From 'We and They' to 'Me and You':
Fostering Inclusion in Daily Care Practice in Terms of Equal Partnership and Valued Roles

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Abstract

Inclusion for all is an essential theme in current societies, but less so in care. In 2017, Briggs and Harris argued for more debate about the meaning of the concept of inclusion in different settings, including health care practices. The question of this paper is how professionals in long-term care can address inclusion and contribute to more inclusive policies. To answer this question, we first describe the characteristics of inclusion in long-term care from the perspectives of theory, care-users and professionals. Then we illustrate the forementioned with two practice examples to demonstrate how inclusion in long-term care might play out. Finally, we reflect on the lessons learned; what can professionals do to establish inclusion in long-term care?

Most professionals in care services find user involvement important, and user involvement has shifted expectations and broadened the roles of care-users in health care. However, real partnerships remain difficult to achieve. Belief in the dignity, skills and knowledge of the other person, sharing, openness and tuning in the relationship, are important to establish partnership. Person-centred care in fact is relation-centred care. Further, inclusion asks for more, such as valued roles in long-term care for people with disabilities. Thinking in terms of partnership and valued roles might further challenge all stakeholders to rethink the essence of inclusion: to go beyond labels – we and they – and to reduce this concept to daily life – me and you.

Key words: Inclusion, person-centred care, participation, long-term care, partnership, valued roles.

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Introduction

The United Nations described an inclusive society as one where every individual has an active role to play (UNESCO 2012). As such, inclusion is a moral mandate for society in the sense that it is based on promoting the participation of individuals and on reducing marginalisation. The UN Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006) provides a benchmark for assessing human rights and citizenship for people with disabilities. The CRPD emphasizes equity, equality, social justice, human rights and freedoms, and diversity as fundamental guiding principles. An inclusive society should be equipped with the appropriate mechanisms to enable all citizens to participate and feel valued and belong (Wooster 2009; UN 2006).

In this journal, Briggs and Harris (2017) argued for more debate about the meaning of the concept of inclusion in different settings, including health care practices. According to them social inequities in health, for example unfair differences in health status across groups in society, result from an uneven distribution of social goods, resources and from social exclusion. Participation in community life is vital for health and wellbeing, for promoting a sense of belonging, networks of social support and opportunities for physical activity (Carroll et al. 2018). Briggs and Harris point at the question how professionals address specific inclusion and exclusion issues, and contribute to more inclusive policies and equitable outcomes in their work (Briggs & Harris 2017).

This paper focuses on inclusion in long-term care for people with physical or intellectual disabilities. Long-term care consists of practices that support people with enduring disabilities in their daily lives. The outcomes of care are often defined in terms of community participation and quality of life (Schalock, Gardner & Bradley 2007).

In this paper we explore how inclusion can be translated to long-term care practices. What processes of working and relating are essential for facilitating inclusion in long-term care, and what are accompanying characteristics and practical consequences? Firstly, we describe the characteristics of inclusion in long-term care from the perspectives of theory, care-users and professionals. Then we illustrate the forementioned with two practice examples. Finally, we reflect on the lessons learned and what professionals could do to establish inclusion in long-term care.

Inclusion in Long-term Care from Three Perspectives

The perspective of theory

In long-term care practices, person-centred care has broadened the role of care-users involvement (Mezzig et al. 2010; Pound 2011). The essence of person-centred care is partnering with the people using health and social services, in all phases and aspects of care, to ensure their needs are met. There is no one single definition of person-centred care. Concepts like patient-centred, user-centred, individualised or personalized care are used as well (McGilton et al. 2012).

Several important theoretical elements of inclusion, such as multidimensionality (Harris & Briggs, 2017), diversity and valuing the person (Waters & Buchanan 2017; UN 2006), the dynamic and relational process (Cobigo et al. 2016) and the impact of environmental factors (Simplican et al. 2015; Cobigo et al. 2012), resonate with person-centred care:

- Person-centred care is a multidimensional concept, capturing various meanings

related to who the care-user is, what care is needed, and different understandings of care-user capabilities. Terry and Kayes (2019) defined four themes for person-centred care in neurorehabilitation: 1) care-users experience should be understood in terms of a different new reality, 2) the need for a relational orientation, 3) the importance of trust, and 4) professional and care-user together co-construct efficacy.

- The attitude of the professional is an important starting point for person-centred care, which means creating room, building a relationship, facilitating agency and participation, committing to inclusion and citizenship, being strengths/capacity focused, and acknowledging the person 'behind' the disability (Waters & Buchanan 2017).

