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Perspectives on neighbourhood social inclusion of people with intellectual disabilities

A study on social inclusion in the neighbourhood from the perspective of people with intellectual disabilities, neighbours and group home staff members

Tessa Overmars-Marx



Perspectives on neighbourhood social inclusion of people with intellectual disabilities
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Perspectives on neighbourhood social inclusion of
people with intellectual disabilities

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Chapter I

General introduction and discussion



*The problem with the 'single story' is not that it is untrue,
but that it flattens the human experience.*
Chimamanda Adichie 2009

This quote, by Adichie (2009), represents a single story about Africa told in the West. Her TED talk describes her experiences with American people during her study time in the United States. Her first experience was with a roommate who positioned her as an African, in a kind of patronizing, well-meaning pity. In this single story, there was no possibility of Africans being similar to her roommate, in any way. Adichie explains how she perceives Africa in an entirely different way; as a continent with beauties and difficulties. During her stay in the United States, she realizes that US citizens have seen and heard different versions of a single story about Africa through different media. This single story creates stereotypes – and the problem with stereotypes is not that they are untrue, but they are incomplete. They rob dignity, and make it difficult to recognize equal humanity.

Adichie emphasizes that many stories matter, and we should realize that there is never one, single story. Similarly, society's views on the position of people with intellectual disabilities is often based on a single story: one that is developed within a cultural context and omits the perceptions of the groups involved.

A short historical overview shows how the position of people with intellectual disabilities in Western societies has changed over the decades, and how these developments relate to the views held in society. Historically, people with intellectual disabilities in the West, including the Netherlands, have experienced stigma based on a combination of pity and fear (Scheerenberger, 1983). Historical references show that during the Middle Ages, people with intellectual disabilities were banished from the cities if, for example, they displayed behaviour considered inappropriate (Mans, 1998). People with intellectual disabilities were viewed as 'other' and occupied their own place (Kitchin, 1998; Meininger, 2013). From the mid-nineteenth century until the third quarter of the 20th century, care for people with intellectual disabilities was mainly concentrated in large-scale institutions, segregated from the rest of society (Collins, 2015). These institutions aimed to provide safety and security that was not assured for these individuals elsewhere in society (Mans, 1998).

Models of social care developed from the 1950s onwards. In subsequent decades, people with intellectual disabilities became more visible in society. In many European countries, large institutional settings (geographical places of exclusion) have been declining, and people with intellectual disabilities moved to ordinary neighbourhoods (Beadle-Brown, Mansell, & Kozma, 2007; Overmars-Marx, Thomése, Verdonchot,

& Meininger, 2014). The development of deinstitutionalization was inspired by the normalization model, which held that people with disabilities could also contribute to society (Wolfensberger, 1983). This principle asserts that people with intellectual disabilities should have opportunities to live like other citizens (Oliver, 1996) and proposed smaller community-based services to allow for more opportunities for self-determination and choice making than larger, congregate settings (Van Alphen, 2011). This increasing awareness of human rights encouraged further developments regarding systems of care and support in the community (Collins, 2015). In the most recent decades, social inclusion of people with intellectual disabilities has become a dominant focus of care organizations and policy makers in many Western countries, including the Netherlands.

In the context of these developments, the United Nation Convention on the Rights of Persons with Disabilities was adopted in December 2006 (United Nations Convention, 2006). The Convention is intended as a human rights instrument with an explicit, social development dimension. It reaffirms that all people, with all types of disabilities, must enjoy all human rights and fundamental freedoms. This asserts that people with disabilities should have the opportunity to make their own choices, based on the principle that they should have the same opportunities for full and effective participation and inclusion in society as any other citizen.

Social inclusion is a key component of the Convention (Quinn & Doyle, 2012) and it is an important aspect of the quality of life of people with intellectual disabilities (Buntinx & Schalock, 2010). Cobigo, Ouellette-Kuntz, Lysaght, & Martin (2012) use an ecological approach to conceptualize social inclusion. They define social inclusion as a series of complex interactions between environmental factors and personal characteristics that provide opportunities to: access public goods and services; experience valued and expected social roles of one's choosing based on his/her age, gender and culture; be recognized as a competent individual and trusted to perform social roles in the community; and belong to a social network within which one receives and contributes support. If social inclusion is conceptualized as an outcome of the interaction between individual and environmental characteristics, then it is important that any research in this field involves actors who form part of this interaction, using a multi-perspective approach.

Despite the developments of deinstitutionalization and policies focusing on social inclusion, society's views about people with intellectual disabilities do not seem to have changed (Cummins & Lau, 2003; Verdonschot, Reichrath, Buntinx, & Curfs, 2009a, 2009b; Overmars-Marx et al., 2014). Until now, the movement from institutions to neighbourhoods has been mainly a physical development, and the desired social

change has not occurred. In itself, spatial location (or relocation), does not seem to be a sufficient condition for realizing social inclusion (Meininger, 2013). This might be because inclusion policies ignore the exclusion faced by people with intellectual disabilities in society. They may have left the geographical places of exclusion, but the discriminatory context into which they move remains unchanged, and they are still regarded as 'other' (Hall, 2005; Meininger, 2013). As Collins (2015) states, there is huge difference between living within the community as part of the community and living within the community but isolated. People with intellectual disabilities feel isolated from ordinary neighbourhood activities, and have fewer contacts with neighbours than people without disabilities (see, for example, Cummins & Lau, 2003; Hall, 2005; Cobigo & Stuart, 2010). They still encounter discrimination and rejection (Cobigo & Hall, 2009; Hall, 2005). Spaces are more organized in a way that allows people with intellectual disabilities to live in the presence of others. However, for if these spaces are to facilitate true inclusion, this requires not only adjustments from people with intellectual disabilities, but changes within society (Clegg & Bigby, 2017). The difficulty in translating changes to date into changes in people's lived experience suggest that more knowledge about the process of social inclusion is needed to realize the goal of social inclusion.

Our study focuses on social inclusion in the neighbourhood. Little is known about the relationship between neighbourhood characteristics and social inclusion of people with intellectual disabilities (Overmars-Marx et al., 2014). Neighbourhood characteristics can be divided into social and physical aspects (see, for example, Martin & Cobigo, 2011; Van Alphen, Dijker, Van Den Borne, & Curfs, 2010). Social aspects relate to the interactions with neighbours, group home staff members and other actors in the neighbourhood. Physical aspects refer to the presence and accessibility of neighbourhood facilities that offer opportunities for social inclusion. Our study aims to provide insight into social and physical aspects of the neighbourhood that relate to the process of social inclusion in the neighbourhood from the perspective of various groups involved in this process. It thereby makes a crucial contribution by providing new knowledge that helps to facilitate the interaction between people with intellectual disabilities and their neighbourhood. Returning to the words of Adichie, we strove for a multi-perspective approach that would ultimately result in valuable knowledge to guide service providers towards effectively promoting the process of social inclusion in the neighbourhood, taking into account the perspectives of the involved groups: people with intellectual disabilities, their neighbours and group home staff members. This resulted in the following central question:

- What social and physical aspects of the neighbourhood play a role in the process of social inclusion in the neighbourhood of people with intellectual disabilities, studied from the perspective of people with intellectual disabilities themselves, their neighbours and group home staff members?

To explore the different perspectives on social inclusion in the neighbourhood of people with intellectual disabilities, it is important to define the group of people with intellectual disabilities that involves our research, so that the involved groups (mainly, neighbours) know who is concerned. In our study, we include people with mild (IQ: 50-70) to moderate (IQ: 35-50) intellectual disabilities who live in group homes in ordinary neighbourhoods. In line with the developments towards social inclusion, we consider an intellectual disability not only as a limitation in intellectual and adaptive skills, but also as a problem in the life situation as a whole, depending on their individual context (Buntinx & Schalock, 2010; Tassé, Schalock, Thompson, & Wehmeyer, 2005). A more detailed definition of intellectual disability is available at: <http://aaid.org/intellectual-disability/definition#.VbcsBfnSSVM>.

In this introduction and discussion chapter, we first discuss the concept of neighbourhood social inclusion from three perspectives: people with intellectual disabilities, neighbours and group staff members. We will relate our research question to these three perspectives. Next, we address the study design and research context and present a summary of each chapter of this dissertation. This summary is followed by the discussion, in which we reflect on our findings related to the literature and present the strengths and limitations of our research that lead to recommendations for future research. We conclude this chapter with practical implications.

Social inclusion in the neighbourhood: including different perspectives

The developments related to deinstitutionalization, and the current situation regarding social inclusion, show that the physical presence of people with intellectual disabilities did not automatically lead to social inclusion. Many studies show that people with intellectual disabilities who live in ordinary neighbourhoods still do not have equal opportunities for full inclusion (Cummins & Lau, 2003; Verdonshot et al., 2009a, 2009b; Overmars-Marx et al., 2014). Meininger (2013) suggests this might be due people with intellectual disabilities moving into environments with discriminatory characteristics. We therefore stress the importance of using an ecological model to gain more understanding about the process of neighbourhood social inclusion. This

type of ecological approach emphasizes the importance of the interactions between personal and environmental characteristics (Scheidt & Norris-Baker, 2003). In our opinion, using an ecological approach inevitably means involving the actors that participate in the interaction. This is in line with the recommendation of Cobigo et al. (2012) that an ecological model should be guided by a multi-perspective approach. We stress the importance of this approach because each of the various actors in the same neighbourhood has their own position and perspective on their environment. There may be differences in how people view the nature and the extent of social inclusion. This may, in turn, affect their behaviour with regard to the social inclusion of people with intellectual disabilities. No earlier studies focus on operationalizing this ecological approach by involving different groups of actors within the same contexts. Our study aims to provide insight into the perspectives of the three different actors involved in neighbourhood social inclusion: people with intellectual disabilities, neighbours and group home staff members. Within the context of studying different perspectives, we acknowledge that besides the three groups we included in our study, there might be more additional relevant groups that occupy certain roles who influence the process of social inclusion. However, we wanted to focus on these three groups because they are directly involved in the process of social inclusion in the neighbourhood.

Neighbourhood social inclusion and the literature

Before conducting our empirical study, we wanted to gain more insight into the relevant literature to explore the knowledge gaps. We aimed to find out which factors relate to neighbourhood social inclusion, according to the literature, and how the identified factors facilitate or hinder social inclusion in the neighbourhood. We based our exploration of the literature on the conceptualization of Cobigo et al. (2012), which emphasizes the importance of the interactions between personal and environmental characteristics (Scheidt & Norris-Baker, 2003). However, where Cobigo et al. (2012) address inclusion in general, our focus was on social inclusion in neighbourhoods. This resulted in the following sub-question:

- What elements of social inclusion are covered in the selected studies, and what important barriers and facilitators for neighbourhood social inclusion do they highlight?

Perspective of people with intellectual disabilities

First, we incorporated the voices of people with intellectual disabilities in our research. Including the perspective of people with intellectual disabilities contributes to the validity of the research because it allows for an authentic analysis of their beliefs or knowledge related to the research questions (Jurkowski, 2008). The methods used

to involve people with intellectual disabilities are often limited to interviewing and conducting focus groups (Jurkowski, 2008). However, there is a question around whether these more traditional methods are always effective for assessing the views and experiences of people with intellectual disabilities. Conventional research methods often do not overcome the barriers for people with intellectual disabilities – for example, those who have difficulty with direct communication and cognitive impairment (Sigstad, 2014). Sigstad (2014) discusses the need to use alternative strategies and methods, in order to gather richer information. Photovoice appears to be one such promising method. This is a photographic intervention, qualitative research method, that enables participants to visually document, share and collectively interpret their stories (Ottmann & Crosbie, 2013), with responses focusing on concrete issues instead of abstract themes (Finlay & Lyons, 2002).

We selected the photovoice approach in order to gain more insight into the perspective of people with intellectual disabilities concerning their social inclusion in the neighbourhood. Conceptualization of social inclusion from the perspective of people with intellectual disabilities has been underexposed in the studies up until now. Cobigo et al. (2012) address the importance of involving the subjective perspective of people with intellectual disabilities to understand the process of social inclusion. Studies that do focus on this subjective perspective show that people with intellectual disabilities can feel excluded, that they do not belong, different or unsafe in the neighbourhood (see, for example, Abbott & McConkey, 2006; Hall, 2005; Van Alphen, Dijker, Van Den Borne, & Curfs, 2009). However, these studies do not provide information on what neighbourhood social inclusion actually comprises, from the perspective of people with intellectual disabilities. Our research aims to provide this information. Therefore, we formulated the following sub-question:

- How can social inclusion in the neighbourhood be conceptualized from the perspective of people with intellectual disabilities?

Perspective of neighbours

The second group that we involved was that of neighbours. Neighbours form an important part of the neighbourhood environment of people with intellectual disabilities, and people with intellectual disabilities are, in turn, part of their neighbours' environment. The neighbours' perspective is crucial because they are the most important partners for achieving social inclusion in the neighbourhood. However, we found only a few studies that involved neighbours of people with intellectual disabilities (Van Alphen et al., 2010, Bredewold, 2014).

By involving neighbours in our study, we would obtain more knowledge about neighbours' experiences of their relationships with people with intellectual disabilities living in their neighbourhood. Studies that focus on the (hypothetical) relationships

between people with intellectual disabilities and their neighbours show various barriers: for example, privacy issues, unconventional and unaccepted behaviour, neighbours' perceptions of the group context, the caring role and a lack of skills to interact (Van Alphen et al., 2010; Bredewold, Tonkens, & Trappenburg, 2015; Wiesel & Bigby, 2014). Positive contacts were identified during fleeting encounters. These studies show isolated factors, but focusing only on the interaction between people with intellectual disabilities and neighbours. In contrast, in our study we consider these interactions as part of general neighbourly relations. Neighbouring in general, might help to understand the social interactions between neighbours with and without intellectual disabilities. Do neighbours see people with intellectual disabilities as part of their neighbourhood, and their neighbouring patterns, or as a separate group? And does this view vary for different types of neighbour relations? This led to the following sub-question:

- Which neighbouring patterns can be identified, and how do people with intellectual disabilities fit into these patterns?

Perspective of group home staff members

The third perspective incorporated in our study is that of group home staff members. In many studies, professionals act as informants on the actual participation and roles of people with intellectual disabilities in the neighbourhood and the staff members' role in developing the skills to fulfil these social roles (Kozma, Mansell, & Beadle-Brown, 2009; O'Brien, Thesing, & Tuck, 2001; Thorn, Pittman, Myer & Slaughter, 2009). Our study does involve group home staff members. However, it views them not as informants but as part of the social inclusion process. The process of deinstitutionalization, and related goals to social inclusion, calls for a fundamental change in the focus of group home staff members: from a caring role to one that is more supportive (see Abbott & McConkey, 2006; Van Alphen et al., 2009; Bigby & Wiesel, 2015). However, enhancing this role requires more information about group home staff members' perceptions of their role in neighbourhood social inclusion.

We reflect on this performance through the concept of professional role identity. The way professionals act towards the neighbourhood and neighbours strongly depends on how they view their professional identity (Pratt, Rockmann, & Kaufmann, 2006; Weick, 1995). The enactment of their profession is also influenced by institutional forces (Chreim, Williams, & Hinnings, 2007): professionals adjust the enactment of their professional identity in their professional role to their perceptions of the expectations and support of service providers. Thus, to understand the performance of group home staff members in supporting social inclusion, we aimed to gain insight how neighbourhood social inclusion is embedded in two areas: first,

their perceptions of how they should contribute to the process of neighbourhood social inclusion, and second, the experienced support from, and expectations of, the institutional environment in relation to social inclusion. Therefore, we address the following sub-question:

- How is neighbourhood social inclusion embedded in the professional role identity of group home staff members?

Our study provides new insights by focusing on various perspectives through obtaining knowledge from different groups. However, we do recognize the fact that we assigned each participant a certain role: either as a neighbour of people with intellectual disabilities or as a staff member who supports people with intellectual disabilities. It might be that participants would respond differently if they were questioned without being assigned these roles. As well as the effect of being questioned in the context of a certain role, we also expected individual differences within the groups. Studying social processes inevitably involves generalizing to certain groups instead of studying each individual separately, our study aims to obtain knowledge from the three groups as described. However, where possible, we also provide insight into the individual differences within the groups, where they become visible in our study. Hence, we present differences and similarities between the groups, and between the individuals within these groups. These insights will help to create and maintain valuable collaborations between these groups and individuals from different groups.

