

Forum

## Introducing an Equal Rights Framework for Older Persons in Residential Care

Håkan Jönson, PhD,\* and Tove Harnett, PhD

School of Social Work, Lund University, Lund, Sweden.

\*Address correspondence to Håkan Jönson, PhD, School of Social Work, Lund University, PO Box 23, 221 74 Lund, Sweden. E-mail: [hakan.jonson@soch.lu.se](mailto:hakan.jonson@soch.lu.se)

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### Abstract

This article reconceptualizes residential care for older persons by introducing a framework developed from a rights-based principle of disability policies: the normalization principle. This principle is part of the social model and states that society should make available for people who have impairments living conditions that are as close as possible to those of “others.” Using the framework on the case of eldercare in Sweden shows that although disability policies have used people without impairments as a comparative (external) reference group for claiming rights, eldercare policies use internal reference groups, basing comparisons on other care users. The article highlights the need for external comparisons in eldercare and suggests that the third age, which so far has been a normative reference group for older people, could be a comparative reference group when older persons in need of care claim rights to equal conditions.

**Keywords:** Disability policies, Social model, Normalization, Long-term care

This article contributes to the reconceptualization of residential care for older persons by introducing a framework developed from a rights-based principle of disability policies: the normalization principle. This principle states that society should make available for persons with impairments living conditions and patterns of everyday life that are the same or as close as possible to those of “others” (Nirje, 1970, 1992; Tideman, 2000). Internationally, researchers have proposed that adopting successful models developed within the field of disability studies would improve gerontology (Krassioukova-Enns & Ringaert, 2012; Naue & Kroll, 2010; Oldman, 2002; Putnam, 2002). In particular, the social model has been cited as having the potential to enhance the welfare of older persons who age with or into impairments. The social model emphasizes that although individuals may suffer from functional impairments, disability is caused by the way society exposes individuals to unresponsive or hostile environments (Tideman, 2000).

In this article, the use of a disability lens refers to a process where concepts, models, and aims that have been developed within the disability field are used to compare and reframe care for older people. In the United States, similar attempts to use disability policies as comparison have occurred in proposals to apply the Olmstead Decision (Williams, 2000) onto eldercare (Palley & Rozario, 2007).

Given differences between welfare states, our argument is not that the Scandinavian normalization principle should be exported and used internationally, but rather that the type of references presented in the equal rights framework we propose may be used to reframe and rethink eldercare in many countries.

### The Scandinavian Normalization Principle

Alongside goals of integration and participation, Swedish disability policies have been guided by the normalization principle aiming to provide persons with impairments the

living conditions that enable them to live normal lives (Nirje, 1992; SOU, 2008:77; Tideman, 2000; Tøssebro et al., 2012). The first outlines of the principle appeared in Denmark and Sweden in the 1950s, and in 1970, Nirje suggested eight normalizing rights for young people with developmental impairments (Nirje, 1970). A characteristic of the Scandinavian normalization principle was that it used people in general as the comparative reference group and identified persons with impairments as deprived relative to other members of society.

Similar to the social model, the normalization principle has been presented as an alternative to the medical model that casts disability as an individual problem associated with abnormal body functions, in which the individual is considered to be normal/healthy or abnormal/sick (Tideman, 2000). Most notably, the principle is expressed in the legislative reform introduced in Sweden in 1994 that gives individuals with lasting, long-term support requirements the right to personal assistance (Government bill 1992/93:159). Although Swedish policy documents have now abandoned the actual concept of normalization, the core idea of the principle is still present and expressed in the goal that persons with impairments should be able to live “like others” (National Board of Health and Welfare [NBHW], 2011; SOU, 2008:51). A similar comparison to nonimpaired members of society is visible in the Americans with Disabilities Act, ADA (1990), in the goal to ensure “equality of opportunity” for people with impairments.

### From Normalization Principle to Equal Rights Framework

Is it possible to transfer the ideas of the normalization principle to eldercare? Can society make available for older persons in residential care living conditions that are as close as possible to those of “others”? Who are those “others” who could be a comparative reference group in demands for justice? What kind of comparable living conditions should policies aim to achieve?