- In the process of person-centred care care-users and professionals work together as partners and connect their specific types of knowledge, i.e., scientific knowledge, professional knowledge and experiential knowledge (Terry & Kayes 2019). A dynamic, responsive and flexible way of working is key (Waters & Buchanan 2017).

- Sumsion (1997) stressed that environmental considerations are important aspects of a person-centred practice and that professionals actively need to seek knowledge about the context of care-users. The cultural, economic, legal, physical, political and social environments influence how we behave (Sumsion 1997). Also, organizational factors may hinder or facilitate person-centred care (Waters & Buchanan 2017).

Despite abovementioned theoretical notions about person-centred care, much still needs to be clarified. For example, a mutual understanding across contexts is lacking, and the concept of person-centred care is hardly reflected upon (Waters & Buchanan 2017). Moreover, research about what defines the meaning, use, and characteristics of person-centeredness across services is scarce (Waters & Buchanan 2017). Translating theory into practice remains difficult. What about the perspective of care-users and professionals concerning inclusion in long-term care?

The perspective of care-users

The disability movement slogan 'Nothing about us without us' breaths inclusion. The disability movement refers to participation in care as a right and a practice, and states that participation and choice-making are essential to achieve valuable individual-related outcomes (Oliver 1990; UN 2006). Research shows that for example amongst older people with an intellectual disabilities, choice-making (key-life choices as well as everyday choices) is not yet common practice (McCausland, McCallion & Brennan 2018). And also in rehabilitation practice, more professional education seems to be needed to improve shared decision making (Rose, Rosewilliam & Soundy 2017). Early Disability Studies scholars developed the social model of disability (UPIAS 1976; Finkelstein 1980; Oliver 1990). The social model of disability encourages professionals to rethink roles and practices, and to pay attention to issues of power and control (Swain & French 2008). As such, the social model marks the start of a care-user-perspective and states that people with a disabilities are not disabled by their impairments but foremost by the disabling barriers faced in society (Oliver 2013). The social model helps to explain what is happening to people with disabilities in society, and helps to understand the mechanisms of inclusion and exclusion in long-term care. Pound (2011) states that developing robust and positive identities of people with disabilities is a key tenet of the social model. Care-users' stories and their experiences with care show however that person-centred care is still not common practice (Docherty et al. 1997; Pols 2013).

Cobigo and colleagues (2016) interviewed people with intellectual disabilities about their views on inclusion, which resulted in four items rated as highly relevant to all respondents: a) belonging to a group, (b) having interpersonal relationships, (c) being accepted as an

individual, and (d) having reciprocal relationships. This corresponds to the themes that people with disabilities have identified as being key for involvement in society: belonging, being valued, accessibility, and having agency (Yeung, Passmore & Packer 2008; van Heijningen et al. 2021). So, despite appealing descriptions and key elements, existing definitions and practices of inclusion are not (enough) based on the perspectives of the people concerned (Cobigo et al. 2016; Hammell 2013; Fadyl, Teachman & Hamdani 2020).

The perspective of professionals in care

Most professionals find care-user involvement or person-centredness important in care services (Slomic et al. 2016), but implementation of this involvement remains difficult (Mudge, Stretton & Kayes 2014). Professionals often speak and write about care-users in a way that maintains and reinforces the dominant assumptions and social constructions of disability and the 'othering' of the care-users, fitting the institutional and systemic context they operate in (Donaldson, Halligan & Wall 2003; Kulkarni 2017).

Thinking about minorities, 'them', and 'groups' strengthens thinking in opposites. In doing so, the concepts of *we* and *they* are born, together with the generalisations, discrimination, stigmatising, and social prejudice of other people (Campbell 2009). Minorities are often stigmatised by their deviation: the poor, the immigrants, the unskilled, the unable-bodied, the 'feeble-minded', and the vulnerable. It is dangerous for definitions to only be about deficits that need to be normalised (Corijn & Lemmens 2007). Thinking in terms of 'we' and 'they' is not conducive to appreciating diversity between individuals; it is also counterproductive for the partnership between people with disabilities and professionals. Moreover, thinking in terms of 'we' and 'they' is an invitation to draw attention towards care-users and less towards the characteristics of the relationship, the organisation, or the public space in which the encounter and dialogue take place in long-term care.

In long-term care practices, inherent power and position inequalities between care-users and professionals often are incorporated in ways of working or theoretical models, like the medical or individual model (Oliver 1990; Meininger 2013), which is why it is so difficult to change. In addition, the increasing protocolisation of care practices (e.g., treatment guidelines, protocols, pathways and administrative burden) might further hamper person-centred care (Hermsen et al. 2014). In the next paragraph, we describe two practices in which (formal) care-users were enabled to participate, and professionals were encouraged to meet in diversity, to demonstrate how inclusion in long-term care might play out.