Study design and research context

Study design

Our study, including all data collection, was conducted in three neighbourhoods in 'de Achterhoek', in the eastern part of The Netherlands (see Figure 1). The nature of our study design was both descriptive and explorative. Studying different groups within the same contexts helped us to gain a better understanding about the process of social inclusion in the neighbourhood. The aim of our study was not to provide final and conclusive answers about how to build social inclusion, but to depict the views and experiences of the people involved in neighbourhood social inclusion in an accurate way that provides insights that can help enhance neighbourhood social inclusion. We used several qualitative techniques to involve people with intellectual disabilities, their neighbours and group home staff members in our study. Detailed methodological information is incorporated in the chapters that follow, each of which focuses on a different group of participants.



Figure 1 – ‘De Achterhoek’

In this section, we set out more information about the research context of our study. First, we describe the system of care for people with intellectual disabilities in The Netherlands, followed by a description of the service providers involved and their residents. Finally, we address the selection procedure of the neighbourhoods.

The Dutch context: care for people with intellectual disabilities

Care for people with intellectual disabilities is part of the Dutch Long Term Care system. Long-term care in the Netherlands was reformed comprehensively in 2015 and is now spread over three Acts. The first, the Long-term Care Act (*Wet langdurige zorg*), regulates care in institutions (residential care) and the community (group home care) for people who need 24-hour, government-funded care. Home care is regulated by the Health Insurance Act (*Zorgverzekeringswet*) and funded via health insurers. Other support for people at home is regulated by the Social Support Act (*Wet Maatschappelijke Ondersteuning*) and is the responsibility of the municipality (Kroneman, Boerma, Van den Berg, Groenewegen, De Jong, & Ginneken, 2016). Our study includes people with a mild-to-moderate intellectual disabilities (93% of the people with intellectual disabilities in the Netherlands). In the current situation, people with mild-to-moderate intellectual disabilities either live in group homes in the community, where they receive 24-hour residential care or supported at home under responsibility of the municipality (referred to in the Netherlands as ‘ambulant care’).

Service providers and people with intellectual disabilities involved in our study

The study received financial and practical support from four service providers operating in this area, which helped select neighbourhoods and recruit participants. These providers all support people with mild-to-moderate intellectual disabilities, in some cases combined with mental health problems and/or autism spectrum disorders, both in residential care and in their home situation. One also supports people with more severe intellectual disabilities and/or people that need intensive physical care. Two have a specific focus on youth care. On average, the service providers support 1,100 residents with intellectual disabilities, ranging from 600 to 2,500 residents (across both residential and home care).

Our study focuses mainly on people with intellectual disabilities living in group homes. The group homes included in our study house an average of 15 people each. We acknowledge that focusing on people who were identifiable as having an intellectual disability might raise certain preconceived views within the environs of the group homes. This might be different if the label would be less identifiable, for example concerning people with intellectual disabilities supported in their home situation. The decision to focus on residents of group homes was made for two reasons. First, this approach fits with the move towards deinstitutionalization. Second, choosing people receiving support in group homes was essential to help us gain understanding about the actual views and experiences of their neighbours and their interactions with people who were identifiable as an intellectual disability. Among the participants with intellectual disabilities we also recruited people supported in their home situation, to maximize our insights.

Selection procedure of the neighbourhoods

The selection procedure was carried out in consultation with the four service providers, with selection criteria based on the following requirements:

- **Equal representation of the four service providers.** This resulted in studying one group home in one neighbourhood, four group homes in the second neighbourhood, and a further four in the third neighbourhood.
- **Variation between the residents** All residents included in our study must have a mild-to-moderate intellectual disability. However, different group homes housed different residents with different profiles. Two group homes housed some residents who also had mental health problems and a further four, some residents had physical support needs too.
- **Variation between the neighbourhoods** Neighbourhoods must represent some variety in terms of the degree of urbanization, the level of facilities, the type demographic of the inhabitants, and the level of neighbourliness. This variation

indicates a diversity of social and physical neighbourhood features relating to social inclusion that we expected to find.

Based on these selection criteria, we included three neighbourhoods. Two were situated in a low-urbanized area with approximately 15,000–20,000 inhabitants. The neighbourhoods differed in their level of facilities. Both offered shopping, catering and leisure facilities, but one had a greater availability of the various facilities that attracted people from across the region, while the other had more of a village-like atmosphere.

Both neighbourhoods had fairly similar sociodemographic characteristics, with a relatively high percentage of people aged above 65 years (23% and 26%, compared to 17% of the Dutch general population (Centraal Bureau voor de Statistiek, 2014). The average income of neighbourhood residents was defined as just below the average income of the general Dutch population (€29,500): between €24,400 and €26,600 gross per year.

Both neighbourhoods were known as sites where a modern kind of neighbourliness played an important role. In the past, there had been a strong sense of neighbourliness (*noaberschap*). Neighbours were not just neighbours who one knew and chatted with in the street: neighbours played an important role in the people's lives, in their successes and sadness (Abbas & Commandeur, 2012). Neighbours were expected to support each other practically and emotionally (*noaberplicht*). Each neighbour had his or her own role in the neighbourhood, with related tasks. By the time of our study, this original concept of neighbourliness had developed into its current form, in which neighbours contributed to the quality of life of their neighbourhood (*modern noaberschap*). Supporting each other and reciprocity were still key elements of *modern noaberschap*. However, the obliged character of *noaberschap* is replaced with a sense of mutual responsibility and trust (Abbas & Commandeur, 2012).

The third neighbourhood was a suburb of a small town with a population of 55,000 inhabitants. This neighbourhood had high levels of socio-economic deprivation. Neighbourhood residents had an average gross yearly income of €21,200 – below the national average – and a relatively high percentage (47%) of residents were in the 40% of the lowest incomes in the Netherlands (Centraal Bureau voor de Statistiek, 2014). Like the other two neighbourhoods, this neighbourhood contained a relative high percentage of people aged above 65 years (25%). The group home included in our study was situated in an apartment building and residents have their own apartments spread over three blocks of flats. In our study, we considered the

neighbourhood as a subjective entity. This meant there were no explicit geographical barriers to the area.

Our study among neighbours was conducted in two of the three neighbourhoods. The third neighbourhood (not included in this study) was home to only one group home, which housed residents in different apartments across three blocks of flats. This implied that many neighbours would not be aware of the presence of people with intellectual disabilities and, because of the physical construction of the neighbourhood, there were limited opportunities of chance encounters. To maximize the likelihood of conscious encounters between neighbours and people with intellectual disabilities, we excluded this neighbourhood.

The overall aim of our study was not to compare the three neighbourhoods, but to gain as much information as possible about the process of social inclusion. By selecting neighbourhoods with the presence of a diverse range of service providers and related group homes and residents, combined with a variety of social and physical neighbourhood aspects, we tried to meet the conditions to reach this aim.

Chapter overview

The process of social inclusion was researched from different perspectives. These perspectives are explored and described in different studies, summarized in Table 1.1. The major findings are summarized, by chapter:

Summary of the findings

Chapter 2 – Neighbourhood social inclusion: exploration of the literature

The exploration of the literature in chapter 2 aims to provide further insight into which factors are important in developing social inclusion in the neighbourhood. We studied the literature to maximize our understanding of factors that could be relevant to social inclusion, focusing especially on neighbourhood factors. Based on the literature, we identified five domains of factors that relate to social inclusion in the neighbourhood:

- individual characteristics,
- informal network,
- professional care,

Table 1.1 – Overview of the dissertation

Aim	Method	Participants	Results
Chapter 2 Explore facilitative and obstructive factors that could be relevant to social inclusion in the neighbourhood	Literature search in PubMed and CINAHL	N/A	We identified five domains barriers and facilitators for social inclusion in the neighbourhood: individual characteristics; informal network; professional care; neighbourhood characteristics; and government policies. Social inclusion in the neighbourhood appears to be a dynamic process between environmental factors and personal characteristics.
Chapter 3 Develop and test a more standardized approach to photovoice, built on clear methodological choices, to optimize its effectiveness.	Literature search and photovoice study	14 participants with mild-to-moderate intellectual disabilities	Clear methodological decisions during the photovoice process were helpful in using photovoice. It was important to cater to the needs and capabilities of each participant. Most participants with intellectual disabilities benefitted from a guided approach.
Chapter 4 Conceptualize social inclusion in the neighbourhood, taking the perspective of people with intellectual disabilities as a starting point.	Photovoice study	18 participants with mild-to-moderate intellectual disabilities	Six themes relating to neighbourhood social inclusion emerged from the qualitative analysis: attractiveness of the neighbourhood; social contacts in the neighbourhood; activities in the neighbourhood; social roles in the neighbourhood; independence; and public familiarity. Public familiarity proved to be of great importance and could be encouraged by investing time in the related themes.
Chapter 5 Gain more understanding about individual neighbouring patterns and how people with intellectual disabilities are incorporated in these neighbouring patterns.	Interviews guided by a topic list	26 neighbours of people with intellectual disabilities living in group homes	Based on a combination of responses to seven themes, we were able to identify four neighbouring patterns: feeling an outsider; fleeting contacts; individualized neighbourliness; and sense of community. The four different groups of neighbours, categorized within the neighbouring patterns, show a variety of norms and behaviour towards neighbours. For people with people with intellectual disabilities, contact with neighbours is often limited to greeting. Reasons for this might be that participants perceived neighbours with intellectual disabilities as being 'different': difficult to approach and showing inappropriate behaviour. Most general perceptions were shared among the groups, but there were subtle differences. The first two groups mostly had fleeting encounters whereas the last two groups seemed more open to communal activities and assisting neighbours. In enhancing social inclusion, group home staff need to be aware of these neighbouring patterns.
Chapter 6 Obtain insight into the perspective of staff members and their professional role identity concerning neighbourhood social inclusion.	Group interviews	9 teams, each with an average of 8 staff members, working in group homes	Our analysis yielded five themes: staff perceptions of residents' neighbourhood contacts; positive and negative experiences; staff perceptions of residents' needs and capabilities; staff perceptions of neighbours and neighbourhood; staff perceived role in social inclusion in the neighbourhood; and staff-perceived role of the service provider. The professional role identity of group home staff members is strongly related to a caring role, and group home staff members experience a lack of skills, since they seem to face difficulties with social inclusion tasks. Service providers are recommended to invest time in training group home staff members and facilitate them with the required sources related to neighbourhood social inclusion.

- neighbourhood characteristics,
- government policies.

These factors cannot be seen as isolated factors: they clearly are interlinked.

These findings confirm that neighbourhood social inclusion should be approached as the outcome of an interaction between the individual person with intellectual disabilities and the neighbourhood environment. However, we found only a few studies about neighbourhood social inclusion from the perspective of people with intellectual disabilities and their neighbours.

Chapter 3 and 4 – People with intellectual disabilities about their neighbourhood

Obtaining insight into social inclusion needs to start with the perspective of the group facing exclusion. The slogan 'nothing about us, without us' is very relevant here. Involving people with intellectual disabilities in our study required us to reflect on appropriate and adequate ways of achieving participation. The third chapter describes how we developed the method of photovoice further to tailor it to people with intellectual disabilities. Based on a literature study, we developed a standardized approach of photovoice. The approach involved clear methodological decisions during four stages of photovoice:

- Stage 1: preparation
- Stage 2: taking the photos
- Stage 3: the interview
- Stage 4: post interview.

However we then introduced a new element during the second stage of the photovoice approach, which we called 'guided photovoice', where participants take photos together with the researcher. The researcher is guided by the participant during a walk, but does not interfere with the content of the photos.

The aim of the study was to test the applicability of this approach by interviewing people with intellectual disabilities. Limiting the influence of staff members requires the researcher to be strongly involved during the process. The guided element of the approach proved valuable for a significant group of participants. It helped participants overcome practical and psychological barriers. During the interviews, follow-up questions and asking for examples seemed to be important for obtaining more in depth and concrete information. In the last stage of analysing the data, we concluded that the stories that were revealed during the interviews could not be deduced from the photographs alone. It would not be recommended to analyse photographs without the related stories of participants. The results of this

methodological study reveal the importance of clear methodological decisions that meet the needs and capabilities of participants with intellectual disabilities. We found the guided photovoice approach successful in eliciting rich stories of participants.

Photovoice was used to further conceptualize neighbourhood social inclusion from the perspective of people with intellectual disabilities. Eighteen people with intellectual disabilities took photographs of their neighbourhood and discussed their photographs during an interview. In the fourth chapter of this dissertation we discuss the results of the content analysis of the interviews, which was done with ATLAS.ti. This analysis led to an identification of six themes related to neighbourhood social inclusion, from the perspective of people with intellectual disabilities: attractiveness of the neighbourhood; social contacts in the neighbourhood; activities in the neighbourhood; social roles in the neighbourhood; independence; and public familiarity. The attractiveness of the neighbourhood relates to the presence of shops and parks, where participants have social encounters or just enjoy the view from a bench. Some participants described joining in activities in the neighbourhood, for example a sport club, a theatre or the leisure club for people with intellectual disabilities. These locations were shown and photographed with enthusiasm. In some cases, participants shared stories about performing social roles in the neighbourhood, based on the photographs they took. Participants considered the opportunity to go shopping by themselves and being able to welcome their own visitors in privacy as important aspects of living in the neighbourhood.

Finally, participants repeatedly cited the importance of public familiarity, in the form of short encounters in the street and in shops. This public familiarity appeared to play an important role in determining how they felt in their neighbourhood. It can be encouraged by investing time in creating possibilities for joining activities or performing social roles. Local shops and family contacts also play an important role in this regard, as encounters with family members and shop assistants provide a feeling of being recognized, which proved to be important.

Chapter 5 – Neighbouring and people with intellectual disabilities: perspective of neighbours

The aim of the study presented in chapter five was to identify patterns of neighbouring and to explore how people with intellectual disabilities fit into these patterns. We conducted 26 interviews with 29 neighbours of people with intellectual disabilities. During the interviews, we used a topic list. This focused on the relationships between neighbours; how do respondents characterize their relationships with neighbours and what social norms play a role within these relationships. In some cases, to gain more insight in the neighbours' views about people with intellectual disabilities, we used fictitious scenarios or asked them to expand on their personal experiences

within or outside the neighbourhood. Data analysis was done with ATLAS.ti and led to a categorization of seven themes: perceived neighbourhood identity; perceived opportunities for social contact; chance encounters: the importance of being recognized; pre-arranged social contact and expectations; neighbour assistance; social control versus privacy; and experienced disturbances. These themes reveal the norms and behaviour of neighbours related to the contact with neighbours with and without disabilities. During the final stage of analysis, we were able to identify four neighbouring patterns based on a combination of the responses to the seven themes: feeling an outsider; fleeting contacts; individualized neighbourliness; and sense of community.

The first group of neighbours who reported feeling like outsiders, had limited contact with neighbours and their contact primarily focuses on fleeting encounters. This group of participants wished for more contact and felt excluded. The second group of participants also concentrated on fleeting encounters. However, this group was satisfied with these contacts and showed positive feelings towards their neighbours. The third group, which focused on individualized neighbourliness, had closer relationships with their neighbours. These relationships were based on individual contacts and consisted of mutual activities, providing assistance and limited social control. The fourth group experienced a sense of community. They focused on social gatherings with neighbours, provided assistance to all neighbours that belong to the community and reported a strong sense of social control.

In general, the perceptions of the four groups of participants towards their neighbours with intellectual disabilities were identical. They experienced them as 'different' because of the institutional context within which they lived: they walk by in groups and have staff to rely on. Aside from aspects related to the institutional setting, the participants in our study expressed worries about that the person with intellectual disabilities might invade their privacy and they assumed that a normal conversation people with intellectual disabilities may not be possible. These general perceptions might hinder them from having a closer connection with neighbours with intellectual disabilities. The contact was limited to a greet in the street, which participants experienced as being positive.

Apart from the general perceptions, the four groups of participants showed subtle differences in the opportunities for social contact they offered. The first two groups were open towards people with intellectual disabilities and willing to engage with them during fleeting encounters. The group of participants that focused on individualized neighbourliness was open to activities with people with intellectual disabilities and might offer opportunities for individual contacts. It was seen as important to meet the needs of neighbours. Focusing on mutual interest was part of this, and an individual approach was considered preferable. The last group, which

had a strong sense of community, welcomed people with intellectual disabilities in neighbourhood activities. Staff might benefit from taking a different approach to reach this group. Instead of taking an individual approach towards neighbours, it is important to establish the group home as part of the neighbourhood, rather than a separate unit.

