring relocation to a residential home to the fore?
How do older people interpret family members’ and professionals’ views regarding relocation and independence, and what impact does it have in terms of a stigmatization process?

With the ambition to understand various influences on older people during this time, Goffman’s dramaturgic perspective is used (Goffman 1959/1987) together with the analytical concept of stigma (Goffman 1963/1990). In order to understand the inner rhetoric of their reasoning, the analysis also departs from Scott and Lyman’s (1968) employment of ‘accounts’; statements made to bridge the gap between expectations and actions. According to Scott and Lyman, accounts may be classified by content as justifications and excuses, which in practice neutralize an act or its consequences when one or both are called into question. Since the impact of professionals in the Swedish welfare system is extensive, more knowledge is needed within the field of social work about how older people think when they consider relocation to a residential home.

Relocation as a stigmatizing process

The international policy principles for older people approved in the United Nation’s General Assembly in 1991 were followed up on a European level in a political declaration and a regional implementation strategy (UN 2002a, 2002b). Accordingly, there are similarities between various European national objectives of elderly policy. At the same time, Europe is divided into countries with family-oriented systems versus individual-oriented systems (Blackman 2000), but ‘orientation’ also indicates that there is no dichotomy between the two systems. While the national system makes informal family care a widespread phenomenon, for instance in Italy
(Lamura et al. 2001) and Greece (Triantifillou & Mestheneos 2001), the tax-financed nursing and care make formal care a more prominent feature in for instance Sweden (Hässler 2001). A common trend in Europe points to increased longevity, increased chronic health conditions, spiralling health care costs, and a shorter hospital stay, which altogether increases the expectations on the informal caregiving system (Borgermans et al. 2001). In an international comparison Scandinavian welfare services are often characterized by a good accessibility to state-financed and publicly produced services offered to and utilised by all social groups. Nevertheless, the 1990s was a turbulent decade in the field of welfare service and at the end of the twentieth century the application of this ‘universalistic welfare model’ is questioned (Szebehely 2005).

Partly due to the current ideology of ageing in place, there is an air of stigma over the relocating process. From the perspective of older people, the view of independence might be modified at this point of time and there is a distinction between independence as self-reliance in activity versus independence as autonomy, self-determination, or choice (Russell et al. 2002). Collopy (1988) argues that the physically dependent older people become increasingly vulnerable to external coercion and from an ethical perspective a loss of autonomy in action argues for greater protections for a decisional autonomy. Earlier studies have showed that older people strive for being independent before receiving help (Gunnarsson 2009), as well as in the phase of asking for public home help (Janlöv et al. 2005). On the contrary, they experience being dependent at the time of relocating to an assisted living facility or a residential home (Svidén et al. 2002, Tracy & De Yong 2004). What has not been studied before, and what is the focus of this article, is how older people interpret the culture of independence when they consider relocation to a residential
home, how they interpret family members’ and professionals’ views regarding relocation and independence, and what impact it has in terms of a stigmatization process.

**Theoretical framework and methods**

For older people today, independence encompasses not only self-reliance but also self-esteem, self-determination, purpose in life, personal growth, and continuity of the self (Secker *et al.* 2003). Independence might theoretically be divided into physical, psychological, and spiritual dimensions. The definition of independence applied in this article primarily corresponds to the spiritual dimension referring to continuity in the sense of identity for a person over time, and that the person’s life is consistent with his or her long-term values and meaning of life (cf. Hofland 1990). Thereby the phenomenon of independence is given a rather holistic and culturally determined meaning. In line with this cultural overlay, this article draws attention to the process of personal long-term values interfering with the experience of personal declining capacities. This interference is looked upon in terms of a stigmatizing process where the person either decides to honestly present the stigma with a possible rejection as a consequence, or to hide the stigma in the striving for being ‘normal’. When there is a gap between what a person ought to be (‘virtual social identity’) and what a person is (‘actual social identity’), a stigmatizing process is initiated (Goffman 1963/1990). This calls for an internal battle between meaning of life, long-term values, and the perception of one’s declining capacities, and it makes the individual an active co-worker in the stigmatizing process. Goffman’s (1959/1987) use of the theatre as a metaphor for everyday life is also applied as a tool. The individual is being watched by an audience, at the same time as he or she is an audience for the viewers’ play. According to
Goffman, an individual attempts to control the impression that others might make of him or her by adjusting the setting, appearance and manner. What influences the social interaction is that all the actors involved are anxious to avoid being embarrassed or embarrassing others (Goffman 1959/1987).