Spaces of Partnership in Daily Practice – Two Practice Examples

Practice example 1: Experts by experience with intellectual disabilities

In a care organisation with residential and ambulant care and support for people with intellectual disabilities in the Netherlands, experts by experience work with care-users and professionals. Some of them have been trained as an expert by experience to be able to support care-users by sharing their knowledge. They also advise professional teams, participate in the board of care-users, and participate as trainers in the training of new staff. A coach from the same organisation supports the experts by experience in performing their work. Others have not completed the official training but have learned to support others with their experiences by doing and being coached. They have other jobs during the day but value these activities in their leisure time as volunteers. In addition, outside the care organisation, these experts by experience are guest teachers in universities for future medical doctors and social workers.

Experts by experience also participate in research teams as researchers (van Asselt-Goverts et al. 2017). For example, in one of these teams consisting of people with and without intellectual disabilities, a game was created about sharing experiences of loneliness and social relations. The goal of the game is to connect by playfully practicing in social contact (Heessels et al. 2019). The findings of working in this research team indicated that openness, tuning and taking time, sharing experiences, valuing each other's input, support for all participants by a coach, and sincerity were crucial for meaningful collaboration (van Asselt-Goverts et al. 2017).

Practice example 2: experts by experience with aphasia

In a treatment centre for people with acquired brain injury and aphasia in the Netherlands, health professionals work with volunteers who have aphasia. The centre is convinced that people can learn the most from people who have experienced something similar and therefore employs and trains the volunteers that are experts by experience.

If needed, the professionals act as coaches before or after training sessions of the experts by experience that support care-users that visit the centre. Experts by experience and professionals aim to go beyond the strengthening of communication of the care-users. An important aim is that the care-users adapt to or develop themselves in the new situation in their lives. The professionals and experts by experience are keen to link people to learn from each other; they search for the ideal mix of care-users in treatment groups. Observations are therefore an important aspect of the work of the professionals and experts by experience.

The experts by experience support the care-users in the centre by guiding small groups who learn to use a tablet or exercise speech and reading. They feel responsible for the tasks they perform. Nevertheless, they do not want a paid job at the centre because of the accompanying responsibilities. The experts by experience do not consider themselves role models, but they do speak about their own disability experiences, and they notice that in such cases, an openness in the contact with a care-user can arise: "*You know what the person is going through*". Openness deepens the relationship, and the relationship sometimes evolves into friendship. The atmosphere in the centre is one of a community; the care-users, professionals, and experts by experience know each other well and have lunch together. The experts by experience talk about the happiness and feelings of belonging their work with care-users provides ("*My work makes me happy*") as well as in the relationships with the professionals, who are considered equal ("*We are like colleagues*").

Lessons Learned from the Practice Examples

In both practice examples belonging is established by the valued roles of experts by experience that work side by side towards the same goal with health professionals, which is facilitating communication skills and empowering people with intellectual disabilities or aphasia. The experts by experience are employed because of their own disability experience, but this is not central in the way they are approached. Partnerships are established by creating a community in which feelings of belonging and empowerment are fostered.

The challenge to implement the concept of inclusion into long-term care is to involve people with and without disabilities in shared experiences without being forced to identify people as belonging to a specified group. In both practice examples, shared experiences are about working together in a team, having valued roles and being valued as an expert. As mentioned in the introduction, an inclusive society should be equipped with appropriate mechanisms to enable citizens to participate and feel valued and belong. The two practice examples might be

considered as a kind of micro society that shows what mechanisms are necessary to facilitate inclusion in long-term care. The following characteristics and practical consequences might be drawn from these examples.

First, firmly believing, as an organisation, that experiential knowledge of people with disabilities is needed and therefore also valued in care or support is the essential first step. One step further would be to carry out this believe on different levels, as a governor or manager, but also as a caregiver. Yet, professionals in long-term care hardly take up an advocacy role, e.g. in public debates about policy in care and inequalities in society. Their knowledge is also crucial to change situations that hamper inclusion.

Second, valuing different perspectives and differences in the care team, by hiring people with disabilities in valuable roles is the next step. Belonging is established by valued roles, as already described in the social role valorisation theory of Wolfensberger (2000). On top of that, experts by experience can become positive role models for people with disabilities and increase knowledge about lived experiences for professionals.