Chapter 6 – Neighbourhood social inclusion and professional role identity of staff

Chapter six focuses on the perspective of group home staff members on neighbourhood social inclusion. We aimed to provide more insight into the ways in which individual group home staff members' perceptions of social inclusion and the institutional environment are embedded in their professional role identity. We conducted nine group interviews, each of which was attended by average of eight group home staff members. One of the advantages of the group context is that participants tend to inspire one another during the interview. This benefits the richness and scope of the data. To encourage the group discussions, we used a topic list that focused on the perceptions of group home staff members of their role in relation to social inclusion, which neighbourhood opportunities they perceive, and how their service provider facilitates them to create opportunities for neighbourhood social inclusion.

ATLAS.ti was used for data analysis. We identified five themes based on the stories of participants: staff perceptions of residents' neighbourhood contacts: positive and negative experiences; staff perceptions of residents' needs and capabilities; staff perceptions of neighbours and neighbourhood; staff perceived role in social inclusion in the neighbourhood; and staff perceived role of service provider. The first theme covered the current contacts of people with intellectual disabilities and their neighbours, according to our participants. In most cases, contacts were limited to a greet. Some exceptions showed more contact, for example drinking coffee or being connected on Facebook. Group home staff members considered the difficulties that neighbours had with the behaviour of their residents to be a barrier preventing more extended contact. Participants mentioned cases where residents had become more involved in activities, for example by joining a sport club. Group home staff had taken the initiative in developing neighbourhood activity, but in most cases neighbours attended only the introductory meeting, and there seemed to be little interest in subsequent activities. In the second theme, participants stressed the importance of meeting the needs of their residents. However, they said the neighbourhood was not a topic they often discussed with their residents. Participants believed that residents had no, or only limited, need for contact in the neighbourhood and felt that residents did not have sufficient social skills to develop

connections with neighbours. As well as eliciting their opinions about their residents, the third theme focused on the perception of group home staff that neighbours and the neighbourhood are not very open to having contact with their residents. They sometimes hesitated to encourage contact with neighbours who they saw as possibly having a negative influence on their residents (for example because they might encourage residents to drink alcohol). On the other hand, staff members said that residents felt welcome in their neighbourhood. In the fourth theme, most participants said they did not have time to focus on contact between their residents and neighbours and cited other priorities. Some participants take an active role in initiating neighbour contacts and experienced the value of these contact for their residents. In the final theme, participants described feeling unsupported by their service providers in promoting neighbourhood social inclusion. They experienced a lack of time to initiate contacts and felt they lacked the appropriate skills to enhance neighbour social inclusion.

Our study showed that staff members tend not to discuss the neighbourhood with residents. As they do not recognize the opportunities in the neighbourhood, they do not actively encourage social inclusion in the neighbourhood. These perceptions seem to correspond with a traditional professional role identity focusing on home-bound care tasks, and highlight difficulties with social inclusion tasks. Staff members lack related skills and have doubts about whether their residents' had the skills needed to engage with people in the neighbourhood. They believe that neighbours are not looking for contact, or describe possible bad influences from neighbours. Staff also feel they lack the time needed to encourage neighbourhood social inclusion. To enhance neighbourhood social inclusion, service providers need to reflect on ways to help staff members find a balance between enhancing neighbourhood social inclusion and protecting their residents from possible harm. Providing support and training might staff them find time and opportunities for neighbourhood social inclusion.

Discussion

The overall research objectives were 1) to gain insight into social and physical aspects of the neighbourhood that play a role in the process of social inclusion from the viewpoint of people with intellectual disabilities, their neighbours and group home staff members view neighbourhood social inclusion and 2) to explore how these insights can contribute to enhancing the process of neighbourhood social inclusion. Each chapter provides information about these differing perspectives.

The general principle of our study was that each involved group, and each individual within those groups, has their own perspective on the nature and the extent of social inclusion. The results show how each unique perspective has its own perception on the social and physical aspects of the neighbourhood that either facilitate or hinder the process of social inclusion in the neighbourhood. Table 1.2 shows the main social and physical aspects highlighted by people with intellectual disabilities, neighbours and group home staff members. These findings emphasize the importance of an ecological approach in studying the process of social inclusion. Our study was a first attempt to provide more insight into this ecological approach related to the neighbourhood context. In this section, we reflect on the interaction between the perspectives and how insight into this interaction can be useful in enhancing social inclusion.

Table 1.2 – Overview of the main social and physical aspects related to neighbourhood social inclusion from the perspective of people with intellectual disabilities, neighbours and group home staff members

	People with intellectual disabilities	Neighbours	Group home staff members
Social aspects	Public familiarity – fleeting encounters (Small) social roles Joining neighbourhood activities Presence of family and acquaintances	Public familiarity – fleeting encounters Social contact – welcome at activities and individual contact based on mutual interest and needs (related to neighbouring patterns) (Expected) behaviour people with intellectual disabilities – barrier for social interactions Institutional context – barrier for social interactions Open and intermediary role of staff members	Interaction with people with intellectual disabilities – perception of needs and capabilities – barrier for social interactions Interaction with neighbours – perception of neighbourhood and neighbours – barrier for social interactions Perceptions on their own professional role (related to, for example, initiating contact, organizing activities, protecting residents) – barrier for social interactions
Physical aspects	Presence of facilities: shops, restaurants, sport clubs, welfare facilities	Physical layout of the group home - barrier for social interactions	Physical layout of the group home - barrier for social interactions

Historically, people with intellectual disabilities have been abandoned from the so-called spaces of normality (Mans, 1998; Meininger, 2013). In recent decades, people with intellectual disabilities moved away from the large institutions, and social inclusion of people with intellectual disabilities became an important goal of policy makers. Including people in mainstream society was considered to be morally just, and could offer opportunities to cut back public expenses (Trappenburg, 2013; Bredewold et al., 2016). People with intellectual disabilities became geographically located in ordinary neighbourhoods. Living in these ordinary neighbourhoods – spaces of normality – might offer opportunities for social inclusion. However, this depends on whether society's ideas about what is 'normal' have changed, and whether (and to what extent) people labelled with intellectual disabilities in fact meet, connect and associate with other people (Meininger, 2013). The developments of deinstitutionalization and policies related to social inclusion are often associated with high expectations of caring relationships between people with and without disabilities (Bredewold et al., 2016). However, this picture of a caring community where people care for those in need does not seem to correspond with views from the participants included in our study. Their stories indicated that a caring community might also find its foundation in regular, but superficial, contact in the neighbourhood. Study participants – including people with intellectual disabilities and neighbours – attached great importance to greeting each other and having chats in the neighbourhood (Van Alphen et al., 2009). Blokland and Nast (2014) refer to such (implicit) relationships as 'public familiarity': both recognizing, and being recognized, in public spaces. Recognizing each other is a feeding ground for creating a so-called relational space, within which the encounter with 'the other' and 'otherness' can take place (Foucault, 2009; Hetherington, 1997; Meininger, 2013). Neighbours included in our study experienced these fleeting encounters as normal, and found it important to recognize, and be recognized by, their neighbours. When considering the importance of these fleeting encounters in the street, they did not make a distinction between their neighbours with or without intellectual disabilities. Here, otherness does not seem to play a role. This observation implies that mutual recognition within the new spaces of encounter has the potential to establish and maintain social connections between neighbours with and without intellectual disabilities when differences and strangeness are allowed to remain (Meininger, 2013). This therefore appears to be an important aspect of social inclusion in the neighbourhood (see, for example, Bigby & Wiesel, 2011).

We emphasize the significance of fleeting encounters, but where there is a wish for closer neighbouring contact, exclusion begins to appear. Our studies found that people with intellectual disabilities were barely involved in neighbourhood activities and neighbouring assistance. They did not seem to be part of general neighbouring

patterns (see also Bredewold et al., 2015). Neighbours referred to their 'otherness' by stating that a normal conversation with someone with an intellectual disability is not usually possible, or voiced fears about inappropriate behaviour. This perception of 'differentness' is also influenced by neighbours' views about the institutional context in which people with intellectual disabilities live, the physical layout of the building, and the fact that they walk by in groups in the constant presence of a staff member. As well as the institutional setting, neighbours view people with intellectual disabilities as different because they believe they are unable to conform to the prevailing social norms related to neighbouring – for example, the norm of friendly distance that refers to the importance of maintaining privacy (Wilmott, 1986 in Crow, Allan, & Summers, 2002).

However, the views of these neighbours do not mean that there are no opportunities for closer neighbouring contact. We found four neighbouring patterns that offered different opportunities for neighbourhood social inclusion. Neighbours who focus on fleeting encounters could be of significance regarding recognition in the street. Neighbours who appreciate stronger forms of neighbouring – based on individual relationships or on a sense of community – might also offer opportunities for individual contacts involving their neighbours with intellectual disabilities, taking into account mutual interests, or may welcome people with intellectual disabilities at neighbourhood activities.

The role of group home staff members

Group home staff members play a pivotal role in encouraging social interactions between people with intellectual disabilities and their neighbours (see, for example, Abbott & McConkey, 2006; Van Alphen et al., 2009; Overmars-Marx et al., 2014). Neighbours expressed their view on, and experiences with, the (physical) character of the group home and the behaviour of the people with intellectual disabilities, and described how these factors influence their social interactions with people with intellectual disabilities. Group home staff members play an important role in breaking down these barriers, recognizing opportunities and responding to those opportunities. They can support people with intellectual disabilities to create social connections in the neighbourhood to build public familiarity, which appears to be of great significance.

However, our study found little evidence of social inclusion in the neighbourhood forming part of the group home staff members' professional role identity. In general, staff did not incorporate social inclusion into their daily activity. They seemed to have difficulty coping with the dilemmas they faced concerning social inclusion, and often highlighted the risk that their residents might be harmed – a priority that corresponded with the caring aspect of their role. Group home staff believed that

neighbours would find it difficult to interact with people with intellectual disabilities, or feared a negative influence of neighbours. These results suggest that group home staff members struggle with a delicate balance between protecting their residents from any harm and encouraging social inclusion (see also Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2017). Living in ordinary neighbourhoods may never be risk free (Collins, 2015), but among the neighbours we found willingness and opportunities for creating contact, while staff members mostly referred to barriers. Usually, the perceptions of staff members were not based on actual experiences of contact with neighbours. At the same time neighbours' perceptions might be based on incorrect assumptions – for example, that the presence of staff precludes the need for neighbour contact. More interaction between neighbours and staff members may help to change these perceptions.

Individual differences within the involved groups

In our study, we collected information from different groups and viewed these groups as entities. The advantage of this approach is that it provides an overview of information – in our case, social and physical aspects of the neighbourhood, from each group – which is useful for advancing social inclusion. However, our study also shows that within these groups, individuals have their own perspectives on social inclusion. The view on social inclusion can vary widely between people categorized in the same group. This variety was, for example, expressed in the four neighbouring patterns we distinguished. Group home staff members also revealed different views on their role. And, although we found no significant differences between our participants with intellectual disabilities, in most cases they emphasize the importance of public familiarity, the way public familiarity can be created differs within this group and also the need for (extended) social contact varies between participants with intellectual disabilities. It is important to account for the diversity within groups and the needs of the individuals involved. This suggests that stimulating and supporting the development of neighbourhood relationships must be based on the individual needs of the involved persons.

Strengths and limitations

Several strengths and limitations in our research should be mentioned. Cobigo et al. (2012) define social inclusion as an outcome of the interaction between individual characteristics and the environment. Our research was a first attempt to provide insights from the various groups involved within the interaction regarding neighbourhood social inclusion: people with intellectual disabilities, their neighbours

and group home staff members. Instead of studying objective indicators, we focused on subjective views and experiences. This was a strength of our research. The results show that neighbourhood social inclusion cannot be reduced to one perspective, so we emphasize the different aspects of social inclusion, in relation to different perspectives.

We used several qualitative techniques to collect the data from the different groups. Qualitative techniques are considered more powerful than questionnaires to elicit narrative data and can investigate people's perceptions in greater depth, within their natural setting (Kvale, 1996; Cohen, Manion, & Morison, 2007). This was the aim of our study. By using different techniques, we were able to adapt each method to the needs and capabilities of the participants within the three groups. These multiple sources of information provided us with an accurate and comprehensive picture of neighbourhood social inclusion (Amado, Stancliffe, McCarron, & McCallion, 2013).

We initially conducted a photovoice study involving the participants with intellectual disabilities. They were the experts on their own feelings and experiences regarding the neighbourhood (Verdugo, Schalock, Keith, & Stancliff, 2005; Forrester-Jones et al., 2006). Based on literature search and our learning from a small-scale pilot study, we developed a standardized approach of photovoice, including a new element: guided photovoice. This element proved to be a strength of our research. Some participants found it easier to verbalize attitudes and feelings when 'in place'. This way of gathering information produces richer data (Aldridge 2007; Evans & Jones 2011; Garcia, Eisenberg, Frerich, Lechner, & Lust, 2012). Although this was a powerful method, it was not without limitations. Our study participants mainly photographed positive aspects of the neighbourhood. They may have perceived barriers to taking photographs of negative aspects or people (see also Akkerman, Janssen, Kef, & Meininger, 2014). This positive view of people with intellectual disabilities might also be related to the selection of our participants. In this study, we found few concrete examples of stigmatization, while we know from other studies that bullying and other forms of harassment can have great influence on the lives of people with intellectual disabilities (Jahoda & Markova, 2004, Bredewold, Tonkens, & Trappenburg, 2016).

The results of our study among neighbours appeared useful in providing insight into neighbouring patterns in general, and into how people with intellectual disabilities are incorporated in these patterns. Studying a combination of norms and behaviour related to neighbouring helped us get a better understanding of the position of people with intellectual disabilities in their neighbourhood. Although we recruited neighbours living close to the group homes, they still had limited contact with people with intellectual disabilities. By using fictitious situations, we tried to gain more information about the perceptions of neighbours related to

interaction involving people with intellectual disabilities (Barter & Renold, 2000). However, we realize that responses to fictitious situations do not always represent how participants would react in real life.

The perspective of group home staff members helped us understand how this group perceived their role regarding neighbourhood social inclusion. We conducted nine group interviews and were able to incorporate group home staff members supported by four different service providers. This was a strength of our research. By including a wide range of service providers, and finding no remarkable differences, we can conclude that the perspectives of group home staff participants are probably representative of most staff members working in comparable group homes and comparable neighbourhoods.

In general, the strength of this research is that the data collection from all involved groups took place within the same three neighbourhoods. This suggests that the data gathered among the three groups are comparable and provide valuable insights into the process of social inclusion in the neighbourhood, with opportunities to encourage this process. However, the three neighbourhoods within this study do not represent all neighbourhoods in the Netherlands. Two are situated in a low-urbanized area and are known as communities where the modern kind of neighbourliness described earlier (*modern noaberschap*) plays an important role. Mutual support and reciprocity are key elements of this approach (Abbas & Commandeur, 2012). The third neighbourhood is a suburb of a small town. Relationships between neighbours might be closer and more focused on assistance than more metropolitan neighbourhoods (Van Alphen et al., 2010). Wiesel and Bigby (2014) found more contact between neighbours with and without intellectual disabilities in country towns than in metropolitan suburbs, which suggests larger barriers in creating contact.

Since our study focused primarily on social inclusion as an important factor in the quality of life of people with intellectual disabilities (Schalock & Verdugo, 2002), we chose to include the groups that are directly involved in the process of social inclusion. However, there are other relevant groups that also have a perspective on social inclusion – for example, policy makers. They develop policies regarding social inclusion and have their own unique views of the issue. The perspective of policy makers, especially in relation to the political context, needs further study when it comes to social inclusion in the neighbourhood. The focus of local policies on social inclusion has an important impact on the opportunities in the neighbourhood for people with intellectual disabilities. Local policies can create opportunities for social inclusion – for example, in providing facilities, accessibility of facilities, public spaces and social activities in the neighbourhood, and creating opportunities for social networks and social participation. At the same time, service providers struggle with

financial consideration related to developing small-scaled group homes. Tøssebro et al. (2012) show, for example, that since the deinstitutionalization and decentralization of the 1990s, there has been a trend towards larger group homes and inequality across municipalities. This suggests that the opportunities for social inclusion can differ greatly between municipalities. The question remains unanswered as to policies at a local and organizational level create or hinder opportunities for social inclusion in the neighbourhood.