The aim of this article is twofold: (a) to develop the normalization principle into a conceptual framework and (b) to investigate the potential of applying this framework in the context of eldercare. In order to develop the framework, we use analytical concepts from reference group theory and the theory of relative deprivation (Merton, 1968; Runciman, 1966). According to reference group theory, individuals use selected groups as ideals and standards for different types of comparisons. The normative function refers to norms that individuals are measured by or strive to live up to when, for instance, identifying with a particular group. This function is also a foundation of theories on stigma, the singling out of individuals or groups as deviant (Goffman, 1963). The comparative function refers to points of departure for comparisons among individuals, groups, or categories. Comparative reference groups serve as a basis for claims that individuals or groups are treated unjustly relative to others but could

also invoke previous or established rights or standards that the person has enjoyed (Runciman, 1966). The comparative function of reference group theory has been central to theories on inequality, deprivation, and discrimination and is particularly relevant for our analysis.

A review of writings on the normalization principle shows that its main aim has been to base rights on references that are external to care and impairment. In 1970, Nirje operationalized normal living conditions for persons with developmental impairments as a list of rights, including the right to:

1. a normal rhythm of the day
2. a normal weekly rhythm
3. a normal rhythm of the year
4. a normal development experience of the life cycle
5. have choices, wishes, and desires respected
6. live in bisexual world (not in unisexual groups)
7. apply normal economic standards
8. access to physical facilities such as (apartment-like) housing, schools, workplaces, and hospitals that are the same as or similar to those provided for the ordinary citizen.

The framework we propose is derived from Nirje’s general principle and the eight rights and has been reworked into three types of interdependent and interacting references that concern contexts, categories, and personhood.

#### Context-Centered References

Nirje (1970) formed his critique of disability policies within the context of the large institution, the dominant form of housing for persons with intellectual impairments in the early 1970s. In accordance with the right to access physical facilities similar to those provided for ordinary citizens, Swedish disability policy has emphasized that housing should be the same as or similar to ordinary housing. Daily activities should take place in arenas that are external to the context of care; that is, that schools and workplaces should be separate from housing (Tideman, 2000).

#### Category-Centered References

To question institutionalization and categorization according to medical models, Nirje (1970) invoked a number of references to comparative categories external to the institution and to the entire context of impairment and care. In his original article, Nirje specifically commented on normal conditions during childhood, youth (school age), adulthood, and old age. This construction of normality with reference to age (and gender to some extent) has been central to Swedish disability policies (Jönson & Taghizadeh Larsson, 2009).

#### Personhood-Centered References

The right to make choices and have preferences and requests respected could be derived from the unique personhood of every individual and may be used to balance references to context and category: The individual is a unique person

outside the context of care and is more than a member of a category. Personhood-centered references are commonly accompanied by a temporal—biographical—dimension because of claims that the personal history and habits of the individual should be taken as a point of departure when providing help or care. The framework could be used to analyze residential care for older people.

Figure 1 illustrates the aim of moving to external frames of reference.

It is important to note that although different types of references may be used to balance each other, they are also interdependent. The framework has a temporal dimension, expressed in references to the normal rhythm of the day, week, year, and life course that points to categories and contexts. The external reference to a normal rhythm of the week for a teenager, for example, can be invoked as a contrast to the weekly rhythm of a total institution where all days of the week are more or less the same.

In the following sections, we discuss the references used to establish rights within residential eldercare, using a “disability lens.” Because we base our framework on a principle that has been key in Scandinavian countries, we use policy documents, media articles, and research on disability policies and care for older persons in Sweden as examples. Although Sweden stands out as a welfare state with particular characteristics, we believe that our review reveals common patterns in the use of references.