In the empiric material the older people verbally refer to their face-to-face interactions with a third party, consisting of their changing relationship to their own persona, family members, and professionals. Crucial is how they experience their life world in terms of a limited number of shared constructs (Gubrium & Holstein 2000), which here corresponds to the culture of independence, and how it is subjectively perceived as a reality. The older people hold on to their values, but at the same time the values are threatened and thereby inviting to stigmatized processes, which results in the need of expressing accounts (Scott & Lyman 1968).

Data collection and context

With an inductive starting point, the first author met the older people in open semi-structured interviews in their homes, or in exceptional cases at a short-term housing or a day-care centre. After some three-four months, a new contact was established by phone. When the phone-numbers were blocked further information was searched through Internet or family members. Starting out with the idea of carrying out follow-up contacts by phone and visits to the residential homes, the number and kind of contacts were adapted. This was made for reasons of the older people’s health, reduced hearing or speech, and point of time for initiated recruiting. Three persons were met once, six persons twice, ten persons three times, and two persons four times. The recruiting phase was initiated in October 2009, terminated in May 2010, and the last follow-up contact was made in August 2010.
A thematic interview guide was prepared and worked as a checklist during the first interview sessions. In the follow-up contacts the questions built on the preceding interviews. With one exception, all the older people agreed to the request of recording the interviews. When the interviews were not recorded, notes were taken simultaneously as the conversations went by. The interviews lasted from half an hour to just over an hour, and the follow-up contacts by phone 15-30 minutes. Right after each conversation, notes were taken about additional observations. A total of 47 conversations were carried out and transcribed verbatim. Names of persons and places were eliminated, and minor details in the citations changed to ensure confidentiality.

The older people
At the time of the first interviews, the mean age of the older people in the study was 86.5 years and the range was 73-94. Two of them were 70-79, 12 were between 80-89, and seven 90-99. The older people consisted of 14 women and 7 men, including single and married persons. Two persons were married to each other. Most of the persons had children and grandchildren, some even great grandchildren. Three of them were childless, but for two persons there were nieces involved in the decision-making process. Professionally the older people had held a range of white- and blue-collar jobs, employers and employees. 20 persons had a Swedish background and one originally came from a country nearby. Most of them had multi-diagnosis, while others mainly referred to their forgetfulness. At the time of entering the project, 19 persons lived in apartments in a rapidly growing city, one in a terrace house in the outskirts of the city, and one lived in a house in the country. At that time, all but two received home help service ranging from only a few hours a week to assistance round the clock. Two persons attended a day-care centre
on a regular basis. 10 months later, 12 persons had relocated, one had received a refusal to the application, four persons had died of whom two first had relocated, and for various reasons the relocation had been postponed for four persons.

**Procedures and ethical considerations**

The contacts with the older people in the study were established by the assistance of the municipal care managers. They made the opening inquiries among those applying for relocation to a residential home. The care managers handed over ‘Information letters’, written by the project leaders, containing general project-information and a presentation of the research ethical principles. After an approval by the older people, the first author was informed about their names and telephone numbers and an initial contact was established. All of them signed a formal letter of consent. The project was approved by the Regional Ethical Review Board (Dnr 2009/16).

Some additional ethical considerations emerged along the research process. The recruiting of older people was made by the care managers in charge of the management of the applications for a residential home. Consequently, the first author provided no feed-back to the care managers about how the project-related contacts developed and to the older people it had to be clear that no such feed-back was taking place (cf. Creswell 2007).