Beyond policy makers, professionals in other fields (such as welfare) may have different views on social inclusion. Their professional role identity is shaped differently and they are more accustomed to exposing their clients to society, but are less familiar with people with intellectual disabilities. Until the present day, people with intellectual disabilities within 24-hour residential care seldom, if ever, encounter anyone other than care professionals. This might change in the future, when municipalities will be cooperating increasingly with service providers to enhance social inclusion. Other groups that might have their own perspectives on social inclusion of people with intellectual disabilities are, for example, family members or other actors in the neighbourhood, such as shop assistants.

Finally, our findings are related to the Dutch context. Therefore, it is not possible to establish the effects of variation in national policies, cultural norms and beliefs on the perspectives of our participants. Our findings seem to correspond with findings from studies conducted in other Western countries. For example, these also point to the importance of fleeting encounters (Bredewold et al., 2015; Wiesel & Bigby, 2014). They also show, in relation with the role-identity of professionals, the significance of a shift from a caring to a supporting role to enhance social inclusion (see Abbott & McConkey, 2006; Hunter & Perry, 2006). However, we cannot be certain that our findings are directly transferable to other countries.

Suggestions for future research

This study focuses on the views and experiences from three perspectives on neighbourhood social inclusion. An effort was made to enable all participants to share their experiences of neighbourhood social inclusion. In this subsection, we set out some suggestions for future research.

First, we explored the views and experiences of people with intellectual disabilities by using guided photovoice. Earlier studies used photovoice to involve people with intellectual disabilities (for example, Jurkowski, 2008; Akkerman et al., 2014) but we added the guided element and tested it in a small-scale study with 18 participants. To further develop and test guided photovoice, we suggest research on a larger

scale. Guided photovoice could be repeated with a larger and a more diverse group, but also in other contexts – for example, relating to leisure activities, work or in an educational setting. As well as testing the current developed method of guided photovoice, it would also be interesting to develop further variants of the method. We concluded that some participants benefitted from the guided walk, and the interview provided no new information. Therefore, we would recommend future research that uses a combination of walking interviews and photovoice, involving people with intellectual disabilities (Evans & Jones, 2011; Garcia et al., 2012). This may include guided photovoice without the interview. We also found digital tools that were suitable for some participants (for example, Whatsapp). More and new digital tools become available that provide extra opportunities in using photovoice. Geolocation could be added to link location to the pictures in order to conduct spatial analysis, then themes could be related to specific locations (Jones & Evans, 2012; Paulus, Lester, & Dempster, 2014).

The participants with intellectual disabilities included in our study were mostly selected by the group home staff members, and most of those who were willing to participate were positive about their neighbourhood. Participants who had difficulties within their neighbourhood felt uncomfortable telling stories about their experiences. This selection might have led to an underrepresentation of aspects related to stigmatization. As we found in earlier studies, people with intellectual disabilities do face discrimination and rejection as a result of social stigma (Jahoda & Markova, 2004; Bredewold et al., 2016). The study of Jahoda, Wilson, Stalker, & Cairney (2010) shows that stigmatized groups are often aware of their negative social representations (Crocker & Quinn's, 2000) but they tend to show acceptance of these circumstances (Jahoda & Markova, 2004). This suggests a reality that makes it hard to uncover feelings of stigmatization among people with intellectual disabilities. This might be why these processes of social stigma were not an explicit outcome of our study. We would suggest further research on the concept of social stigma and its influence on the lives of people with intellectual disabilities in their neighbourhoods. In conducting such research, we would recommend involving various perspectives, in line with our study.

Based on our statement that the neighbourhoods involved in our study have some unique characteristics regarding to neighbourliness, we would recommend future research in metropolitan suburbs. Social and physical aspects of the neighbourhood related to social inclusion might be different within other contexts. Therefore, we would suggest research that involves different types of neighbourhoods to 1) compare these neighbourhoods and provide specific information related to neighbourhood characteristics and 2) to reveal a representative picture of the

process of neighbourhood social inclusion. This knowledge might be helpful to policy makers and service providers, to enhance social inclusion in the neighbourhood.

Although our study focused primarily on the involved groups close to the neighbourhoods, the process of social inclusion is also influenced by political and policy developments. Internationally, the United Nations Convention on the Rights of Persons with Disabilities (United Nations Convention, 2006), and on a national level the introduction of the Social Support Act (*Wet maatschappelijke ondersteuning*, Wmo) have a significant impact on society's view of people with intellectual disabilities. It is likely that these developments also influence the views and practices of the groups that participated in our study. To increase knowledge of the connection between policies and daily practice, we would suggest future research on how policies influence daily practice.

In our study, neighbours and group home staff members emphasized the physical layout of the group homes as a barrier for social interactions with neighbours. Earlier studies show that some physical features of the group homes reduce opportunities for social contacts between residents and people with intellectual disabilities – for example, a high fence or the absence of a garden (see Van Alphen, et al., 2010). We would recommend future research that uses a multidisciplinary approach, requiring involvement from architects, on the relationship between the physical layout of group homes and social interactions with neighbours. Apart from the physical layout of the group home, the physical structure of the neighbourhood plays a role in the opportunities for fleeting encounters. This was not a specific focus of our study, but we suggest research into how public spaces can be constructed to facilitate social interactions between neighbours – for example, considering designs or using local space, or facilities such as public libraries or community centres, to facilitate encounters (see Bigby & Wiesel, 2011).

Practical implications

Insight into the perspectives of people with intellectual disabilities, their neighbours and group home staff members offers service providers opportunities to connect both worlds and overcome possible obstacles within these relationships. Support from service providers is crucial in encouraging staff members to enhance social inclusion. This support starts with providing staff members a clear understanding of their role in terms of social inclusion and how they should act in relation to this issue. The group home staff members included in our study had varying interpretations on the concept of social inclusion. The findings from our study might help with this.

Group home staff members included in our study seldom experienced or viewed activities that further neighbourhood social inclusion as being part of their professional role identity. Their activity in this area was limited by their own perceptions and also by the experienced lack of support from the service providers (see also McConkey & Collins, 2010a). We recommend that service providers support group home staff members to embrace a supporting role and to explore opportunities in the neighbourhood that are important for advancing social inclusion (Abbott & McConkey, 2006; Hunter & Perry, 2006; Van Alphen et al., 2009).

All staff members recognized the importance of taking the needs of people with intellectual disabilities as a starting point. They are expected to provide opportunities to exercise 'choice and control' over as many aspects of life as possible – which would appear to include neighbourhood life (see, for example, Bigby & Wiesel, 2015). However, in many cases the neighbourhood is not on the agenda during the meetings with residents. We recommend that staff members incorporate the neighbourhood, and the opportunities it offers, as a standard aspect of their discussions with residents and individual support plans. Goal setting might be a helpful method in enhancing neighbourhood social inclusion (McConkey & Collins, 2010b), specifically within a setting where 24-hour staff support is available. Neighbourhood social inclusion can be translated into well-defined support needs and goals within the individual support plan, based on residents' personal choices. Within these goals, it is important to listen carefully to the needs of people with intellectual disabilities. One goal might be 'to extend the person's social network'. However, a larger social network does not always lead to improved wellbeing for an individual (Lippold & Burns, 2009; Van Asselt-Goverts, 2016). Therefore, it is important to evaluate goals and keep the neighbourhood and neighbourhood contacts a regular topic of discussion with residents. According to the needs of our participants with intellectual disabilities, social inclusion does not always mean taking part in activities in the neighbourhood, nor having close contact with neighbours. Public familiarity (see also Bredewold et al., 2015; Wiesel & Bigby, 2014), having a close friend in the group home or participating in activities with people with intellectual disabilities can also provide a feeling of being at home in the neighbourhood. Just like other people, people with intellectual disabilities have a need to connect with other people with shared interests (Baars, 1994). Group home staff members can help meet these needs by looking for, or creating, opportunities to meet people with similar interests.

First, it is important to increase the public familiarity of people with intellectual disabilities (see also Bredewold et al., 2015; Wiesel & Bigby, 2014). Getting to know the neighbours and promoting an open atmosphere that invites neighbours are important in creating initial contacts. This starts breaking down barriers. Staff members should be aware of the image created by people walking by in groups,

and the presence of a staff member during these walks. Neighbours in the study of Wiesel and Bigby (2014) experienced a lack of skills in interacting with people with intellectual disabilities during fleeting exchanges. Staff members have an important intermediary role during these encounters. They are recommended to give just the right amount of support (if needed), with a high level of sensitivity, to help ensure a successful encounter without obviously intervening (see Bigby & Wiesel, 2015). Besides these fleeting encounters in the street, neighbours would appreciate activities initiated by the group homes. These might lead to more understanding, and might also serve as a stepping stone to extended contact (see also Wiesel & Bigby, 2014). The second stage of neighbour contact can be considered the 'maintenance stage'. During this phase, we recommend group home staff to repeatedly organize activities and to focus on individual contacts between people with intellectual disabilities and their neighbours. These activities and interactions should respond to the needs of residents and neighbours alike (see also Baars, 1994).

Our study illustrates that neighbours need information about how to tackle some specific characteristics or/and behaviours of an individual with an intellectual disability. Neighbours also appreciate the possibility of relying on a staff member in case of problems. We would recommend staff members to be aware of individual needs of neighbours to encourage them to have contact with residents and overcome difficulties within these relationships.

As well as taking initiatives to get acquainted with neighbours and to know their needs, it is important to take note of opportunities that already exist in the neighbourhood. To connect the needs of people with intellectual disabilities with the opportunities offered within the neighbourhood, staff must have adequate information about the neighbourhood. Lacking this kind of information can be a barrier to improving social inclusion (Abbot & McConkey, 2006). Collaboration with other local organizations is therefore indispensable. Teams working in group homes might benefit from a staff member who lives in the neighbourhood and is familiar with the local organizations. Encouraging these forms of collaboration is also in line with the current policies outlined in the Social Support Act (*Wet maatschappelijke ondersteuning, Wmo*) and might lead to people with intellectual disabilities taking part in existing neighbourhood activities or buddy projects and performing social roles.

The neighbours included in our study were positive about examples of these social roles (for example, working as a waiter in a bar) and, from the viewpoint of people with intellectual disabilities, small social roles can be an important aspect of social inclusion (see also Cobigo et al., 2012; Wolfensberger, 2000). Although group activities with people with intellectual disabilities were considered valuable, they mostly took place within a distinct social space (see also Wiesel et al., 2013), which

may create barriers for encounters with people without intellectual disabilities. Wiesel et al. (2013) suggest that a mix of encounters within and outside the distinct social space may prove to be most useful. Encounters outside the distinct social space may lead to a new range of social identifications, and people with intellectual disabilities will be able to share these experiences within the safe environment of the distinct social space. This recommendation aims at a fine balance between feeling safe and taking a risk.

In our study among group home staff, we found that staff members faced ethical dilemmas that limited them to encourage social inclusion. Related to their caring role, staff members felt the need to protect their residents from any harm. For example, some felt they should not share any information about residents with neighbours because of confidentiality, or because it might expose residents to a (potential) negative influence as mentioned earlier. We suggest that service providers should be aware of this struggle among their staff members and should support them in taking the risks that neighbourhood social inclusion activities may sometimes present. Living in group homes should not constitute protecting people from any possible risk, but supporting them to deal with difficulties they face in a safe and positive way (Collins, 2015). Building on these experiences helps to encourage social inclusion. During the group interviews, we saw that discussing the topic of social inclusion inspired staff members to think about creating and developing opportunities for neighbourhood social inclusion. This indicated that peer-to-peer coaching (including sharing good practices) might be successful in encouraging social inclusion.

Social and physical aspects of location

The results of our study suggest the importance of public familiarity: being recognized provides a feeling of being at home (see also Wiesel & Bigby, 2014; Bredewold et al., 2015 and Blokland & Nast, 2014). This public familiarity can be encouraged, but in some cases it comes more naturally when family, friends and acquaintances live nearby, or when someone works in the neighbourhood where he or she lives. Based on these findings, we recommend that service providers carefully consider where to locate their residents. According to our participants, the presence of shops presents residents with the possibility of being independent and initiating new contacts. This increases their public familiarity, and they enjoy being recognised when they visit the shops (see also Wiesel et al., 2013). Locating residents in lively neighbourhoods seems to advance social inclusion in the neighbourhood.

We recommended future research that investigates how the physical layout of the group home influences the social interactions between residents and neighbours. Following on from this, we suggest that service providers consider an inclusive design that involves neighbours, staff members and residents (or potential residents)

in developing the physical construction a group home. Many group homes located in the neighbourhood appeared unattractive and did not seem very inviting places for neighbours to visit. Using an inclusive design that covers variation in capabilities, needs and aspirations, from the diverse groups involved in the neighbourhood, might lead to a physical construction that is also attractive for neighbours and therefore creates more opportunities for social interaction.

As well as involving all involved groups before the construction of a group home, service providers could think of, and discuss, ways to transform the existing group homes into attractive, inviting buildings. They could do this by, for example, removing fences and creating open spaces where residents and neighbours can see each other (see also Van Alphen et al., 2010). Service providers might face a dilemma by creating open spaces because despite offering opportunities for social interactions, it might also exacerbate factors such as noise pollution. However, these tensions could be addressed by involving neighbours in the process. So, we recommend work with residents and neighbours to considering the physical possibilities related to the group home in order to encourage social interactions within the neighbourhood.

Using photovoice in daily practice

In our study, we used photovoice as a method for collecting data on behalf of this study. But photovoice can also be used for other goals. Wang and Burris (1994; 1997) show the empowerment aspect of photovoice. Putting a camera in the hand of a vulnerable person who does not have the ability to read or write enables them to record and reflect on their lives (Wang & Burris, 1997). This provides them with a voice, and can empower them to advocate for changes in their living environment. The method proves to be suitable for involving people with intellectual disabilities (Booth & Booth, 2013) who have difficulties with direct communication, or are hampered on a cognitive and conceptual level (Jurkowski, 2008; Finlay & Lyons, 2002; Sigstad, 2014). Service providers might benefit from using this method with their residents with intellectual disabilities to gain in-depth knowledge of the needs of their residents regarding a variety of aspects they face in their daily lives.

A second aim can be to create interaction between people with intellectual disabilities and their environment. This could be done by, for example, organizing an exhibition in which photographs are shown of daily life that enable people with intellectual disabilities to connect with the broader community (Povee, Bishop, & Roberts, 2014; Schleien, Brake, Miller, & Walton, 2013). These exhibitions might be organized together with neighbours. Group home staff members could also think of opportunities to connect people with intellectual disabilities with neighbours by taking photographs together. This could create mutual understanding about how

they perceive the neighbourhood. In our study, we saw how contacts were created or revived during the guided photovoice. Making this as specific aim might offer opportunities to enhance social inclusion.

Final remark

The neighbourhood context is dynamic. This means that supporting social inclusion in the neighbourhood is an ongoing process, in which the different perspectives involved have to be taken into account. In summary, social inclusion in the neighbourhood must be continuously on the staff members' agenda. At the same time, staff members themselves need support to play their role as linking pin between people with intellectual disabilities and the neighbourhood. They must be able to invest time and training in the specific skills needed to take on this role. So, service providers need to keep a constant eye on the needs of their employees in supporting social inclusion.

This chapter is based on:
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neighbourhood for people with an intellectual disability:
an exploration of the literature.

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Chapter 2

Advancing social inclusion in the neighbourhood
for people with intellectual disabilities:
an exploration of the literature



Abstract

Background

The shift from segregated facilities to community settings did not automatically lead to social inclusion for people with intellectual disabilities. Policies are increasingly decentralized but little is known about the factors which are important to realize social inclusion in the neighbourhood.

Method

An exploration of the literature of Pubmed and Socindex resulted in 28 studies eligible to be included in the analysis. The studies examined social inclusion related to intellectual disabilities published since 2000.

Results

This literature study identifies five domains barriers and facilitators for social inclusion in the neighbourhood: individual characteristics, informal network, professional care, neighbourhood characteristics and government policies.

Conclusions

The findings suggest that social inclusion in the neighbourhood is a dynamic process which shows a series of complex interactions between environmental factors and personal characteristics to provide opportunities for people with intellectual disabilities. It is recommended to include the perspectives of people with people with intellectual disabilities and other neighbourhood residents in future research on social inclusion. Specific attention is needed for the role of neighbourhood social capital in achieving social inclusion in the neighbourhood.