### References to Internal Categories and Contexts Are Predominant in Care for Older People

Collective settings such as care facilities tend to make residents the primary reference group for each other. Restrictions may be accepted as fair or natural if all residents are affected equally, for instance, by having to wait a long time for assistance. Residents interact with and must respect neighbors with whom they have not chosen to share their everyday lives. This situation, as Golant (2011) noted, is not always unlike the limitations that people may feel when living with others in their ordinary homes. The risk, however, is that limitations that are actually caused by the organization of society or care

are framed as consideration for other residents or as “natural limitations.” A typical example is when a request from a resident to shower or to go on an accompanied walk is denied with reference to the needs of others at the facility. The social model would suggest that the real reason is that the level of staffing is insufficient but that this reason is concealed through references to possibilities within the particular context.

Looking at the use of categories and contexts through a “disability lens” makes evident a tendency in residential eldercare to use internal rather than external references. Within this construction of goals and rights, contexts and categories relating to care become the prime references for defining injustices and claiming rights. Concepts like equality, justice, and human rights refer to comparisons with the ordinary citizen in media and policy documents on disability. In texts on care for older people, such concepts refer to comparisons within the category of care users, as is exemplified in an interview with the leader of the Swedish Social Democratic party, Mona Sahlin:

What are human rights when you are old? Today there are vast differences depending on where in the country you live—and they include anything from home care fees to residential care and attitudes towards care users, Mona Sahlin concludes. Legislation may be necessary in order to create equality (PRO-Pensionären, 2010:7, pp. 18–19).

The use of internal references in eldercare policies is most visibly contrasted to disability policies as described in government action plans (Government proposition 1997/98:113, 1999/2000:79). In a recent dissertation, Erlandsson (2014) concludes that whereas policy makers and care providers define goals for nonold people with impairments in terms of citizenship (a term frequently used in government investigations on disability policies) and access to society, goals for older persons relate to the quality of care itself. For nonold persons, the goal is to participate in society; for older persons, the goal is to participate in activities relating to home or care, such as social activities at the care facility or household tasks such as peeling potatoes when preparing a meal. This internalizing paradigm of eldercare becomes visible as the absence of goals and concepts like those used in disability policies.

### References to External Personhood Are Used to Establish Rights But Difficult to Uphold in Residential Care

The right to have choices, wishes, and requests respected is inscribed in the laws that govern care and services for younger as well as older persons. Personhood in care for older people has been theorized through concepts like personalization and person-centered care, an approach that is juxtaposed to task-oriented care and institutional molding (Kitwood, 1997; McCormack & McCance, 2006).

Type of references	Internally oriented – care and impairment	Externally oriented – society in general
Context-centered	The contexts of care or impairment	Other contexts invoked as comparison
Category-centered	Other care users or categories relating to care or impairment	Other categories invoked as comparison
Personhood-centered	The unique person in relation to care or impairment	Other aspects of the unique person invoked as comparison

Figure 1. An equal rights framework for persons in need of support and care.

A comparison shows that although the emphasis on the right to decide on personal matters is stronger within disability care (Erlandsson, 2014), disability policies has—partly for obvious reasons—devoted less attention to biographical approaches based on external references that are present in eldercare. A chapter of the Social Service Act of Sweden states that older persons have the right to live with safety and dignity, and the government describes this right as a matter of living according to an established identity and personality, and of keeping interests and habits (Socialutskottets betänkande, 2009).

Biographical approaches that aim to keep the personality and individual habits are used as a shield against institutionalization (Harnett & Jönson, 2010). This could be illustrated by a comment from staff members at a care facility, interviewed in an ongoing study by the authors of this article:

We develop a plan based on how their lives have been before, the way they have lived before they came here. You should not have to readjust; we adapt to the individual (assistant nurse).

However, following this comment, another staff member added that aging and disease changed the personality of many residents and that this change had to be taken into account. The weakness of biographical references lies in the fact that identity can be described both as an object to be replicated and a process that is changeable and context dependent (Wellin & Jaffe, 2004). Contrary to the situation in disability policies, Swedish policies for older people have presented the process of aging rather than the organization of society as the cause to their limitations (Government proposition 1997/98:113). This tendency to evaluate the person-environment fit as a matter of the failing body in a past–present–future process is also present when older people consider relocating to facilitated housing or residential care (Löfqvist et al., 2013). To regard problems during old age as caused by aging constitutes an internal reference to the failing body that is a fundament within ageism (Coupland & Coupland, 1993; Levin & Levin, 1980).