The data consists of three types of written material: transcribed interviews, field notes from follow-up contacts, and from observations. The data was read reiteratively in order to find patterns to follow-up in further interpretation. The reading was followed by a structuring of the text. The coding phase was made in interplay between empirical data, interpretations by the authors, and theoretical perspectives. Thereby, as it is expressed in the hermeneutics, the empirical data was influenced by the cultural context in which it was created, as well as by the
cultural context in which it was subsequently interpreted (Patton 2002). With a special interest in attitudes and values, the first author has inevitably influenced the conversations and interpretations (cf. Kvale 1997). Her continuous impressions have influenced the process, just as well as the gathered personal and professional experiences by all the authors, including experiences from interdisciplinary research within the field of ageing. In that way, the process is influenced also by the authors’ views of independence and stigmatization. Nevertheless through frequent scrutiny and internal discussion, our intention has been to be as reflective as possible to our preconceived notions.

**Findings**

Two approaches were found in the older people’s decision-making process preceding the relocation to a residential home, which have been called *Justifications of a continued life in ordinary housing* and *Excuses of relocation to a residential home*. In the decision-making process the older people tended to go back and forth between these two approaches and either way, they had to handle their resistance to be taken care of. In order to bridge the gap between expectations and actions, the older people used accounts, which have been divided into individual-oriented, family-oriented, and public-oriented stigmas, although the orientations sometimes overlap.

*Justifications of a continued life in ordinary housing*

Even though the older people in this project had applied for a residential home, they expressed strong preferences to remain in their ‘homes’ (cf. Gurney & Means 1993) and they regarded the
home as a source of independence and as an expression of identity (cf. Sixsmith 1990). In individual-oriented accounts for a continued life in ordinary housing, the older people blamed their bodies for breaking the preconditions for being ‘normal’. Sometimes the body was talked about as though it belonged to someone else, or as though it were self-determining. 85 year-old Careen had lived in her home for more than 40 years. She presented herself most of all as a dedicated mother and wife, who always had put a great deal of effort into taking care of her family and home. Now she could not help what was happening to her. She said: ‘Leaving my home is the last thing I do, you know. It is sort of not really me choosing, but rather a natural departure [laugh]’. In the older people’s statements, there was also the individual-oriented account of emphasizing remaining capacities and skills obtained in their earlier working lives. By doing so they held on to ‘normal norms’ and to their efforts for staying ‘normal’, but sometimes there was also an air of irony. The irony helped revealing the stigma at the same time as it permitted an accentuation of preserved ‘normal norms’. Thereby it reduced the risk of a possible rejection. 93 year-old Elaine had prepared the coffee table to the very last detail and with much concern. In these circumstances and besides having lifelong experiences of being a hostess, it appeared, she could refer to herself in terms of being ‘terribly crippled’. She said: ‘I hardly can… I have taken out the cups all by myself, as strange as it might seem’. Over and over, the importance of achieving was emphasized and the older people did their utmost to make the ‘actual social identity’ and the ‘virtual social identity’ to coincide. As they still guarded accepted values, prevailing shortcomings could be smoothed over at the moment and the immediate embarrassment avoided.
The expressions of the culture of independence changed to a large extent from autonomy in action to decisional autonomy (cf. Collopy 1988). As decisional autonomy implied that somebody else had to act, the value of independence for older people could conflict with that of their children’s generation who sometimes preferred not to be hindered by providing informal care (cf. Arber & Evandrou 1993). Partly because of that a continued life in ordinary housing entailed a risk of experiencing being ‘a burden’ to family members. There were domestic duties the home help service did not carry out and tasks the older people for various reasons preferred family members to carry out. In family-oriented accounts for a continued life in ordinary housing, independence was not threatened when the older people were able to balance the feelings of comfort and guilt by focusing on some kind of reciprocity: emotionally, economically, by expressing gratitude or by referring to the occurrence of former reversed roles (cf. Arber & Evandrou 1993).

In Table 1, an overview of the accounts belonging to this approach is presented.