Introduction

Over the last decades people with people with intellectual disabilities have become more visible in society. In many Western societies large institutional settings have been declining and people with an intellectual disability have become part of neighbourhoods (Beadle Brown et al., 2007). The idea that people with disabilities can be a part of society and can also contribute to different life domains was inspired by the normalization movement during the 1980s and 1990s (Wolfensberger, 1972). The normalization principle favours social roles for people with intellectual disabilities because they enhance their social opportunities. Following these developments, the United Nation Convention on the Rights of Persons with Disabilities was adopted in December 2006 (United Nations Convention, 2006). The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. One of the guiding principles is that people with disabilities have possibilities for full and effective participation and inclusion in society. Oliver (1996) marks these developments as a shift from a medical model to a social model. Cross-national variation in the uptake of a social model and the type of policies adapted notwithstanding (Jackson, 2011; Tøssebro et al., 2012), decentralization and deinstitutionalization have long since dominated the policy discourse.

The potential of this shift has not been achieved in practice. People with intellectual disabilities still encounter discrimination and rejection (Cobigo & Hall, 2009; Hall 2005). People with intellectual disabilities have been increasingly exposed to the general community, but studies raise doubt whether they actually benefit from this exposure (Cummins & Lau, 2003; Cobigo et al. 2012; Pretty, Rapley, & Bramston, 2002). On different life domains like work, education and community participation, people with disabilities are not able to participate like people without disabilities, and people with disabilities have fewer meaningful relationships and experience more loneliness. Community-based supports and person-centered and recovery-oriented services hold considerable promise for inclusion of people with mental disabilities, but they are not widely available, nor have they been widely evaluated (Cobigo & Hall, 2009). Our study fills this gap with a literature study on empirically evidence for factors that facilitate or hinder social inclusion in the neighbourhood. This will provide researchers and practitioners with a starting point for more detailed analysis and interventions.

We base our concept of social inclusion on the recent work of Cobigo and colleagues (2012). In recent conceptual reviews, both Cobigo et al. (2012) and Bigby (2012) note a lack of consensus on what constitutes social inclusion. Terms

like social inclusion, community inclusion and participation are used interchangeably, and on many points research supporting the concepts is lacking. Cobigo et al. (2012) further note that concepts of social inclusion tend to be based on models of civil and economic participation that take too little account of the perspective and experiences of the people involved, leading to inflated expectations of success. We also found that conceptualization is often limited to either concrete roles and activities, or to intangible aspects of inclusion, such as feeling accepted (Abbott & McConkey, 2006; Bates, 2002; Chenoweth & Stehlik, 2003; Hall, 2010; Schalock, Gardner, & Bradley, 2007; Uditsky, 1993; Van Alphen et al., 2009). A more comprehensive approach is rare. Cobigo et al. (2012) therefore argue that a concept of inclusion that is valid to research and to practice should be defined as (italics not in original): (1) a series of complex interactions between environmental factors and personal characteristics that provide opportunities to (2) access public goods and services, (3) experience valued and expected social roles of one's choosing based on his/ her age, gender and culture, (4) be recognized as a competent individual and trusted to perform social roles in the community, and (5) belong to a social network within which one receives and contributes support. Cobigo's conceptualization fits in an ecological approach, which emphasizes the importance of the interactions between personal and environmental characteristics (Scheidt & Norris-Baker, 2003).

Where Cobigo et al. (2012) address inclusion in general, our focus is on inclusion in neighbourhoods. Given that people with intellectual disabilities living outside an institution will spend most of their time in their neighbourhood, it is important to gain understanding of specific neighbourhood factors in social inclusion. Our literature review is guided by the following research questions:

- What elements of social inclusion are covered in the selected studies?
- What are important barriers and facilitators for social inclusion in the neighbourhood of people with intellectual disabilities?
- Which gaps in research need to be explored in the future?

Methods

Search strategy

Because of the explorative nature of the study, we searched literature that maximized our understanding of factors that could be relevant to social inclusion. We strived for diversity and validity of possible factors, rather than aiming to be exhaustive. Studies for this research were identified in the following way.

Searches were carried out in Pubmed (2000–2010) and Socindex (2000–2010) databases. These two databases were chosen because they each cover a large, distinct part of the relevant literature. Pubmed focuses more on medical information while Socindex contains information from a sociological perspective. Both databases contain relevant journals in the field of social inclusion and people with disabilities. To check if the databases yielded enough relevant articles we selected three reference articles, which were found in both databases. Finally the references of all the selected articles were studied to detect important omissions. We may have missed relevant studies from other databases, most notably studies from non-ISI journals, which are less likely to turn up in PubMed or Socindex. More recent literature on social inclusion (Bigby, 2012; Cobigo et al.; 2012; Lysaght et al., 2012) gives no indication that we missed important publications.

Search terms were related to social inclusion and people with an intellectual disability. Keywords used for social inclusion were inclusion, participation, community involvement, community care, social isolation, informal network. For the population we used keywords like intellectual disabilities, learning disabilities, development disabilities and some related keywords. In all search strategies, we combined several terms for people with an intellectual disability with a broad range of keywords related to social inclusion.

Procedure

Two investigators independently assessed the relevant content of the initially identified studies by using a 3-point scale (0 = irrelevant, 1 = possibly relevant and 2 = relevant). The references were scored in three phases:

Phase 1 – rating the title using the 3-point scale by using the following predefined selection criteria: period 2000–2010, English language, western cultures, aspects of the population: people with intellectual disabilities in title and/or (indicators of) social inclusion in title. References with a total score below two were discarded as irrelevant.

Phase 2 – rating abstracts using the 3-point scale on the following predefined selection criteria: abstract mentions data on adults with intellectual disabilities, and factors influencing the level of social inclusion in the local community and western cultures. Studies could score between zero and four. References with a total score below two were discarded as irrelevant.

Phase 3 – rating full texts by one investigator using the 3-point scale employing the following predefined selection criteria: the group of people with intellectual disabilities is outlined in the population characteristics, population characteristics are described, methodology is described, used measurement instruments are mentioned, factors that influence social inclusion in the local community are described and

analysed, the group of people with intellectual disabilities is mentioned separately in the population characteristics, the results are described separately for the group of people with intellectual disabilities, and the influence of factors on social inclusion in the local community is separately described as outcomes. References with a total score below two were discarded as irrelevant.

Results

The search for publications resulted in 3,315 initial hits, including 22 double references. After phase I 176 titles remained. In the next phase we scored the abstracts of these 176 studies, and 74 abstract were identified as relevant. These 74 articles were scored by one investigator. 28 studies met the predefined selection criteria and were included in the study. An overview of this procedure is given in figure 2.1.

Thirteen studies were categorized as quantitative studies, 8 as qualitative studies and 7 as reviews. In order to get a complete overview of the important factors related to social inclusion we chose to include the review studies. We used the reviews as validation of our results. The results of the reviews are only described if they are additional to or opposing the results in the selected studies.

A methodological assessment was conducted on the thirteen selected quantitative studies, in order to get an impression of the methodological quality. A criteria list based upon different criteria lists for non-randomized studies was used (Downs & Black, 1998; Verdonschot et al., 2009b). This list consists of 15 items: describing the level of informativity (six items), external validity (four items) and internal validity (five items) (see table 2.1). In general, the selected studies have a high score on informativity. The authors describe the purpose, the data collection, the mean outcomes, the population, the response and the main findings of their study clearly. The selected studies show much lower scores on external and internal validity. Most of the studies describe the age range (external validity) and the measurement instruments (internal validity) but the other indicators for external and internal validity lack in most selected studies.

Most of the selected studies use the label intellectual disabilities for identifying the target population, but they may refer to different groups and characteristics. Often the people with intellectual disabilities are selected because they are connected to a care organization which supports people with intellectual disabilities. If the authors give more information about the target group this is incorporated in table 2.2 or in the description of the results.

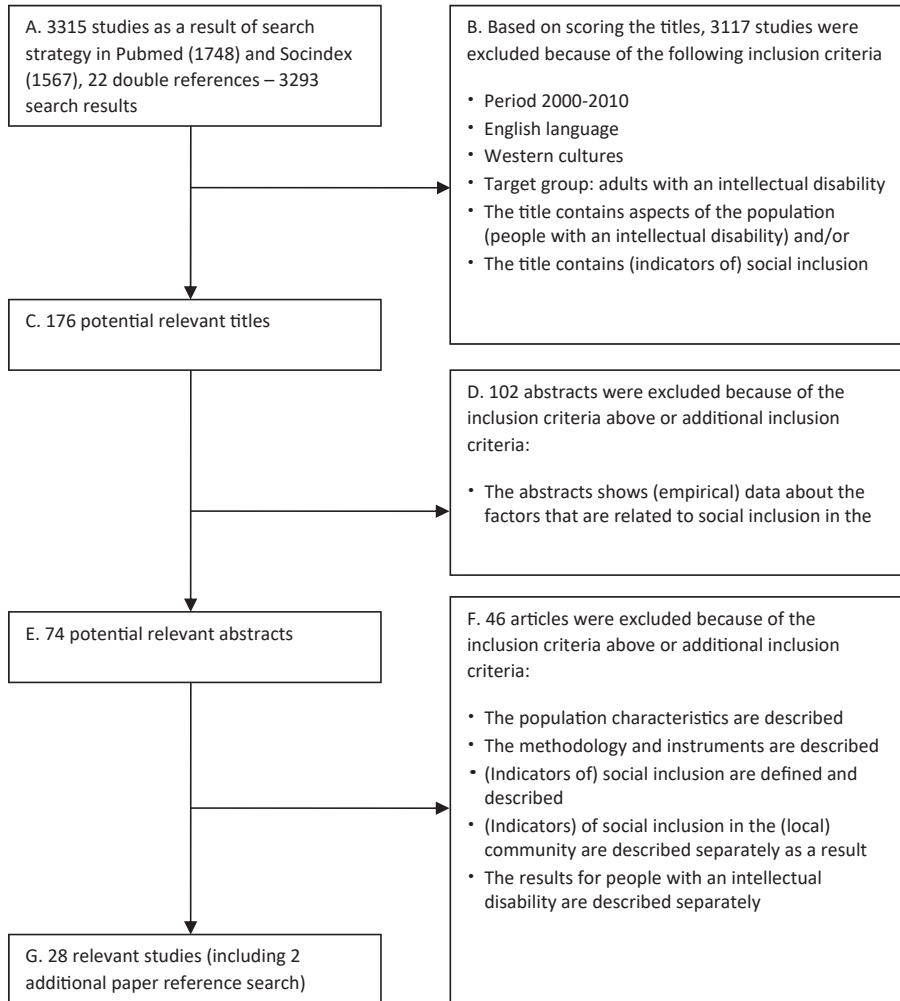


Figure 2.1 – Selection procedure

The measurements used are very different. Data was gathered through focus groups, interviews, databases and questionnaires. The variation of measurements for the different elements of social inclusion is partly a consequence of different conceptualizations. We also see variation within a similar conceptualization. For example, different instruments were used to measure social relationships, like the Guernsey Community Participation and Leisure Assessment or the Life Experience Checklist (LEC) (Abraham, Gregory, Wolf, & Pemberton, 2002; Ager, Myers, Kerr, Myles, & Green, 2001; McConkey, Walsh-Gallagher, & Sinclair, 2005; McConkey, 2007). This variety in measurements shows the complexity of the concept of social inclusion, and makes it hard to compare the results of the studies. Because of this,

Table 2.1 – Quality assessment of selected quantitative studies

Studies	Informativity							External validity					Internal validity						
	a	b	c	d	e	f	subtotal	g	h	i	j	subtotal	k	l	m	n	o	subtotal	Total
Abraham et al. (2002)	+	+	+	+	+	+	6	-	-	+	-	1	-	-	+	+	+	3	10
Ager et al. (2001)	+	+	+	+	+	+	6	-	-	+	-	1	-	-	+	+	-	2	9
Beadle-Brown et al. (2006)	+	+	+	+	-	+	5	-	+	+	-	2	-	-	+	-	-	1	8
Bigby (2008)	+	+	+	+	+	+	6	-	-	-	+	1	-	-	+	-	+	2	9
Buttimer & Tierney (2005)	+	+	+	+	+	+	6	-	-	+	-	1	+	-	+	-	-	2	9
Egli et al. (2002)	+	+	+	+	+	+	6	+	+	+	-	3	-	-	+	+	-	2	11
Heller et al. (2002)	+	+	+	+	-	+	5	-	+	+	+	3	-	+	+	+	+	4	12
McConkey et al. (2005)	+	+	+	+	+	+	6	-	-	+	-	1	-	-	+	+	-	2	9
McConkey (2007)	+	+	+	+	-	+	5	-	-	+	-	1	-	+	+	-	+	3	9
Robertson et al. (2005)	+	+	+	+	-	+	5	-	-	-	-	0	-	-	+	-	-	1	6
Schwartz & Rabinovitz (2001)	+	+	+	+	+	+	6	-	-	+	+	2	-	-	+	-	-	1	9
Thorn et al. (2009)	+	+	+	+	+	+	6	+	-	+	+	3	-	-	+	-	-	1	10
Vine & Hamilton (2005)	+	+	+	+	+	+	6	-	-	+	-	1	-	-	+	-	+	2	9

a, the purpose of the study is clearly described;

b, the method of data collection is properly described;

c, the main outcomes to be measured are clearly described in the introduction or methods section;

d, the description of the characteristics of the population is sufficient;

e, the response rate is $\geq 70\%$, or the information on the non-respondents is sufficient;

f, the main findings of the study are clearly described: simple outcome data should be reported for all major findings;

g, the subjects asked to participate are representative of the entire population from which they were recruited;

h, the inclusion and exclusion criteria are described;

i, the age range is specified;

j, the study period is described;

k, the data are prospectively collected;

l, a comparison group is used and properly described;

m, the measurement instrument(s) is/are described;

n, the main outcome measures used are accurate (valid and reliable);

o, age- and gender-specific outcomes are reported;

+, positive;

-, negative.

Table 2.2 – Characteristics of the selected studies

Author	Country	Year	Design	Data collection	Questionnaires: instruments	Sample Size	Domains
Abbott & McConkey	Ireland	2006	Qualitative study	Focus groups	-	68 people with ID	Individual characteristics, professional care and setting, neighbourhood characteristics
Abraham et al.	UK	2002	Cross-sectional study	Questionnaire and interviews	Guernsey Community Participation and Leisure Assessment SOS (social support)	50 people with mild to moderate learning difficulties	Informal network
Ager et al.	UK	2001	Cohort study	Questionnaires and diary	Life Experience Checklist Index of Community Involvement	76 people with ID	Professional care and setting
Alphen, van et al.	The Netherlands	2009	Qualitative study	Semi structured interviews	-	39 people with ID	Informal network, neighbourhood characteristics
Beadle-Brown et al.	UK	2007	Review	Explores recent literature academic journals mainly 2006	-	-	Government policies
Beadle-Brown et al.	UK	2006	Survey sample: descriptive and analytical study	Semi structured interviews	-	30 residents	Individual characteristics, informal network, professional care and setting
Bigby	Australia	2008	Cohort: longitudinal study	Interviews with staff, telephone survey with family members (20) and case studies subgroup (11)	-	24 people with ID	Informal network, government policies
Burttimer & Tierney	Ireland	2005	Cohort study	Semi-structured interviews and questionnaire	Trail Leisure Assessment Battery	34 students with ID	Individual characteristics, informal network, professional care and setting, neighbourhood characteristics
Egli et al.	USA	2002	Quantitative analyse: no design specified	Photograph rating, questionnaires and observations	Community Living Attitudes Scales of Mental Retardation Resident Lifestyle Inventory	18 residences for adults with mental retardation	Professional care and setting

Author	Country	Year	Design	Data collection	Questionnaires: instruments	Sample Size	Domains
Felce & Emerson	UK	2001	Review	Review	-	-	Individual characteristics, professional care and setting
Hall	UK	2005	Qualitative analyse	Group interviews	-	21 people with learning disabilities	Individual characteristics, professional care and setting, neighbourhood characteristics government policies
Hartnett et al.	Ireland	2008	Qualitative analyse	Questionnaire and interviews	Quality of Life Questionnaire	8 participants with severe ID	Professional care and setting
Heller et al.	USA	2002	Cohort: Longitudinal study	Interviews, review resident records, observations	Physical Attractiveness Scale	186 adults with mental retardation	Individual characteristics, informal network, professional care and setting
Hunter & Perry	UK	2006	Qualitative analyse: interviews on 2 occasions	Questionnaires, interviews and three case scenarios	Not specified	19 people with learning disabilities	Professional care and setting
Kozma et al.	UK	2009	Systematic review	Surveyed research from 1997-2007	-	-	Individual characteristics, informal network, professional care and setting
Mansell & Beadle-Brown	UK	2009	Systematic review	Evaluate available research	-	-	Professional care and setting
Mansell	UK	2006	Review	Review deinstitutionalization	-	-	Professional care and setting, government policies
McConkey	Northern-Ireland	2007	Quantitative analyse: no design specified	Questionnaire	Standard pro forma based on measures used in past research	620 people with ID	Individual characteristics, professional care and setting
McConkey et al.	Northern-Ireland	2005	Quantitative analyse: no design specified	Questionnaires	Index of Social Competence Life Experiences Checklist	106 people with ID	Individual characteristics, professional care and setting

