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Community care and the care transition in the Netherlands

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COMMUNITY CARE AND THE CARE TRANSITION IN THE NETHERLANDS

SAMENVATTING

“Community care” en de zorgtransitie in Nederland

De transitie in de gezondheidszorg in Nederland is al jaren een centraal thema in de politiek en het maatschappelijke debat. De recente veranderingen vereisen (opnieuw) aandacht in onder andere onderzoek en onderwijs. In dit artikel reflecteren we op de ideologie en doelen die schuilen achter de transitie in Nederland en linken we deze naar het onderzoek en onderwijs dat georganiseerd wordt door het lectoraat Community Care. Wat betekent het “nieuwe denken” van de transitie voor het Community Care gedachtegoed in relatie tot onderwijs en onderzoek?

Het lectoraat Community Care van de Hogeschool van Amsterdam houdt zich bezig met verschillende onderzoeksonderwerpen verdeeld onder drie stromingen: informele zorg, sociale inclusie en netwerkversterking. Binnen deze drie onderzoekslijnen wordt er gefocust op zorg door de samenleving en hoe dit gelinkt kan worden aan professionele zorg. In dit artikel zetten we uiteen waarom dit relevant is in onderzoek en onderwijs, zeker wanneer de transitie in Nederland eens te meer benadrukt dat zorg in en door de samenleving belangrijk is, en de rol van de zorgprofessional verandert. Tot slot reflecteren we op de manieren waarop we dit gedachtegoed en het huidige zorgbeleid kunnen vertalen in onderwijs voor studenten die later in het sociaal- en zorgdomein werkzaam zullen zijn.

Trefwoorden

Community Care, zorg in en door de samenleving, transitie in de Nederlandse zorg, zorgbeleid, onderwijs

ABSTRACT

Community care and the care transition in the Netherlands

The transition taking place within the Dutch healthcare system has been a central theme in politics and public debate for decades. The recent changes again demand the full attention of researchers and educators in the field. In this article, we reflect on the current ideology and goals of the transition and link these to the range of ideas that lie behind the ideal of “community care”. Additionally, we pose the question of what these changes may mean for research and education within the social care domain in general and for our research group in particular. The AUAS Community Care Research Group covers a variety of research topics that are clustered into three

"streams": informal care, social inclusion and network strengthening. Within these streams, we focus on care by society and link this to professional caregiving.

We will also explain why our research interests are specifically relevant in the context of the transition of the healthcare system, as this transition explicitly accentuates the importance of a "caring society" and thus a change in role for the care professional. We will also reflect on how we can best translate our research results into the curriculum of education programmes for students who will soon work as professionals in the social and/or care domains.

Keywords

Community care, healthcare transition, Dutch policymaking, education

INTRODUCTION

The philosopher Emmanuel Levinas (2003) writes about the nature of the relationship of the self to the other. He claims that when you realize that "you are you" and "I am I", you face the "forceful demand of being open for and prepared to experience the endless responsibility that is imposed on us through the radical otherness of the other" (Levinas, 2003, p. 12). This is an opening up to the other person that enables us to feel a moral obligation to care for one another. This philosophical perspective on human relationships can – according to Beneken genaamd Kolmer, Tellings, Garretsen & Bongers (2007) – be translated into the very practical aspects of care. We feel that, in fact, it is precisely a shift to this perspective that the transition taking place within the Dutch healthcare system demands of its citizens. It demands, among other things, that we be open to the other and affirm the feeling of an obligation to care for one another.

The will to change the welfare state regime to one where the government is less visible and transmits more responsibilities to its citizens has influenced Dutch governments since the 1980s. In the declaration of his first coalition's policy, former Prime Minister Lubbers announced the government's withdrawal from public arrangements in welfare and care, among other areas (Tweede Kamer, 1982, 1983). This, he suggested, would leave more room for citizens' initiatives and commitment. The ongoing changes in the welfare and care regime are now felt even more acutely, after a seemingly radical "transformation" marked by the introduction of new laws from 1 January 2015 (Participation Act, Youth Care and Chronic Care Act; Movisie, 2015; Social Support Act, 2015). Whether or not this new legislation could be called a radical transition, the fact remains

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that the transformation to which the Netherlands is subject, has affected every aspect of the social domain. This change not only affects the financial streams in the healthcare system, but also demands that care responsibilities are divided differently between the government, local authorities and citizens. It is a matter of debate whether these changes can realize their intended potential when they are accompanied by budget cuts and rapid adjustments to laws. Nevertheless, in reality, successive Dutch governments have been guided by this ideal and worked towards this transition for a long time.