*Table 1. How a continued life in ordinary housing was justified*

<table>
<thead>
<tr>
<th>Stigmas</th>
<th>Individual-oriented</th>
<th>Family-oriented</th>
<th>Public-oriented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts</td>
<td>Referring to affections related to the home</td>
<td>Balancing feelings of comfort and guilt by giving something in return, or by referring to that there have been reversed roles over the years</td>
<td>Claiming own achievements are better than those of the home help service</td>
</tr>
<tr>
<td></td>
<td>Distancing oneself from the body</td>
<td></td>
<td>Speaking ironically of the home helpers’ short visits</td>
</tr>
<tr>
<td></td>
<td>Emphasizing remaining capacities, and skills obtained in earlier working life</td>
<td></td>
<td>Adapting an ‘exit-behaviour’ as a result of experienced humiliation</td>
</tr>
<tr>
<td></td>
<td>Presenting ‘normal norms’, staying ‘normal’</td>
<td></td>
<td>Stating not being in such a bad shape as residents at residential homes</td>
</tr>
<tr>
<td></td>
<td>Speaking ironically about own achievements</td>
<td></td>
<td>Not pleased with the residential home offered</td>
</tr>
<tr>
<td></td>
<td>Claiming the ability of making autonomous decisions</td>
<td></td>
<td>Taking considerations to limited societal resources</td>
</tr>
</tbody>
</table>
In relation to the home help service, the older people applied public-oriented accounts for a continued life in ordinary housing. The experience of being able to receive assistance and simultaneously remain an active agent was crucial (cf. Hammarström & Torres 2010). In a way to handle that, the older people spoke ironically for instance of the home helpers’ short visits and they compared their visits with the play ‘passing-by-peek-a-boo’. In addition, the achievements of the home helpers were criticized, mainly by the women. All her adult life 91 year-old Elizabeth had taken care of herself and her one room and kitchen. Only recently she had engaged the home help service for laundering and washing the floor, but she thought it did not work. She still had to wash the floor under the carpets and when it came to the laundering, she commented:

Imagine, that they book my laundry room, but they don’t tell me what time they have booked (--) and the towels look like scouring-cloths, you know. They don’t look like my towels [laugh].

When both the decisional autonomy and the autonomy in action were jeopardized, the engagement of the home help service, as well as the potential relocation, was questioned. Here an ‘exit-behaviour’ (Hirschman 1970) was applied as a protest-act directed to the public sector. Elizabeth declined the home help service as well as her application for a residential home. She said. ‘It felt good when I said that, but now I have not been feeling well for a while’. Her body threatened to ruin her ambitions and lifelong ideal of being able to manage on her own.
In public-oriented accounts, the older people also talked about a potential relocation as though it was not of immediate interest, but rather a possibility in the long run. After all, they did not really belong to a residential home (cf. Merton 1968). In line with this approach, the ones already living at the residential homes were considered very sick (cf. Fisher 1990). The residents were characterized as persons not being able to walk, or persons with dementia. This created a conception of a stereotyped existence at the residential homes. The ideal of expected order and diligence (activity) created what they feared the most in terms of a visualized idea of a forced laziness (passivity). ‘Still, I don’t want to get in, because what in the whole world would I set about all day?’ as 90-year-old Gabriella summed up. She managed in her apartment with some assistance from family members. Later in the process she declined relocation, but engaged the home help service for washing the floor. She said: ‘It works, but it is not as when I wash myself’. The home help service did not correspond to her expectations and in that sense she felt more capable than them and therefore less embarrassed. Along the decision-making process, some of the older people were offered a room and they had to decide whether to accept it or not. It could have an undesired location, or look as though someone just had died there. One person was never offered any room, but instead regarded ‘far too healthy’. When relocations for various reasons were cancelled, the older people declared they did not want to burden limited societal resources after all.