Minton & Dodder	USA	2003	Qualitative analyse	Interviews and observations	-	25 people with development disabilities	Professional care and setting
O'Brien et al.	New Zealand	2001	Qualitative analyse	Interviews	-	54 people with ID	Individual characteristics, professional care and setting
Richardson	UK	2000	Qualitative analyse	Participatory research	-	6 people with learning difficulties	Informal network, professional care and setting
Robertson et al.	UK	2005	Matched groups design	Questionnaires and semi-structured interviews	Adaptive Behaviour Scale Aberrant Behaviour Checklist	64 neighbours of people with ID	Informal network, professional care and setting
Schwartz & Rabinovitz	Israel	2001	Survey	Questionnaires	Neighbourhood questionnaire Facility managers questionnaire	208 neighbours of people with ID	Professional care and setting, neighbourhood characteristics
Thorn et al.	USA	2009	Longitudinal study	Databases facilities	-	556 people with ID	Individual characteristics, professional care and setting
Verdonschot et al.	The Netherlands	2009a	Review	Review of empirical findings	-	-	Professional care and setting
Verdonschot et al.	The Netherlands	2009b	Systematic review	Systematic review 1996-2006	-	-	Individual characteristics, informal network, professional care and setting, government policies
Vine & Hamilton	Australia	2005	Cross-sectional study	Questionnaires	ComQoL Adaptive Behaviour Scale Vineland Adaptive Behaviour Scale Resident Choice Assessment Scale Life Circumstances Questionnaire	37 males with ID	Individual characteristics

we decided to focus the substantive results, and consider results on similar concepts as comparable regardless of the instruments and methods which were used. Our purpose is not to evaluate the selected studies on their used instruments but to collect as much information as possible about barriers and facilitators for social inclusion in the neighbourhood.

The selected studies were conducted primarily in the UK (12 studies), followed by (Northern)-Ireland (5), the USA (4), the Netherlands (3), Australia (2), Israel (1) and New-Zealand (1), according to Table 2. The research designs chosen are cohort (longitudinal) studies, cross-sectional studies, qualitative studies and systematic reviews.

The author(s), country in which the study was conducted, year of publication, study design, data collection method, questionnaires, sample size and the domain of factor the selected studies address are summarized in table 2.2.

Domains of factors

The literature on people with intellectual disabilities pays little attention to environmental factors in inclusion. We therefore base our domains of factors on the ecological model of M. Powell Lawton, which has been very influential in analysing adaptive behaviours and wellbeing of older adults (Scheidt & Norris-Baker, 2003). In his environmental taxonomy, Lawton distinguished the physical environment, the personal environment (including personal relationships), the small group environment (social characteristics beyond direct personal contacts), the suprapersonal environment (policies and social structures in the local environment), and the social or megasocial environment. These environments may have a better or worse fit with individual competences, leading to varying degrees of adaptive behaviour. We summarize the barriers and facilitators for social inclusion we found in the following five domains of factors:

- individual competences: characteristics of the people with intellectual disabilities relevant to inclusion, e.g., specific skills and knowledge (15 articles)
- informal network (personal environment): support from family, friends and acquaintances (10 articles)
- professional care (suprapersonal environment): support from professionals, type of setting (26 articles)
- neighbourhood characteristics (physical environment and small group environment); e.g. facilities in the neighbourhood, but also contact with neighbours (5 articles)

- governmental policies (megasocial environment): federal and local policies (4 articles)

Most of the studies focus on one or two domains. This means that our discussion of results within a domain may also refer to other domains.

Individual competences

Half of the articles focused on the relationship between individual characteristics and social inclusion. Several of these studies found a relationship between knowledge and skills of the people with intellectual disabilities and different aspects of social inclusion (e.g. Beadle-Brown, Mansell, Whelton, Hutchinson, & Skidmore, 2006; McConkey et al., 2005; Verdonshot et al., 2009b). Concepts of inclusion mostly pertain to the experience of valued and expected social roles, being recognized as a competent individual and trusted to perform in social roles in the community and finally belong to a social network. Authors describe different aspect of social inclusion like participation, community involvement, community activities and social support. Abbott and McConkey (2006) found that a lack of necessary knowledge of the area and literacy and numeracy skills are barriers to social inclusion. Such knowledge and skills are necessary to become an active participant in community life. Based on experiences of people with intellectual disabilities living in the community they identified four elements of social inclusion in the community: talking to people, being accepted, using community facilities and having opportunities, like the availability of staff to support them or having the freedom to go out themselves. Social and practical skills are needed for realizing these elements of social inclusion. These skills are also important for the effective use of recreation time and making friends (Buttimer & Tierney, 2005; McConkey, 2007). Functional skills and adaptive skills (for example opening a door, say hello) are important for community integration and participation (Thorn et al., 2009; Heller, Miller, & Hsieh, 2002). People with a more severe disability were more vulnerable and less able to develop the above mentioned skills (Felce & Emerson, 2001). We further see that the concept of returning a favour is quite unfamiliar to people with intellectual disabilities (Van Alphen et al., 2009), but this does not mean they are unwilling.

The studies above are clear about the necessary individual skills to improve social inclusion at large but we found only little research focusing on individual characteristics necessary for social inclusion in the neighbourhood, but there also are no indications that such local inclusion would put different demands on people with intellectual disabilities. The studies typically focus on skills related to the learning and development disabilities that define the target population, such as cognitive capacities and social skills. They show the importance of these skills for experiencing valued and expected social roles, being recognized as a competent individual and

trusted to perform in social roles in the community and belong to a social network. To create a suitable environment for social inclusion it is important that people with intellectual disabilities have or acquire skills to foster the interaction with neighbours and this would logically imply that neighbours also try to adapt to the skills of people with intellectual disabilities. Professionals support people with intellectual disabilities in these skills, and provide information to neighbours which is needed to build relationships between neighbours with and without intellectual disabilities.

Informal network

The relationship between the informal network and social inclusion was studied in 10 articles. The informal network can be a condition for social inclusion, but support from the informal network is also part of social inclusion. Belonging to a social network can also facilitate the other components of social inclusion we distinguished. Interpersonal relationships and activities enable people with intellectual disabilities to enjoy and contribute to the quality of life in their community, for example engaging in community work and being physically and socially present (Richardson, 2000). Abraham et al. (2002) found social support to increase community participation. Social support from peers was particularly important. Heller et al. (2002) concluded that family involvement was associated with higher levels of participation in activities. Families are often the primary source for expanding social networks outside the residence in the local community where people with intellectual disabilities live.

Professionals can use the informal network of people with intellectual disabilities to realize social inclusion in the neighbourhood. The informal network can be helpful for people with intellectual disabilities to acquire social and practical skills. They are able to support a larger social network and to work on valued and expected social roles. These aspects contribute to being recognized as a competent individual and having the opportunities to perform social roles in the community, like being a neighbour.

Professional care

The domain of professional care was studied in almost all of the articles. This domain includes aspects of the facilities in which people with intellectual disabilities live and features of the staff members, in particular their attitude towards social inclusion. Living in an apartment or small group home has a positive effect on social inclusion. Small settings enable creating contacts with neighbours (McConkey, 2007; Hartnett et al., 2008; Kozma et al., 2009; Robertson et al., 2005; Van Alphen et al., 2009). But as we stressed in our introduction, moving people to ordinary neighbourhoods is no guarantee for social inclusion. Various studies and reviews of the literature show that staff can provide opportunities to people with intellectual disabilities to

develop skills that help them make friends, participate in neighbourhood activities and fulfil social roles like being a neighbour (O'Brien et al., 2001; Kozma et al., 2009; Thorn et al., 2009).

The study of Thorn et al. (2009) highlights how creating a therapeutic milieu fostering learning and practicing functional skills in real-life activities translates to increased community presence for people with severe intellectual disabilities. As we described before, these skills are important for starting social relationships in the neighbourhood. The attitude of staff has a crucial influence on creating these opportunities. Staff initiated social interactions with clients influence community activities significantly. These interactions are correlated positive staff attitudes, so indirectly these attitudes are important for community activities (Egli, Feuer, Roper, & Thompson, 2002). Other authors point out that embracing a supporting rather than a caring role contributes to social inclusion in different environments. (Abbott & McConkey, 2006; Hunter & Perry, 2006; Minton & Dodder, 2003). This means exploring the possibility of reciprocal relationships with neighbours and supporting people with intellectual disabilities in acquiring prevailing social norms and expectations in the neighbourhood. Staff can also create opportunities by organising for example open door days, barbecues or selecting activities in the neighbourhood (Van Alphen et al., 2009). In conclusion staff members can stimulate and support the complex interactions between environmental factors and personal characteristics which are described by Cobigo et al. (2012), that provide opportunities for valued social roles in the neighbourhood and belonging to a social network.

Neighbourhood characteristics

Five articles describe neighbourhood characteristics. Abbott and McConkey (2006) describe different neighbourhood characteristics that influence social inclusion, like lack of amenities in the neighbourhood and attitudes of neighbours. The authors identify a negative attitude in the neighbourhood, as well as lack of activities and information on activities as barriers to social inclusion.

Contact between neighbours and people with severe intellectual disabilities was associated with greater understanding and appreciation by neighbours (Robertson et al., 2005). Intensive neighbourhood contact is not crucial. Seemingly superficial contact, like exchange of greetings and not being ignored contributes more to a sense of belonging for people with intellectual disabilities (Van Alphen et al., 2009). Not having a facility nearby with recreational opportunities can be a barrier to leisure participation (Buttimer & Tierney, 2005). Schwartz and Rabinovitz (2001) analysed neighbourhood acceptance in a multidimensional perspective: acceptance by people in the neighbourhood depended on interactions between facility variables and characteristics of the neighbourhood population. Characteristics of

neighbours that brought them physically or psychologically closer to people with intellectual disabilities, like having young children, having a disabled relative, knowing that the neighbourhood contained a facility, and visiting the facility was positive for acceptance. Facility variables were size, degree of supervision and the strategies used by managers to gain local acceptance. The study found that these variables cannot be considered in isolation. For example visiting the facility was positive for acceptance especially for neighbours with young children or a disabled relative. Not only can we see complex interaction between environmental and individual characteristics from the perspective of people with intellectual disabilities, but these pertain to neighbours as well.

People with intellectual disabilities further noted that to feel at home, the atmosphere in the neighbourhood needs to be just right; they need to feel safe, calm and at ease. When there are instances of public aggressiveness, neighbourhood relations are tense, or when neighbours are annoying or ignore them, the sense of feeling at home is challenged (Van Alphen et al., 2009).

These results show that the availability of meeting grounds and means for activity can facilitate neighbourhood participation. Meaningful neighbourly contacts and, subsequently, inclusion, are facilitated when the local population is predisposed toward a positive attitude. On the other hand, attitudes of neighbours may become more positive as a consequence of contact with people with intellectual disabilities. However, the success of such contact may depend on the right combination of people and situations. Staff can support successful contacts by linking people with intellectual disabilities and their neighbours. They can support people with intellectual disabilities to develop contacts and participate in neighbourhood activities. Staff is also able to create meeting opportunities by involving neighbours in their activities.

Government policies

Deinstitutionalization is a policy goal in many Western societies. The number of people with intellectual disabilities in large institutions is steadily declining. But institutional practices and attitudes may persist in community settings (Beadle-Brown et. al., 2007). The four studies we have found that focus on the relationship between policies and social inclusion address the policy changes necessary to achieve social inclusion. Suggest that economic priorities may get in the way of achieving social inclusion (Hall, 2005; Mansell, 2006). But residents in community-based houses have not benefitted from recent initiatives aimed at community capacity-building such as the appointment of professionals specifically for facilitating community relationships for people with intellectual disabilities (Bigby, 2008). A solution to this seeming contradiction may be the involvement of people with intellectual disabilities in policies that concern them. The involvement of residents in policy making will

increase community integration, conclude Verdonshot et al. (2009b) in their review of the empirical findings. This involvement can be on the level of the organization or the local authority.

Discussion and conclusion

Support in neighbourhoods becomes more important for realizing social inclusion in of people with intellectual disabilities, yet we know very little of factors that may increase or hinder such social inclusion. We discuss 28 studies and reviews that addressed five domains of factors or types of environments relevant to social inclusion in the neighbourhood. The studies addressed diverse populations of people with learning or development problems, or clients of organizations supporting people with intellectual disabilities.

Our concept of social inclusion was based on the multidimensional concept of Cobigo et al. (2012). Often, social inclusion is equated with performance of roles and activities. Cobigo et al. (2012) instead distinguish four dimensions of social inclusion: access to public goods and services, experiencing valued and expected social roles, being recognized as an individual and trusted to perform these social roles and belonging to a social network. Most studies focus on belonging to a social network and participating in activities. We can conclude that especially being able to perform a valuable role in the neighbourhood and being recognized as an individual is still investigated very little in the studies we found. Further, social inclusion is often measured in objective characteristics, i.e., the actual roles and activities performed by people with intellectual disabilities. Cobigo et al. (2012) point out that inclusion is a two-way process, not only involving an external viewpoint. The viewpoint of people with intellectual disabilities and their experiences is often lacking. Some studies focus on the subjective perspective of people with intellectual disabilities (e.g. Abbot & McConkey, 2006; Hall 2005; Van Alphen et al., 2009) and show that they can feel left out, do not feel that they belong, feel different or do not feel safe in the regular environment. These results show the importance of including the perspective of people with intellectual disabilities, because actual participation may not automatically mean that people feel accepted. Future research on the perspective of people with intellectual disabilities related to social inclusion in the neighbourhood is recommended. In order to understand why people with intellectual disabilities do, or do not, feel included it is important to gain more knowledge about exactly what neighbour social inclusion comprises, from the perspective of people with intellectual disabilities.

Social inclusion is a reciprocal process involving commitment and activity from all parties involved. Not only people with intellectual disabilities need to feel included, and need to be able to define what they consider as meaningful participation. The same goes for neighbours, who have their own perspective on meaningful contacts with people with intellectual disabilities, involving people with intellectual disabilities in neighbourhood activities, accepting people with intellectual disabilities, or supporting people with intellectual disabilities and attitudes towards people with intellectual disabilities. Most importantly, the concept of social inclusion is always related to the people or setting which someone wants to belong to. The neighbourhood setting and the people that live in it may interact in supporting or hindering neighbourhood inclusion for people with intellectual disabilities (Schwarz & Rabinowitz, 2001).

Answering the second question of the literature study gives insight in important barriers and facilitators for social inclusion in the neighbourhood. We distinguished five domains of relevant factors, based on the ecological model of Lawton (1999). In doing so, we emphasize the ecological approach inherent in Cobigo's (2012) concept of inclusion: inclusion is the result of complex interactions between personal competences and environmental demands and opportunities. Such an ecological focus is all but lacking in the empirical literature. Each domain is researched to some extent, but little empirical research focuses on the interactions between individual skills and environmental factors. For example, staff and relatives can support individual skills to achieve inclusion of people with intellectual disabilities. Milner and Kelly (2009) show the importance of empowering people with disabilities to locate themselves within the community and creating a sense of belonging. But environmental factors affect each other as well. Local authorities encourage social inclusion in their communities by creating opportunities for activities. The attitudes of neighbours are influenced by the staff and people with intellectual disabilities themselves. These (and many more) relations show the interaction between the domains and give insight in the dynamic process of social inclusion in the local community. The studies we found mainly cover two domains beside individual competences, professional care, and the informal network. Especially the influence of the small group environment and local policies on social inclusion need further study. Little is known about the relationship between characteristics of the local community and social inclusion for people with intellectual disabilities in their neighbourhood. Complex interactions between personal factors and social and cultural aspects of the neighbourhood affect individuals' experience of social inclusion (Martin & Cobigo, 2011; Van Alphen et al., 2010).