Third, in the care- or support relationship, professional knowledge and collective or individual expertise from experts by experience should be combined. Established ways of the care-user/professional relation should be reflected upon by experiential knowledge, because this challenges 'normality' (Fisher 2007). Room for agency or for development of agency of care-users, fine tuning, asking questions, creativity and openness towards the unexpected are important. Professionals need to let the person with disabilities know that professionals cannot do without their experiences and knowledge.

Finally, it is important to create a way of working from different types of knowledge, in co-creation, with an eagerness to learn from each other. How this can become reality will depend on the type of long-term care. It can take the form of a learning community, and in individual care or support it might be important to search for new ways of suitable communication or new ways to invite people to participate. Cobigo et al. (2016) highlighted the importance of creating room for each other to meet, experiment together, and build partnerships. This also asks for a critical appraisal of existing systems; how can new ways of working be created, together with experts by experience and what boundaries are met? This will certainly ask for a change in organisational structures.

Discussion and Conclusion

The focus of this article was that both in society and in care practices, inclusion is important to pursue and, at the same time, difficult to realise (Waters & Buchanan 2017; Rees, Knight & Wilkinson 2007). On the one hand, practices are not enough based on the perspectives of care-users: professionals do underpin the importance of user involvement, but implementation remains difficult (Mudge, Stretton & Kayes 2014). Further, in long-term care person-centred care could be the equivalent of inclusion, but it is not yet common practice and inclusion asks for more, such as valued roles in long-term care for people with disabilities.

With the two examples of care practices, we wanted to demonstrate how working side by side in partnership and dialogue can be realised. Believing in the skills and knowledge of the other person, sharing, openness and tuning in the relationship, and valuing roles and participation are important. O'Brien has stated that *'encouraging valued social roles challenges all people to discard stereotypes, see other people as individuals, and repair the damage done by past prejudiced treatment'* (1989:21). Support needed does not prevent working together. On the contrary, partnership can sometimes only exist when there is room to articulate support needs.

At the same time, attention to and room for agency of care-users or experts by experience must be guaranteed (Hilberink & Cardol 2019). Regarding the two practice examples, the agency of the experts by experience is not placed in the foreground, while from the perspective of care-users agency, power and control are paramount themes when thinking about inclusion (see 2.2). We think this might be a point of continuous attention. We learn from these practices that transparency in the relationship and a structure in which partnerships can develop are essential.

To reach this new way of working, reflection on the care-user-professional relationship, also together with care-users, to become more sensitive to power inequalities and lived experiences and to start the dialogue is necessary. Person-centred care in fact is relation-centred care. Arranging and establishing spaces of dialogue requires more than challenging care-users to raise their voices and become more involved. It is essential for dialogue and partnerships between professionals and care-users that 'we' (the majority, the abled, the professional, etc.) let go of the differences between minorities and the mainstream (we and they). Those working in care settings still largely operate within a framework based on an individual model of disability in which professional expertise is leading, and to make their practice more equal and relevant to the needs of long-term care-users, they need to re-orient their work to a framework based upon the social model (Oliver 2013; Shakespeare 1997). Taking the social model of disability as a starting point in practice might, however, be difficult because it may introduce uncertainties about one's own professionality, and it eliminates the hierarchy between professional and care-user. These difficulties should be discussed and experimented within practice.

In general, professionals are experts in disabilities; care-users are experts in their disabilities in their own lives and contexts. This means that no care-user-professional partnership is identical. The two examples show that inclusion can have different faces depending on persons and contexts. Differences in activities or responsibilities between the professional or researcher and the care-user or expert by experience are not always strictly defined and develop along the way in the process and in the relationship, like the dynamic and developmental processes Cobigo (2016) pointed at. By acknowledging this fact, inclusion in care practices or person-centred care is no longer a matter of ideals but merely a way of *doing* to improve the quality of care in the partnership and in the process of co-working. Doing inclusion seems to help to shape inclusion in different contexts, and in our experience, doing inclusion in care practices can reinforce inclusion in society because people learn from new perspectives and new ways of working together.

Some argue that inclusion still prevails as a dominant able-bodied standard and that equal citizenship is ultimately a matter of diversity (Hilberink 2016; Campbell 2009). The problem is that inclusion still unintendedly implicitly reinforces otherness and the excluded. Any claim of inclusive practice cannot exist without identifying the 'target group' being included, which maintains the binary, us and them. Thinking in terms of partnership might challenge all the stakeholders to rethink the essence of inclusion: to go beyond labels – we and they– and to reduce this concept to daily life – me and you. Equality cannot be included; it is practised, and equality demands mutual respect for diversity, for creating equal opportunities for all.

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