Looking at the domain we are working in, it is understandable that the Community Care Research Group at AUAS is monitoring these changes in policy and practice closely. In our research and education programme – the latter producing future professionals who will work in the social care domain – we aim to connect theoretical ideas about community care to care practice in and by the community (Bulmer's categorization of community care, 2015). In this article, we therefore explore how the transitions in the Dutch social domain are related to the core ideas of community care. Our main question is: How is the body of thought around "community care" influencing the transitions in Dutch social care (and vice versa) and what does this mean for professional carers and their education?

Since our research is closely linked to practice, we will look at the healthcare transition in the Netherlands on different levels. For example, in the search for an appropriate connection between professional care and the needs of citizens, professionals must participate in care relationships in a different manner. Care organizations are looking for ways to relate to the transition. Overall, the transition demands an alternative view on what care could or should be for people in need of it, and for those around them. What role can community care ideas play here? To answer these questions, we will first explain how our research and education programme are organized. We feel that research and teaching play a very important role in bridging the gap between theory about community care and the practice of care. In accomplishing this, we assign a significant task to the care professional and we will explain why this is the case. Moreover, our research specifically focuses on initiatives by citizens, informal care, social networks and social inclusion. We will elucidate the necessary connection and interaction between these citizens' initiatives and professional care. The examples of research that we will touch upon emphasize the need to relate to the goals and laws that have accompanied the transition. As the feminist thinker Eva Feder Kittay writes:

In the same way that we must assume persons to have a sense of justice – albeit one that tends to be imperfectly realized – we must assume that people already possess a moral

sentiment of care. Both the assumption that people possess a sense of justice and a moral sense of care seem to be fair assumptions since it is difficult to imagine humans surviving beyond a single generation without *some* sense of justice and without some elemental sentiment of care. Yet for a more perfect society, both the moral sentiment of care and a sense of justice require cultivation through education and practice, the success of which requires political will (Kittay, 1999, pp. 244–245).

This political will drives the research that we aim to do and, therefore, we tend to remain critical about the ways research and education are combined. To invigorate this assumption and to answer the questions raised above, we will first explain the transition within the care system as stipulated in policy, and the ideology and goals that accompany it.

THE TRANSITION, ITS IDEOLOGIES AND GOALS

As mentioned above, the re-evaluation of the Dutch welfare state is not the new phenomenon that current discussions suggest. As early as 1983, a group of Dutch scientists published their views on “opportunities and perspectives” in the Netherlands in the aftermath of the welfare state, as it was known at the time (Idenburg, 1983). Shortly afterwards, Elco Brinkman, then Minister of Welfare, Health and Culture in the Lubbers I coalition, proclaimed the “return” of the caring society. This was a society where family, friends and neighbours would resume their care responsibilities within their own social circles. Under his regime, the welfare sector experienced drastic cutbacks and citizens were encouraged to deliver voluntary services in diverse public arenas. As a member of the CDA, the largest Christian political party in Dutch politics, Brinkman based his appeal on Christian notions such as common responsibility, social involvement and solidarity. Although his successor, Hedy D’Ancona, as a social democrat, used different terminology, her policy was the same: the government’s responsibilities in welfare and care should be minimized and citizens’ commitment had to grow. When changing Brinkman’s Welfare Act (Welzijnswet) in 1994, she formulated Dutch welfare policy as: “the common effort of governments ... and civil society to enhance people’s opportunities to develop, to be self-reliant and to participate ...” (Stb, 1994, p. 1).

Since then, the Act has undergone various changes, but the goal has remained the same. Alongside this Welfare Act, other acts and regulations concerning the care for and welfare of vulnerable people (psychiatric patients, people with disabilities, the chronically ill, elderly, etc.) have also come into being, all based on the same or similar principles: everyone in need of care must be given the opportunity to live independently, to develop their potential and fulfil their role in

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society (Kwekkeboom, 1990). These principles matched those of the diverse clients' and patients' movements, who also demanded more independence, self-management and freedom of choice.

The promotion of informal caregiving, be it as a family carer or as a volunteer, was also emphasized in Dutch policy on care and welfare. The idea was not only to unburden public provisions, but also to stimulate care awareness in society itself. The expectations were, and still are, that this awareness might lead to more acceptance of those in need of care and hence fewer obstacles to their actual inclusion. In addition, informal caregivers were recognized as the foundation of our care system, without whom the system could not be sustained and would lose its worth (Tweede Kamer, 2007, 2008).