The life history of the individual is thus an important source of rights for older people in need of care, but the external normality of a previous life is challenged by references to the process of aging as the cause to limitations—an internal reference to care and impairment.

### References to External Categories and Context Are Difficult to Find But Constitute a Promising Route for Establishing Rights

What reference to external category and context could a person who is 80 years old and lives in a residential care setting use to claim rights? Looking through the “disability lens,” it becomes evident that age categories of the life course have been crucial for impaired people of younger ages, but relatively absent for the period of old age or retirement. The government investigation that introduced the personal assistance

reform explained how key concepts like accessibility, participation, influence, and equality should be measured:

We have seen it as important to present proposals which mean that people with significant impairments (children, youth, and adults) have equal conditions as others of similar ages (SOU, 1991:46; p. 143).

When providing examples, the investigation associated childhood and youth with the right to have an education and adulthood with the right to live independently (not with parents or in an institution), to work, and to form a family. No examples of normality during old age were provided.

Old age has been described as a period where expectations about proper behavior are vague and weak (Rosow, 1974) and later as a role that new cohorts of older persons will want to avoid (SOU, 2003:91). The lack of standards and norms for older people makes it difficult for residents at care facilities to claim rights through the use of a comparison to “others of similar ages” (Jönson & Taghizadeh Larsson, 2009). Pensioners are free to spend the entire day in a morning gown or have a party at 4 p.m. on a Wednesday. This flexibility makes it possible for care facilities to individualize arrangements, but the absence of external references regarding the rhythm of the day will also make adaptation to institutional routines more likely.

An analysis that focuses on context and category reveals that some external references have been used to establish rights at residential eldercare facilities in Sweden. Following a comprehensive reform in 1992, home care and residential care for older people became the sole responsibility of local municipalities. To normalize living conditions at care facilities, rooms were renamed “apartments,” and although usually referred to as residents or care users, the persons inhabiting these rooms were formally categorized as “tenants” (NBHW, 2011). Since then, the facilities’ standards have been improved, and tenants occupy single rooms that have an en-suite bathroom, personal furniture (except for beds), and in most cases a small kitchenette. An interview with a manager at a care facility (Jönson & Watanabe, 2013, p. 20) illustrates how references to external context and category are used to establish rights within residential care:

We call the residents “tenants.” We are the only place in this district doing that. They are not care users or patients. They are human beings that rent an apartment here. We should not belittle them. They have a name, and they are tenants with a contract. This means that we are guests in their own homes. It is their homes and not our workplace. To a certain extent it is our workplace, but primarily it is their homes. If they had not been here, we would not have been here either. We are here for their sake, which includes a lot. We knock at the door and then we go into the apartment.

The manager used the external reference to the category tenant and the context apartment to establish the rights of residents, in contrast to well-known tendencies to depersonalize and subordinate care users.

The category of “older couples” constitutes a second example that shows the potential of references to external categories. A change in the Social Service Act of 2012 entitles permanently cohabiting couples to live together in residential care in cases where only one member has the need (NBHW, 2013). The change was initiated by the Liberal Party so that “no couples should be forced to live apart during their last years,” backed by the argument that couples who were forced to live apart often perceived a decreased quality of life. The argument invoked a need for biographical continuity during old age, but the claim makers also argued that it was “indecent” to force older couples to live apart: “It is not for municipalities to decide when it is time for older couples to separate/divorce” (Björklund & Westerholm, 2009).

The purpose of the examples is not to idealize Swedish eldercare or disability policies or to deny problems associated with, for instance, treating residents as tenants. These examples are included to show that, although not part of a strategic policy like the normalization principle of disability policies, external categories and contexts have to some extent been used to establish rights that are external to eldercare.