The concept of social capital (Bourdieu, 1986; Coleman, 1988; Portes, 1998; Putnam, 2000) may help to understand the complex dynamic between people with

intellectual disabilities and their local neighbours (Bollard, 2009). This term refers to social networks that share social norms. Social norms play an important role in how neighbours develop their relationships with other neighbours. Therefore, we would recommend research to gain more insight into the role of social norms in developing neighbour relations and the actual behaviours towards neighbours with, and without, disabilities.

Some limitations of this study can be identified, so data should be interpreted with caution. The databases Pubmed and Socindex were searched thoroughly for the period 2000–2010, making use of a combination of MeSH and text words that covered a wide range of the research population. We included articles found in the databases mentioned above. We are aware of the fact that more relevant publications and reports, not included in the searched databases, could exist. Important omissions were detected by searching the references of the selected authors and from the selected articles. Despite the limitations of this review, a significant number of relevant studies was selected and carefully analysed. The review articles we studied, show overlap with the empirical studies we selected. This means that the most important studies are included.

We found a relatively large number of studies from the UK. This is probably related to the fact that policies in the UK strongly focus on social inclusion. Research in other countries than the UK can show whether findings are tied to this specific context.

This will also enable researchers to address the relation between the policy context and social inclusion in the neighbourhood. Social inclusion in the neighbourhood is a widely shared policy goal across Europe and beyond, and it should be researched likewise.

This chapter is based on:

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Chapter 3

Photovoice in research involving people with intellectual disabilities: a guided photovoice approach as an alternative



Abstract

Background

In studies involving people with intellectual disabilities, photovoice is increasingly used to include the voice of participants. Analysing existing literature, we found that photovoice was used in various forms with different outcomes. These studies describe both obstructing and facilitating factors. We designed a more standardized approach of photovoice and developed an alternative strategy: 'guided photovoice'.

Method

The 'guided photovoice' approach was tested on fourteen participants with intellectual disabilities. The outcomes of the approach were evaluated.

Results

The effectiveness of the approach varied with the participants' capabilities and needs. Some participants were talked more while taking photos, others told their story easily during the interviews. The use of follow-up questions was helpful to deepen the interview.

Conclusions

A more standardized, guided photovoice approach is a helpful addition to the various options for using photovoice; it is important to decide which approach best fits the needs and capabilities of the participants.

Introduction

In an increasing number of studies, photovoice is used to involve people with intellectual disabilities in research (Jurkowski & Ward, 2007; Booth & Booth, 2013; Akkerman et al., 2014). In a typically photovoice procedure, participants take photographs which are later used to facilitate reflection on their feelings, ideas and experiences (Mitchell, 2011).

Photovoice was first developed and applied by Wang and Burris (1994; 1997). They used photovoice to gain insight in the perspectives of rural women in China on their health. According to Wang and Burris (1997), photovoice offers several advantages compared with other research tools; it enables participants to address their needs and it offers researchers insight into the perspectives of participants. The method is explicitly useful in vulnerable populations because it does not presume the ability to read or write. Booth and Booth (2013) emphasize its suitability for people with intellectual disabilities. It helps to include people in research who for example have difficulties with direct communication or are hampered on a cognitive and conceptual level (Jurkowski, 2008; Finlay & Lyons, 2002; Sigstad, 2014).

One of the main goals of photovoice is to enable participants to record and reflect on their lives (Wang & Burris, 1997). This provides participants with a voice, that can empower them to advocate for changes in their living environment, (Wang & Burris, 1997). Our study did not focus on the empowerment of the participants in our research project and their opportunities for effectuating changes. We concentrated on the research goal: providing people with intellectual disabilities a voice and using this voice to answer research questions. In the studies in which photovoice was used in research involving people with intellectual disabilities, there was variation in how photovoice was applied. This variation concerned the practice of qualitative research in general (for example the recruitment of participants) as well as specific aspects of photovoice (for example the number of photos taken or the type of camera used) or the level of intellectual disabilities of the people involved in the research (for example the level of assistance needed). Although some studies critically reflect on photovoice (e.g. Jurkowski & Paul-Ward, 2007), it is unknown how this variation affects the outcomes of research. The aim of our study was to develop a more standardized approach to photovoice, built on clear methodological choices, to optimize the effectiveness of photovoice.

First, we analysed existing research to identify the obstructing and facilitating factors of photovoice to help the voice of people with intellectual disabilities be heard. During the next step, we discussed our methodological considerations and choices based on the obstructing and facilitating factors found in step one. These considerations and choices led to a more standardized approach. In step three,

the approach was tested in a small scaled study with fourteen participants with intellectual disabilities, analysed and discussed.

Literature search

A literature search was conducted to identify studies in which photovoice was used to interview people with intellectual disabilities. A search was conducted in CINAHL, ERIC, Web of Science, PubMed and PsycINFO, combining one of the keywords 'photovoice', 'photo elicitation', 'photo elicited interview' or 'photographic research' with the keywords 'intellectual disabilities', 'learning disabilities', 'mental retardation', or 'development disabilities'. We identified eleven relevant titles. In three publications – Jurkowski (2008), Jurkowski and Paul-Ward (2007) and Jurkowski, Rivera, & Hammel (2009) – the same dataset was used. We included the article by Jurkowski and Paul-Ward (2007), because it is in this article the use of photovoice is described in detail. Nine publications were included in our comparative analysis. Table 3.1 shows an overview of the included studies and the way photovoice was applied in the stages that we will describe below in more detail.

In our comparative analysis, we distinguished different stages in the photovoice research process:

- Stage 1: preparation
- Stage 2: taking the photos
- Stage 3: the interview
- Stage 4: post interview

After describing each stage, we examined what the obstructing and facilitating factors were. The obstructing and facilitating factors we identified were of theoretical, practical, ethical, and methodological nature.

Stage 1: preparation

The stage of preparation involved the recruitment and selection procedures, the consent procedure and providing information to participants and training them. The first step, the recruitment and selection of participants, is relevant in all qualitative research. However, the recruitment and selection procedure of people with intellectual disabilities is of a special nature, since the recruitment is not done directly by the researchers themselves but via care organizations, schools or other agencies involved in the research project or with the people with intellectual disabilities (eight out of nine studies). The studies of Aldridge (2007) and Povee et al. (2014) included nonverbal participants.

Because of the vulnerability of the target group, people with intellectual disabilities, a proper consent procedure is essential. This procedure was described clearly in six out of nine studies. There was a focus on confidentiality and anonymity. For example, if photographs were presented, the photographer should remain anonymous. In three out of these six studies, the consent forms were adjusted to the cognitive level of the participants, for example by adding photos. In the study of Povee et al. (2014), the consent procedure was an ongoing process during the entire research project. Prior to each meeting, participants were asked if they would like to continue being involved in the project.

Training the participants is an important aspect of photovoice. In the studies examined, participants were informed and trained in different ways, either individually or collectively. Participants were informed collectively, for example, during a focus group or an information meeting (O'Brien et al., 2009; Jurkowski & Paul-Ward, 2007; Ollerton & Horsfall, 2012; Povee et al., 2014; Schleien et al., 2013). Participants were trained, individually or collectively, in the ethical aspects of photographing (for example asking written consent when photographing another person) and instructed how to operate a camera.

Obstructing and facilitating factors during the stage of preparation

The studies described some ethical and methodological obstructing and facilitating factors during the preparation stage.

An important methodological question is to formulate the criteria on which a participant should be included or excluded in the study. A photographic intervention does not work for everyone. An important consideration is whether or not to include nonverbal participants. Jurkowski (2008) describes photovoice as useful for engaging those who cannot read or who have low literacy levels. On the other hand, the method is difficult to use with people who are nonverbal. They may be able to participate in the photography component of the project but it would be difficult for them to engage in reflecting on their photographs taken and relating themes to their daily lives. Ottmann and Crosbie (2013) state in their study that the combination of using photographic images and an interview seemed to be an effective mix to represent the views of people with intellectual disabilities. As Aldridge (2007) emphasizes, it is not appropriate to analyse photographs without having heard the story of the photographer, because without it, a researcher cannot interpret the significance of what is depicted in the photograph.

Aldridge (2007), also addresses the challenge the consent and confidentiality procedures pose. In cases where participants were not able to provide consent because they could not understand the consequences of their participation, consent was sought from parents or guardians.

Table 3.1 – Overview of studies in which photovoice was used in research with people with intellectual disabilities

Reference & country	N	Research aim	The stages of photovoice
Akkerman et al. (2014) The Netherlands	9	Photovoice was used to identify themes related to job satisfaction.	<p>Stage 1: Recruitment through a care organization. Participants were first informed and after providing their consent trained individually.</p> <p>Stage 2: Participants used a digital camera to take photos individually and were assisted in practical aspects if necessary.</p> <p>Stage 3: Participants were interviewed individually and the interviewer focused on open questions.</p> <p>Stage 4: Interviews were transcribed verbatim and analysed with ATLAS.ti.</p>
Aldridge (2007) United Kingdom	19	The study explored photographic participation and elicitation techniques as a way of including vulnerable respondents more effectively in social research studies	<p>Stage 1: Participants of specific projects were recruited. After the informed consent participants were instructed about their assignment.</p> <p>Stage 2: Participants used a disposal camera to take photos and general guidance was provided if necessary.</p> <p>Stage 3: All participants were asked individually to choose five favourite photos and, where possible, to explain their reasons for their choices.</p> <p>Stage 4: Photos were content analysed, as well as the explanations of the participants.</p>
Booth & Booth (2003) United Kingdom	16	The mothers' photo albums provided insights into discriminatory views of the women as deviant mums.	<p>Stage 1: The participants were part of project and volunteered to participate. Participants were instructed about their assignment.</p> <p>Stage 2: Participants used a disposable camera. No guidance was provided.</p> <p>Stage 3: The albums were discussed individually and afterwards a group session took place to share concerns and common threads that characterized their lives.</p> <p>Stage 4: The content of the photo albums were analysed in the context of personals stories.</p>
O'Brien et al. (2009) Ireland	19	Photovoice was part of a mixed-method approach to investigate the experiences of students with intellectual disabilities in gaining access to university.	<p>Stage 1: Photovoice was part of data triangulation. Students were invited to participate.</p> <p>Stage 2: Participants took photos across a typical day in their student life.</p> <p>Stage 3: The photographs were discussed during a group meeting.</p> <p>Stage 4: Open, axial and selective forms of coding were used to synthesise the material.</p>
Jurkowski & Paul-Ward (2007) USA	4	The study had three goals: (a) to raise awareness of health disparities, (b) to describe the strategy of using photovoice, and (c) to encourage the use of photovoice.	<p>Stage 1: Participants were recruited from focus groups. Participants signed an adopted informed consent. Participants and staff members were trained individually.</p> <p>Stage 2: Participants used a disposable camera. Participants were provided with examples during a peer group session. Staff members encouraged participants and the researcher was frequently available if participants had any questions.</p> <p>Stage 3: Participants were interviewed individually in a private setting at the community agency during their day program</p> <p>Stage 4: Interviews were transcribed verbatim and analysed together with the outcomes of the focus groups. Afterwards participants were brought together in a member-check focus group. The researcher created scrapbooks of photos.</p>

Ollerton & Horfall (2012) Australia	5	Photovoice was used to show that people labelled with learning difficulties can do research, leading to positive social change.	<p>Stage 1: Participants self-referred to an information session and voluntarily joined the project. Participants were trained individually.</p> <p>Stage 2: Participants had the choice to use a disposable camera, digital camera or mobile phone to photograph barriers to their self-determination.</p> <p>Stage 3: The resulting photos were printed and used as the basis for research team discussions.</p> <p>Stage 4: Photos were categorized and coded by the participants. Afterwards discussions took place about each theme. Having identified disability rights concerns, the participants devised actions to assert their rights and to tell others.</p>
Ottmann & Crosbie (2013) Australia	11	The study compared the results of a suite of qualitative methods, including photovoice, and identified the advantages and disadvantages of each method.	<p>Stage 1: Participants were recruited through their case manager or teacher. All participants and, where appropriate, their guardians signed an informed consent form.</p> <p>Stage 2: Participants used a digital camera or a mobile phone to photograph the most important aspects in their lives. Some participants drew on carer assistance to take the photos, due to physical or vision impairments.</p> <p>Stage 3: Semi structured interviews and focus groups were part of the approach but it is not described how the photos were discussed.</p> <p>Stage 4: Data were thematically coded and the results were entered into a spread sheet for comparison.</p>
Povee et al. (2014) Australia	18	The aim of the study was to explore the process, opportunities and challenges associated with the use of photovoice with people with intellectual disabilities. They used the 'This is me' project to explore photovoice.	<p>Stage 1: All members of an advocacy agency were invited to participate. Participants were provided with an adapted consent. Information and training was provided during a group meeting.</p> <p>Stage 2: Participants used a digital camera. The researcher provided assistance if necessary.</p> <p>Stage 3: Members were interviewed individually, in pairs or in small groups at their home. Some participants requested that their parent or guardian was present.</p> <p>Stage 4: Interview transcripts were analysed using causal layered analysis. Participants selected their own photos which were displayed at a public photograph exhibition.</p>
Schleien et al. (2013) USA	7	Photovoice, was used to give seven individuals ID/DD the opportunity to document their lives through the use of photography and discuss their interests, hopes and dreams.	<p>Stage 1: The participants were recruited through an organization and responded to an invitational letter. Participants were informed and trained during a group meeting. All participants signed an informed consent.</p> <p>Stage 2: Participants used a digital camera. Assistants provided support in the technical aspects, in prompting to complete photography assignments, and in transporting to and from programme meetings or photography locations.</p> <p>Stage 3: An individual interview took place between the instructor, participant and his/her assistant.</p> <p>Stage 4: Programme staff discussed the content of photos and transcripts using the constant comparative approach. Individual transcripts were coded and discussed again. The identified themes were presented to the participants group discussion as a member check. Afterwards two community exhibitions took place.</p>

In the studies of Povee et al. (2014) and Schleien et al. (2013), participants were informed and trained collectively. Povee et al. (2014) mentions the collectivity of the training as a facilitating aspect, because participants were able to encourage and help each other.

Stage 2: taking the photos

During the second stage, taking the photos, decisions have to be made on instruction, assistance provided, restrictions in time or number of photos taken, and on type of camera used. All these decisions concern aspects of photovoice or conducting research with people with intellectual disabilities. In the studies, an open instruction procedure was used, allowing participants to take any photographs they wanted. The instructions varied from 'take photos of people, places and things that are important to you' to 'take photos showing a typical day in your student life' (see table 3.2). In one study, examples were provided by peers (Jurkowski & Paul-Ward, 2007).

In six out of nine studies, some level of assistance was given to the participants with intellectual disabilities. There was great variety in the form of assistance provided: assistance was given by either a staff member or a family member and it stretched from mere technical support to helping the person to remember the purpose of taking the photos. The studies also varied in the level of restrictions. Seven out of nine studies did not mention any restrictions on the number of photos taken. Six out of nine studies did mention a restriction on the total amount of time permitted to take the photos. The time available varied from seven days to three months. In four out of nine studies, participants used a digital camera; in three studies a disposable camera was used. In one study both types of cameras were used.