_EXCUSES OF RELOCATION TO A RESIDENTIAL HOME_

By expressing individual-oriented accounts, the older people referred to circumstances that made a relocation appear less of a failure. There was an air of guilt and shame in their formulations and they handled it by taking the role of being the audience in the drama called their own lives. They
felt they did not have any choice but to relocate, which makes the notions of ‘voluntary’ and ‘involuntary’ relocations questionable (Nay 1995). With a sense of responsibility belonging to the culture of independence, the relocation was conceptualized as a ‘preventive measure before the health would deteriorate’, or as a ‘measure that had been postponed for as long as possible’. 94 year-old Nelly had struggled for so long. She said: ‘I can’t bend. I have a sick back, but I do much, much, much more than I can [deep sigh]’. Assistants originating from the same country as Nelly were engaged one after another, but at the time this arrangement did not work any longer. Old age and disability contributed to excusing a potential relocation. Again the body, and a too long life-span, was blamed for causing this new phase when ‘everything is worn out’. On the one hand nature had to take its course. On the other, it was hard to accept being ‘unable to care for self’. By referring to being a ‘person dying’ (Nay 1995), the older people presented another individual-oriented account for excusing relocation. 92 year-old Harry always tried to make lunch every day before the home help service would come for this very task. He rather wanted them to come for a chat, but he did not want to relocate even though others did. He said ‘I suspect they [the care manager and family members] want me to’. Harry told they had said: ‘You need more help as time goes by’. Harry then turned into a statement about that the end was near, but he also said: ‘For as long as I live, I will do as well as I can’.

In Table 2, the accounts belonging to this approach are presented schematically.
Table 2. How relocation to a residential home was excused

<table>
<thead>
<tr>
<th>Stigmas</th>
<th>Individual-oriented</th>
<th>Family-oriented</th>
<th>Public-oriented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts</td>
<td>• Referring to old age and disability</td>
<td>• Explaining that and why family members cannot assist</td>
<td>• Regarding the relocation as a preventive measure or as a measure that has been postponed for as long as possible</td>
</tr>
<tr>
<td></td>
<td>• Distancing oneself from the body</td>
<td>• Declaring a desire of not being a burden</td>
<td>• Regarding the home help service as an intrusion</td>
</tr>
<tr>
<td></td>
<td>• Calling attention to that efforts already have been made in order to postpone the relocation</td>
<td>• Degrading own importance in relation to family members</td>
<td>• Criticizing the achievements of the home help service</td>
</tr>
<tr>
<td></td>
<td>• Blaming a too long life-span</td>
<td>• Referring to desires and opinions of family members, and symbolically referring to them in terms of the highest leadership</td>
<td>• Not having the strength to supervise the home help service</td>
</tr>
<tr>
<td></td>
<td>• Referring to that nature must take its course</td>
<td></td>
<td>• Referring to the right to withdraw after a life-long working life</td>
</tr>
<tr>
<td></td>
<td>• Identifying oneself as a ‘person dying’ rather than ‘unable to care for self’</td>
<td></td>
<td>• Experiencing limited possibilities to afford more home help service</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Showing consideration for the delimited resources of the home help service, and of the hospital</td>
</tr>
</tbody>
</table>

One explanation after another was presented about why the children could not come to visit and help more often. In that way the relocation was excused by family-oriented accounts. The older people referred to that the family members already had a heavy work-load, their own families to take care of, and a long way to go. Besides, ‘there is not much to come to either, you know’, as 86 year-old Valencia formulated the explanation to why her child’s visits were rare. She was aware of that there was something wrong with her head and she preferred the company of the staff, possibly in order to ease her embarrassment. In that way, the older people were taking part in the stigmatizing process directed to them by diminishing their own importance and by referring to that they were ‘bothering’. In another kind of family-oriented accounts, the older people experienced they had been incapacitated by family members. By referring to synonyms for the highest leadership such as ‘the almighty’ or ‘the board’, the older people transformed
themselves to being an audience that could not really help what happened on the stage. Still living in her apartment 85 year-old Gisela summed up her life by saying: ‘I moved here from mother and father, only, and I only had one job, only one man’. Later, in the taxi after a period in hospital, she was told she would not go back to her apartment but to a residential home. She commented: ‘It is as though I was declared incapable of managing my own affairs and I am deprived my identity’.