## Discussion—Searching for Comparative Reference Groups

The equal rights framework introduced in this article reveals a strong tendency to make care for older people its own context for comparison. Consequently, justice is framed as a matter of equal treatment of care users, within care settings. Within disability policies, references that are external to care and impairment have been used to normalize the living conditions of people with impairments—working against social exclusion and institutionalization.

Although approaches like person-centered care and culture change have provided paths to moving away from task-oriented in hospital-like nursing homes (Corazzini et al., 2014; Kitwood, 1997; McCormack & McCance, 2006), these approaches can be supplemented by the equal rights framework focusing on the rights of older people to live like others, just as is claimed for nonold persons with impairments.

A care facility may deny requests to help a resident shower daily by referring to the fact that others at the facility only shower weekly, an example of using an internal reference. The resident may defend the request by referring to the fact that he or she has always had a daily shower, applying an external personhood-centered reference. Our suggestion is that the resident can go beyond relying on biographical claims and also defend the request on the basis of another external reference, just as a nonold person

with impairments might: by arguing that it is normal nowadays for people in general to have the possibility of showering daily and that he or she should not be deprived of living conditions similar to those of other citizens.

The key issue is to identify and disseminate knowledge about external categories that are and could be used as comparative references. In this article, we have mentioned two reforms that enable care users in Sweden to claim rights: establishing status as a tenant and status as a member of a cohabiting couple. In addition to these efforts, it is possible to use younger persons with impairments as a comparative reference group and to ask why older persons with impairments are entitled to less help and are “educated” to have lower aspirations for their quality of life, a situation that internationally has been described as a case of ageism (Kane & Kane, 2005, p. 52). The introduction of new frames of references could be used to challenge ageism as well as the “self-handicapping” (Coupland & Coupland, 1993) tendency among older people to attribute health problems to age.

Could persons of the third age be used as a comparative reference group for older persons in need of care? The third age has evolved as a period of life associated with a number of activities and lifestyles: studies, travel, leisure, involvement in the family, and volunteer work. Could it be claimed that an older person who has aged into impairments should be able to live a life like others who are older and visit relatives, travel, study, and participate in volunteer work?

So far, the concept of the third age has, similar to the concept of successful aging (Rowe & Kahn, 1997), been presented as an achievement during old age. When introducing the general theory of the third age, Laslett (1989) emphasized that for the individual, the difference between the third and the fourth age was a matter of function and lifestyle rather than chronology. Although introduced as an alternative to a decline and loss paradigm, normative divisions based on function have been criticized for being a “new ageism” that associates success and failure during old age with the absence or presence of illness and impairments (Holstein & Minkler, 2003; Peterson & Martin, 2015). There is a striking similarity between this criticism and a comment by Nirje (1985) on attempts to normalize younger persons with impairments through strategic association with valued roles and attributes (Wolfensberger, 1972). Nirje (1985) argued that the normalization principle should deal with living conditions of persons with impairment and not with attempts to make people adjust in order to “pass” as normal. Following Nirje and activists of the disability movement, we suggest a reframing of normative references, which so far have appeared in discussions on successful aging and the third age, into a matter of achieving equal possibilities and living conditions.

It is easy to question the introduction of the third age as a comparative reference group for older people in need of residential care. It may deny characteristics that are unique to the fourth age and transform rights into normative expectations. People who have been happy with having a weekly shower

may become unhappy realizing that they are deprived relative to the “ordinary citizen” who enjoys a daily shower.

These problems are real, but it is useful to note that although disability policies and research have wrestled with similar issues for several decades, the goal of providing persons who have impairments with conditions that are similar to those of other citizens is still regarded as fundamental to policies and practice (Tøssebro et al., 2012). Research on language and interaction has shown that prevailing ideas about age categories play an important role in communication between members of different age groups (Hummert, 2010). Our ongoing research indicates that when the third age and other categories external to care are invoked as comparison in discussions on eldercare, people reflect on the rights and possibilities of care users in novel ways. The route is worth investigating for gerontology.

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