This focus was seen as a good basis on which to justify the "withdrawal" of the Dutch government from the sector. In line with other Western societies, they moved towards more liberal preferences, and also made cutbacks to public services. While the care recipients and their carers did not necessarily want more funding or more extensive public support, they did not like their own wishes being used as an excuse for downsizing. This explains the actual opposition to the transition that started with the protests against the introduction of the predecessor of the Social Support Act 2015: the Social Support Act that was introduced in 2007. Although this Act relied on an ideology that most people adhered to (self-reliance, independence, inclusion, etc.), their protest pointed out that the conditions under which the Act was introduced were counter-productive, as the minimum level of provision was threatened. The three acts that came into being in 2015, were met with the same reception.

Thus, it would seem that people do not necessarily disagree with the ideology behind the new laws, but oppose the conditions under which they came into being. The ideology relates to the ideas of "caring in" and "caring by" the community, which our research group focuses on. The transition demands that citizens rethink the ways they address the need for care, but it also means that professionals who encounter care recipients and their informal carers must commit themselves to put into practice the reasoning that the new acts promote. This not only requires the professionals to have an understanding of the historical background and ideological grounding of these laws, but also to find answers to questions such as:

- Who are these informal caregivers and what can I do to help them to persevere with helping their loved one?
- Why do people volunteer for caregiving, offer neighbourly help, or become active citizens and what is my role in supporting their activities?

- What do people with disabilities need to be able to go to school, have a satisfactory job, perform as an artist, achieve results as an athlete, etc., and how can I assist them?
- How do I determine the degree to which someone can live and act independently and where professional care should come in?
- What can or must I do when society excludes my clients and they are threatened with exclusion and loneliness?

These and similar questions are taken on by the Community Care Research Group with the aim of providing our students, especially those who enrol in a minor in Community Care, with sufficient knowledge to determine their own role in the transition and deal with it responsibly. We believe that the idea of community care provides the necessary space for students, researchers and professionals to exchange knowledge. In the following section, we will touch upon this idea of community care and highlight examples of our own research and the way it is necessarily connected to education and care practice. We will also explain how our research results might have an impact on the work of current and future social work professionals.

COMMUNITY CARE

Due to its applied research focus, the Community Care Research Group plays an important role in maintaining the connection between research, education and the practice of care. These different arenas complement each other, with research and education contributing to the practice of care, and the latter adding to research and education. The Community Care Research Group covers a variety of research topics that are clustered into three “streams”: informal care, social inclusion and network strengthening. This means that, following Bulmer’s (2015) distinction between caring in and caring by the community, we focus first and foremost on care that is carried out by members of society itself. Evolving from this starting point, the group’s research seeks to elucidate its results with respect to formal care that is provided in society. We believe it is important to constantly maintain that relationship and see it as a basic responsibility of the research group to convey our findings to society.

One way of doing this is by educating future social work professionals, as will be touched upon later in this article. In the context of education, the practice of care and welfare offers teaching materials such as practical examples that can be used in courses to clarify theory. The transition in care in the Netherlands is a current and pressing issue, it is of note that Community Care research and education is linked to it in various ways. In the following sections, we will discuss two examples from our research that elucidate this link, and demonstrate how we attempt to connect

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research, education and practice. Informal care, social inclusion and social network strengthening are core themes in our research programme and they all add to the practice of social work and accord with community care ideas. Below, we will elaborate on the research we conduct on informal care and social inclusion, which we will link to community care, the education of social work professionals and the transition that the Netherlands is currently undergoing.

INFORMAL CARE

As mentioned above, informal support is key to ensuring the transition is sustainable and successful. Since 2012, the Community Care Research Group has been working on a project called "Diversity and Informal Care". This project investigates the possible differences between several groups of people in relation to giving and receiving informal care and the consequences of this on desires and expectations with respect to formal care. The informal caregivers' perspective is central to this project.

The transition demands that Dutch citizens be open to others and feel that the obligation to care for one another is important. As our research shows, this is exactly what citizens already do. Most informal caregivers provide care out of love and affection for others (HvA, 2014). However, we should be careful not to overburden informal caregivers through further extensive budget cuts that have accompanied the transition. Under the Social Support Act, local authorities are given responsibility for providing certain types of care, help and support. In addition, they are responsible for providing conditions under which everyone can participate in society to their full potential. Access to publicly funded care provisions is being reduced, and this means more demands are being placed on informal caregivers. It is necessary to pay more attention to the informal caregivers' perspective here: although the aim of the Social Support Act is also to improve the position of informal caregivers, in reality the informal caregivers are not always being heard (Verbeek-Oudijk, Woittiez, Eggink & Putman, 2014). An important conclusion from our research on informal care is that it is unclear to what extent informal caregivers can take on – and want to take on – more caring responsibilities in the future.