Relocation to a residential home was also excused by means of public-oriented accounts. At times the older people experienced the home help service as an intrusion into their everyday life (cf. Olaison & Cedersund 2008). The time of the home-helpers´ entrances was experienced as unpredictable and their achievements were regarded unsatisfying. Earlier these arguments were used in order to decline external assistance and to justify a continued life in ordinary housing, but here they worked as excuses of relocation. The older people thought they did not have the strength to supervise the home-helpers any longer and that they had the right to withdraw at this point. In addition, they were worried their pension would not cover any expansion of the engagement of the home help service. Nor did they experience they could demand even more assistance from them, or from the hospital, since there were so many other older people in need of assistance.

Concluding discussion

The findings from the study referred to in this article show that the value of independence, originally intended to protect the position of older people, in practice lead to stigmatizing
processes. The personal decision to relocate to a residential home is systematically questioned in the needs-assessment as such. It is not only that the final decision is taken by somebody else, but also that personal desires might clash with official guidelines. The official guiding principles of advocating ‘environments that are safe and adaptable to personal preferences and changing capacities’ (UN 1991, see ‘Independence’) primarily means ‘to reside at home for as long as possible’ (UN 1991, see ‘Independence’). From the perspective of older people, the fact that residing at home is advocated with references to the culturally treasured value of independence, contributes to making it rhetorically hard to argue against the ideology of ageing in place, as well as against a rejected application for relocation to a residential home. In that way the findings draw attention to the importance of complementing earlier research on physical- and psychological dimensions of the concept of independence with the spiritual dimension emerging from older people’s long-term values and meaning of life. The older people want to perceive themselves as independent and simultaneously they experience that the body, family members and professionals have a great impact on the preconditions for how this ideal might be expressed. This gap leaves the older people with the perceptions of themselves as lacking in judgement, being of no value, and as bothering and loading family members as well as the society. Therefore, we argue that:

- older people push the limits for what is possible
- older people lay modest claims to assistance for as long as possible
- older people feel bad for not fully corresponding to value-laden expectations

Personal ideas, beliefs, attitudes, and social pressures are reinforced by the welfare system in which these processes are taking place. The predominant needs-assessment procedure under the
management of the municipal social services in Sweden turns in itself the formal decision-making process into supplying a ‘conditioned’ universal distributive system, where the care manager is the active agent. Just like the selective welfare system is regarded to generate stigmatizing processes (Titmuss 1968), the findings from the study referred to in this article show that the ‘conditioned’ universal distributive system reinforced by the culture of independence produces the very same effects. So while the policy principles for older people call for the culture of independence, the application of the needs-assessment procedure deprives the citizens their preconditions for holding on to these values like in an internal contradiction. In addition, by not having any insight in the distribution system, the older people tend to feel personally excluded or neglected.

Goffman (1963/1990) uses the terminology ‘the good-adjustment line’. He argues that the stigmatized persons are advised to accept themselves as essentially the same as ‘normals’, at the same time as they voluntarily would withhold themselves from situations in which ‘normals’ would find it difficult to accept them. Since the good-adjustment line is presented by those who take the standpoint of the wider society, it means that the unfairness and pain of carrying a stigma will never be presented to them, nor will they have to admit to themselves the limitations of their tolerance (Goffman 1963/1990). It is uncertain whether the care managers in good faith think they do the best for older people, or whether they intentionally play the role of a gatekeeper where the decisions easily slide over to first and foremost gain the interests of the organisation. From the perspective of the older people it is all about hard work and persistent self-training, and about an adjustment to not being a burden neither to society, nor to family members. The older people in this study presented their stigma of not being ‘fully achieving
persons’, at the same time as they formulated various accounts. The unfairness and pain of having to carry a stigma has thus been an ingredient in their performance, just like references to how it should be according to what is considered ‘normal’. This contributes altogether to making the anticipated and carried out relocation a stressful and threatening event.

Long-term values do not change just because the body does. This is not to say that everything would be fine if it would not be for the culture of independence, but rather that predominating cultural values and political guidelines contribute to making the experience harder. Since these values contribute to older people’s experience of being insufficient, special caution is needed. For a better understanding and thereby implementation of the policy principles for older people, further research is needed for sorting out the meaning of the culture of independence within the value judgements underlying the decision-making process in different welfare systems. Another implication of the findings is that the social services’ needs-assessment system must be thoroughly reconsidered in Sweden.

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References