In addition, informal caregivers are not always satisfied with the provision of professional care for their loved ones: in one study almost half of our respondents (n = 579) reported that the professional care was inadequate, while 25 percent indicated there was a need for more professional care for the care recipient (Wittenberg & Kwekkeboom, 2014). People in the Netherlands are caring for each other out of love and affection but cannot take all the care

responsibilities on their own shoulders. Professional help should therefore be maintained and held to a certain standard (Kwekkeboom, 2010, p. 21). This is one example of how we attempt to influence professional care through our research. Based on the findings of this study, it is quite clear that the transition should not lead to the reduction of professional care to a minimum while being justified by pointing to the responsibilities and duties of citizens. Rather, it means that the government and local authorities should facilitate ways in which professional and informal caregivers can work together and think of ways to create desirable forms of community care.

We consider these outcomes to be very important in relation to updating the education programme for professionals in social work. Social workers can form the link between the bureaucratic world of policy and the everyday world in which citizens live, but they should also be aware that their role is to assist, rather than take control. Together with the demand that is made on citizens to rethink their care role in society, there is also a need to rethink the role of the social work/care professional. Care that is being given by the community forms part of the new core of care; therefore, social workers should help citizens to reach their goals with other citizens by making use of or developing social support structures (Jager-Vreugdenhil, 2012). Future professionals in the field should be trained in how to collaborate best with informal caregivers and volunteers to personalize care and to meet the needs of the entire care triad of informal caregivers, professionals and clients.

By using our research results in designing social work curricula, we aim to connect the professional field to the objectives of the transition, and contribute to training students in this field. This training is one way of connecting education to the practice of care. Students are encouraged to actively find connections to practical care organizations. They undertake internships and also form direct links to these organizations when doing research for their degree. Because our research group has close links to various organizations, we facilitate connections between students and these organizations to exchange knowledge. Students learn, for example, how organizations are dealing with the transition within the healthcare system, and the organizations also learn how students view their role as social workers. This constant dialogue between practice, education and research is crucial in navigating the constant changes in the healthcare system and society.

SOCIAL INCLUSION AND IMPROVING ACCESSIBILITY

Another central theme in our research group is social inclusion, meaning the ways in which society and its citizens conduct inclusive policy. The introduction of the Social Support Act not only

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entailed changes in the way people were encouraged to take care of each other, it also entailed a change in the way society was organized (Cobigo, Ouellette-Kunz, Lysaght & Martin, 2012). It required that ways be found to ensure everyone can fully participate in society. For example, rather than giving people individual aid to participate in an activity at a welfare centre, welfare centres in general are stimulated to become accessible to people with disabilities, so that they can participate independently of any aid provided by the government (Gemeente Amsterdam, 2011). The social inclusion of people with disabilities (regardless of the cause or character of their impairment), became an important goal of the Social Support Act. Inclusion here means not only helping people to participate, but also stimulating society itself to become more accessible to and accepting of people with different needs.

Social inclusion is an important and essential concept when thinking about “a caring community”. It not only concerns the ways in which people include others, which implies too much of a hierarchical way of thinking, but also that society itself and all its institutions are inclusive. Society, if we think of it as a place, has enough “room” to include people with various backgrounds and different mental and physical abilities.

The concept of social inclusion as defined here is derived from the social model of disability developed by Oliver (1996). In this theoretical model, the terms “disability” and “impairment” are separated, with “impairment” understood in terms of the physical difference with a healthy person, and “disability” understood as the ways in which this person is disabled by an inaccessible environment. Disability is thus regarded as something that society itself creates by not removing barriers that disbar a person with different needs from participating. This model also fits with the current ways of thinking about care and society, in which the focus lies more on social relationships and community building than on medical terms and physical impairments. It demands that people be aware of how society can be disabling, and not just on how people – due to illness or impairment – are less able to participate.

The social model of disability has more impact when it is translated into policies that improve accessibility. It changes the way we think about who is responsible for ensuring that people with disabilities can participate. Should the person with the disability be given help to participate, or should organizations alter their ways of working to accommodate people with different needs? When the individual support of people with disabilities was suspended by the Social Support Act (VWS, 2008), organizations such as neighbourhood community centres were expected to improve their accessibility and thereby welcome the people who had lost this individual support (Gemeente

Amsterdam, 2011). In a research project that we carried out for the local authorities of Amsterdam, three important problems became visible when we asked the social work professionals from these community centres how they had improved accessibility.

Firstly, they found it difficult to know how to address everyone's needs, particularly when the disability was variable or invisible. Obvious disabilities, such as using a wheelchair, are easier to deal with than disabilities of which the symptoms and the severity are unclear or variable. This left some professionals uncertain about when or how to offer help or introduce adjustments. Secondly, the professionals found it difficult to accommodate people with disabilities that are often stigmatized, such as psychiatric problems or contagious diseases. They did not always have the tools to create an environment in which visitors from the neighbourhood were accepting of and inviting towards the people with disabilities. Thirdly, another issue was that the professionals had problems communicating with people with disabilities that affected how they communicate. For example, they were not sure how to best communicate with someone on the autism spectrum, or with someone affected by a physical disability such as a hearing impairment (Van Zal & Kwekkeboom, 2013).

These research findings demonstrate the difficulties currently faced by professionals in the field when expected to give shape to the changes that the Social Support Act demands of them. The results also point us in new directions in relation to what students should be taught if they are to have the skills required to create an accessible and welcoming environment in organizations such as community centres. This new knowledge has been woven into educational programmes so that students are prepared for a future in which an inclusive society is no longer an individual but a societal responsibility.

This way of thinking about social inclusion in relation to the social model of disability plays a very important role in the education programmes that our research group develops. It goes without saying that advancing the concept of social inclusion in a positive way, as the Social Support Act is supposed to achieve, is relevant to future professionals, as it demands new ways of connecting everyone, whereby citizens are encouraged to rely more on each other or in different ways. Professionals in the field will not only have to work on helping a client but also help the people around them to be welcoming to and accepting of people with disabilities. This implies a shift in responsibility from the client to the entire environment (Kal, 2008; Van Regenmortel, 2009). When society is made responsible for enabling participation and being open and accessible, what facilitating role can social professionals play?

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To achieve positive outcomes, it is necessary that “inclusion” is understood less ideologically and more practically, so that it can be translated into everyday practice for professionals as well as for those whom they support (Van Zal & Kwekkeboom, 2016). The first step required to achieve this is the inclusion of the notion in education. Social inclusion seems to be a basic ingredient when thinking of community care, and particularly in relation to our focus on care in and by the community. However, as mentioned above, inclusion is too often thought of ideologically. To ensure future social work professionals understand the real value of the idea, it should be translated into more practical notions. Examples of practical ways to work on social inclusion include: improving accessibility, connecting clients to fellow citizens, and “kwartiermaken”. This is a method developed by Kal (2008) to stimulate acceptance and reduce stigma among psychiatric patients. However, it starts with awareness of what the term can mean. In our minor in Community Care this awareness is touched upon in various ways. While we teach theory about community care and how social inclusion plays an important role in it, we mainly discuss what students feel social inclusion is, implies or might be.

CONCLUSION

Returning to the main question of this article: How is the body of thought around “community care” influencing the transition in Dutch social care (and vice versa) and what does this mean for professional carers and their education? We can now respond by drawing attention to several issues. Firstly, we emphasized that the transition within the care system in the Netherlands must be accompanied by research to ensure the goals of policy are met. Secondly, the transition demands that care is given by communities, and our research shows that such forms of care are possible. The idea of community care has a place within the social domain as long as professionals, informal caregivers and care recipients are able to formulate their desires and care needs together, and provided that concepts such as social inclusion and social networks are incorporated. This demands a different attitude, not only from the professionals but from citizens as well.

Practical research, such as that conducted by our group, should be executed with caution to make sure that care in and by the community is not used as an excuse for budget cuts. We conclude that a healthy form of community care is crucial to society. The transition demands citizens be more involved in taking care of one another and, as a result, students of the AUAS also find themselves at this intersection. When undertaking research or teaching, a single focus in the social domain is therefore not desirable. Social work and care can and should be looked at simultaneously, as should formal and informal care. The continuation of applied research in relation to the transition seems to

be a productive form of dealing with all the aspects that accompany this transition, with ideology and practice both continuously developing and changing. To conclude, as a research group, we support the appeal made to people to care for one another, but we argue that the appropriate circumstances should also be created so that we can first see and acknowledge the other.

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