Obstructing and facilitating factors during the stage of taking the photos

In the photo taking stage, theoretical, practical, ethical, and methodological obstructing and facilitating factors were distinguished. Booth and Booth (2003), face both practical and ethical problems in the use of cameras. One participant said her camera was broken, but did not want to be further involved in the project when she was offered a new camera. Another participant decided to print the photos but did not want to share these photos. Some participants involved in the study, found it difficult to develop their films quickly, and put aside the camera. This meant the project took much longer than planned. This was also the case in the study of Jurkowski and Ward (2007): participants took more time in returning the cameras than foreseen. One participant in the study of Jurkowski and Ward (2007) had trouble handling the camera and some photos were unclear. He was given another camera but never returned it. The study of Akkerman et al. (2014)

Table 3.2 – Questions related to the instruction and questions during the interview

Reference & country	Questions related to the instruction	Questions during the interview
Akkerman et al. (2014) The Netherlands	Participants were instructed to take photos of 'things at work which make you feel good' and of 'things at work which do not make you feel good'.	What is on the picture? Why did you take the picture? Is it something that makes you feel good or something that doesn't make you feel good?
Aldridge (2007) United Kingdom	Participants were asked to take photos on site about projects over a period of time (approximately one month). They were asked to take photos of aspects of their participation in projects that they particularly enjoyed or liked.	The participants commented on the significance or importance of the photos they had taken and to choose five of their 'favourites'. Participants were asked to explain the reasons for their choices.
Booth & Booth (2003) United Kingdom	All participants were asked to photograph people, places and things that 'are important to you'.	No questions were specified. The albums were discussed in order to listen to the stories behind the photos, to learn why these particular snaps had been taken and to understand the significance they had for her.
O'Brien et al. (2009) Ireland	Participants were invited to take photos showing a typical day in their student life.	No questions were specified. Participants took photos of a typical day in their life.
Jurkowski & Paul-Ward (2007) USA	Participants were asked to take photos of "what they felt made them healthy or sick." They were provided with the examples given by their peers during focus groups. The researcher walked around with them when they took their first few photos.	No questions were specified. Participants discussed how the images represented their experiences and how those experiences related to their health. General questions were asked. However, most of the discussion was free flowing.
Ollerton & Horsfall (2012) Australia	Participants photographed barriers to their self-determination. It is not specified which instructions (questions asked) the researchers gave.	A group discussion took place on the following questions: why was the photograph taken and what was happening in the photograph
Ottmann & Crosbie (2013) Australia	The following question was asked: 'In your opinion, what are the most important issues that affect your life?' If needed, the question was rephrased.	No questions were specified.
Povee et al. (2014) Australia	During a group meeting, participants were reminded of the purpose of the research and encouraged to think about and discuss the following questions; 'Who am I?', 'What makes me me?' and 'What is important to me?' They were given no directions as to what to photograph.	What made you take this photograph; and what is happening in this photograph?
Schleien et al. (2013) USA	In the first assignment, participants were asked to take photos of people, places, and activities that were important to them.	Why did you take this photo? What are the people, places, and activities in this photo? What do you like about these people, places, and activities? What bothers you about these people, places, and activities?

faced methodological difficulties because there was no limitation on the number of photos taken, which therefore varied widely between the participants. This meant it sometimes took a long time to discuss all the photos and some interviews were less complete because of the limited amount of photos.

The role of staff in taking photos can be both facilitating and obstructing. Staff can encourage participants and support them in the technical and practical aspects of taking photos, such as reminding the participants to take the photos (Schleien et al., 2013; Akkerman et al., 2014). On the other hand, staff can have an unwanted influence on the content of the photos.

Akkerman et al. (2014), mention another theoretical obstructing factor. Participants in their study were asked to take photos of their workspace. The participants were inclined to photograph the most prominent aspects of the workplace, which may have led to the omission of more neutral aspects. Discussing the photographs alone could have resulted in an under-representation of the more neutral aspects. Another concern, according to Akkerman et al. (2014), is that some participants may have difficulty photographing negative matters. Finally, Akkerman et al. (2014) warn that some concepts may be hard to take a photo of, for example abstract concepts (e.g. vacation) or things which are absent during the time the study is taking place, such as Christmas decorations in summer. Apart from this, Akkerman et al. (2014) mention ethical difficulties in photographing other people. Asking permission caused a barrier for participants to photograph other people. To overcome these limitations, participants were asked if there were any other aspects which they did not photograph but which were important to them to talk about in the interview. However, certain themes may still have been under-represented or absent.

Stage 3: the interview

In all studies, the stage of taking the photos was followed by an interview with the participant. At this stage, several methodological issues concerning the context of the interview need to be addressed: opting for an individual or a collective interview approach, deciding on the presence of an assistant and what kind of interview questions to use. In eight out of nine studies, an individual interview was conducted. In four studies, the individual interview was combined with a group session. The individual interview was, for example, followed by a group meeting in which participants were asked to explain their photos to the entire group (Schleien et al., 2013). The group meeting was also used as a member check. In two studies, participants were interviewed in the presence of an assistant (Povee et al., 2014; Schleien et al., 2013). In one study, input from the assistant was directly checked with the participant for validation. This is relevant, as the presence of an assistant during the interview might influence the type of responses the participant might give. Four out of nine studies reported the use of printed photos and in three out of nine studies participants were asked to select photos. In all studies, open-ended questions were used, offering participants maximum opportunity to tell their story

about the photos they took. Table 2 lists the questions researchers asked during the interviews.

In two studies, photos of nonverbal participants were included (Aldridge, 2007; Povee et al., 2014). In the study of Povee et al. (2014), the nonverbal participants pointed at photos and used gestures and facial expressions to convey their story.

Obstructing and facilitating factors during the interview stage

Also in the interview stage methodological and practical obstructing factors were encountered. The studies which used a combination of an individual interview with a group meeting (Booth & Booth, 2003; Ollerton & Horsfall, 2012; Povee et al., 2014; Schleien et al., 2013), point to the added value of a group meeting in sharing concerns, opening a critical discussion and/or identifying themes together. Staff and peers were able to encourage participants in their reflection process. However, Schleien et al. (2013) mention a methodological limitation: the potentially negative influence of assistants and staff members. They tried to mitigate this negative influence by clearly delineating the role of assistants. However, it should be noted that individuals with intellectual disabilities can be easily influenced, as they often desire to please others. Therefore, comments made by assistants or staff members may have had an impact on participants' answers. Akkerman et al. (2014) state that an individual unassisted interview gives participants the opportunity to express their views without undue influence from others.

In their study in which they compared different methods to represent the views of people with intellectual disabilities, Ottmann and Crosbie (2013) found another methodological limitation. The photographic images predominantly generated concrete issues and missed out on abstract themes, such as living independently in the community. But when the images were combined in a semi-structured interview, these themes did emerge. Reflecting on their own study, Ottmann and Crosbie (2013) point out that it also might have been useful to ask participants if there was anything else they would have liked to have photographed, if they had had the opportunity. This recommendation was also made by Akkerman et al. (2014).

Participants in the study of Aldridge (2007) had difficulty expressing the meaningfulness or significance of their photos. They tended to simply describe the photo. For example, 'That's my friend Diane'.

Stage 4: post interview

Each study approached the last stage differently (see table 3.1). Decisions had to be made on how to analyse the data and what type of data analysis to use, performing a member check procedure and other actions to process the results. The decisions made concerning the data analysis are relevant to qualitative research in general, and are not discussed in this article.

The only aspect of data analysis which specifically concerns the use of photovoice is the question whether a researcher should or should not analyse the photos that are taken (outside the context of the interview). In one study (Aldridge 2007), the photos were interpreted by conducting a content analysis.

In two studies, a member check was mentioned (Jurkowski & Paul-Ward, 2007; Schleien et al., 2013). This member check consisted of discussing the themes that were identified during a group meeting (see also the interview stage).

In the studies, the actions taken on the basis of results varied. This also depended on the aim of the research project: whether it was just a matter of hearing the voice of participants and using this information to answer research questions or whether the topic of the study also had an aspect of trying to generate change and of empowering participants. Four out of nine studies (Jurkowski & Paul-Ward, 2007; Ollerton & Horsfall, 2013; Povee et al., 2014; Schleien et al., 2013) paid specific attention to the dissemination of the results to a wider public, for example by organizing a presentation or an exhibition. Besides their regular report, Jurkowski and Paul-Ward (2007) also reported their results in a format for people with a low literacy.

Obstructing and facilitating factors of the post interview stage

There was only one obstructing factor mentioned by Aldridge (2007) concerning the post interview stage. This was a theoretical obstructing factor having to do with being careful in interpreting the content of the photos taken, because not all participants were able to expand verbally on the meaning of their photos. If photos are analysed without the comments of the participant involved this may lead to false conclusions.

During the member check procedure, or other actions undertaken after the interview stage, no specific obstructing and facilitating factors of photovoice as a research tool were mentioned. Studies which also focused on photovoice as an empowerment tool, point out that, for example, organizing an exhibition or proving photo books could be seen as facilitating empowerment.

Method

Towards a more standardized (guided) photovoice approach

Based on the obstructing and facilitating factors mentioned above, we decided to design a more standardized approach to use photovoice. Also, we decided to develop an alternative option within the approach we called guided photovoice. In our analysis of the literature we presented the most commonly used aspects

of photovoice. Below, we will discuss our more standardized (guided) photovoice approach.

Stage 1: preparation

It is evident from the obstructing and facilitating factors mentioned above, clear selection criteria should be used in photovoice projects which can be used by the caregivers involved:

- Participants should be able to understand the consent procedure, the instructions and the content of the assignment;
- Participants should be able to demonstrate they understand the consent procedure;
- Participants should be able to demonstrate they understand all aspects of the process of taking photos
- Participants should be able to reflect verbally on the photos they have taken.

We recommend to ask staff members to invite all residents who meet the formulated selection criteria of an upcoming research project to cooperate in the research. All potential participants should receive a personal invitation and if they are interested in participating they should have the opportunity to contact the researcher individually. The purpose of the invitation is to explain the research project and what is expected from the participants, written in plain language, supported by photos. Staff members and potential participants should be able ask the researcher questions about the project and the researcher should visit the homes of the participants to provide information about the research project and introduce him or herself as a neutral party. This could reduce unwanted influence of staff members on the (outcomes of) the research process. A neutral party can reduce 'gratitude participant responses' and take away any fear of repercussions of critical answers (D'Eath, 2005; Tassé et al., 2005). Although in earlier studies the collective process of informing and training was said to facilitate enthusiasm and support, we recommend an individual meeting to inform and train participants, for two reasons. The first reason is to create trust and familiarity between the researcher and the participant during this individual meeting. During this individual meeting, participants will also be informed about the consent procedure. The consent procedure should include the aim and the content of the project, the photo voice process itself, information about anonymity and confidentiality and information about how the photos and related stories will be used in the project and beyond. A second reason for an individualized approach lies in the fact that participants should not influence each other by talking about which photos should be taken or about their hesitations to take a certain photo (Slump, Moonen, Hoekman, & Jongmans, 2010).

Stage 2: taking the photos

To include people with intellectual disabilities who would otherwise not choose to enter a photovoice project without the involvement of a staff member, we have developed the 'guided photovoice' option. We define 'guided photovoice' as follows:

'Participants take photos together with the researcher. The researcher is guided by the participant during a walk, but does not interfere with the content of the photos.'

The guided elements make it more informal and easier for people with intellectual disabilities to take the photos (Kusenbach, 2003; Garcia et al., 2012). During the guided photovoice procedure, participants have the option to take their own photos or to instruct the researcher to take the photos for them. This could also prevent problems such as not being able to handle the camera, being unwilling to return the camera or taking too many photos. We advocate that there is always an alternative option of taking the photos without the presence of the researcher. Guided photovoice could also offer a solution to other obstructing factors, such as not being able to photograph abstract aspects or not being able to photograph persons who are not willing to cooperate. Because participant and researcher work (and walk) together, participants may be more inclined to tell about all aspects or persons of concern.

In ethnographic research, detailed field notes or other observations can be advantageous for deepening the understanding of the participants process (Carpiano, 2009; Emerson, Fretz, & Shaw, 1995). This is why we also recommend to take field notes. They can be useful for subsequent analysis and in the guided photovoice procedure, these observations can provide useful information for the following interview.

Furthermore, we recommend the use of a digital camera (or tablet or smartphone), to be able to save the photos which are taken in a computer file. However, a shift from film to a digital camera also poses some challenges. Using a digital camera with many options might be difficult for a person with intellectual disabilities. We would therefore recommend providing an 'easy to use' digital camera together with a clear instruction. In general, there should be no restrictions on the number of photos taken.

Stage 3: the interview

Before the interview starts, we would recommend the researcher to print the photos. This avoids problems such as delays due to participants not having photos developed in time. Researchers can also consider the possibility of using a digital display screen, for example tablet. Kagohara et al. (2015) show the possibility of using

lPods and lPads in teaching programs. Using a tablet is not explored in our study. If necessary, only a selection of the photos, chosen by the participant, can be discussed during the interview. A person who is well-known to the person with intellectual disabilities is probably the best interviewer, as a greater level of communications and trust may already exist between them (D'Eath, 2005). For this reason we do not recommend a single interview, without an introductory meeting and spending time taking the photos together. By the time the interview starts, the interviewer should be able to create an atmosphere of trust in which the participant is encouraged to share accurate information on the topic under discussion (D'Eath, 2005).

It is best to discuss the photos during an individual interview, to limit the unwanted influence of bystanders, peers, assistants or staff members. The interviewer has to formulate open questions and participants should have the opportunity to tell their story without being limited by response categories or structured questions. Participants will typically be asked what is on the photo and why the photo was taken. If necessary, participants will be encouraged by using follow-up questions. We recommend these two sentences: 'could you tell me more?' and 'can you give an (other) example? Finally, participants should be specifically asked about photos they have not taken, following the approach of Akkerman et al. (2014). In this way, limitations mentioned above, such as not being able to photograph abstract concepts or not being able to photograph people who are not willing to cooperate, can be overcome.

Stage 4: post interview

Based on the results of earlier studies, we recommend not to analyse the photos outside the interview context. Photos cannot not be interpreted without the explanation of participants. Photos can be inserted in the interview transcripts to connect stories to the photos.

Because researchers are already involved from the beginning (introduction meeting, (guided) photovoice procedure and interview), a separate member check is not needed.

Necessary precautions should be taken for participants for whom the photovoice process can be disturbing because of the sensitivity of the topics touched upon (Slump et al., 2010). Therefore, aftercare should be provided when necessary.

Figure 3.1 shows the methodological decisions to be considered for our more standardized (guided) photovoice approach.

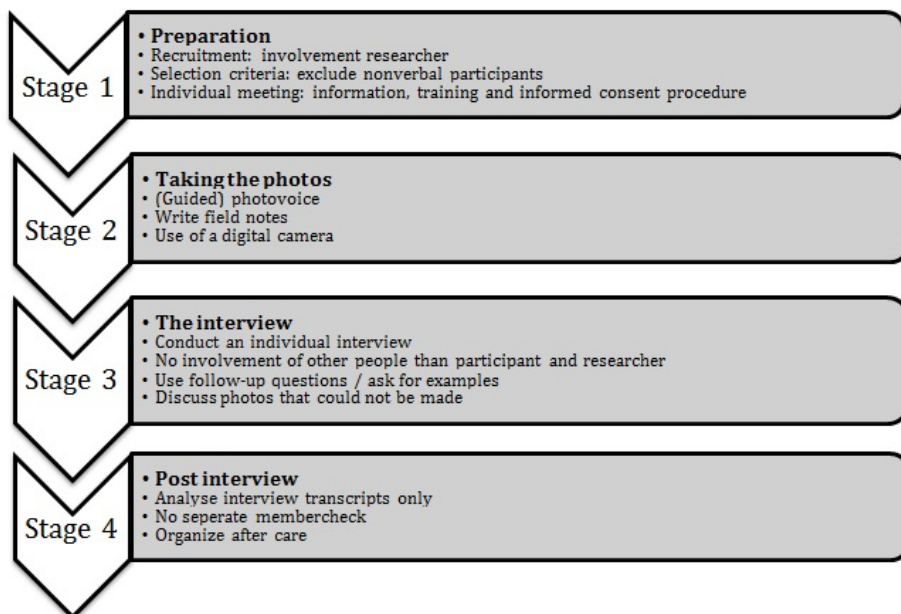


Figure 3.1 – Methodological decisions during the (guided) photovoice approach

The (guided) photovoice approach applied in a study about the social inclusion of people with intellectual disabilities in their neighbourhood

To obtain more knowledge about the perspectives of people with intellectual disabilities on their social inclusion in the neighbourhood, we used the (guided) photovoice approach described above. Together with the participants, we walked around in their neighbourhood. Participants were able to photograph places and people in their neighbourhood together with the researcher. After the photographing stage, the photos were discussed during an individual interview. The next sections provide an overview of the participants, the process of data analysis and the results and a reflection on how the methodological decisions in the various stages of the (guided) photovoice approach worked out in this study. Finally, we reflect on the general outcomes and provide recommendations for future research.

Participants

We included fourteen participants in our study with a mild to moderate intellectual disability, to test our (guided) photovoice approach. Table 3.3 shows the characteristics of the fourteen participants in our study and the steps within the photovoice process followed by each participant.

Table 3.3 – Participants in the study about social inclusion of people with intellectual disabilities in their neighbourhood

	Sex	Age	Photovoice process	Number of photos	Number of photos showing people
A	Male	65	Guided photovoice: participant took photos together with the researcher. Photos were discussed during an interview.	24	0
B	Female	48	No guided photovoice. Participant took photos without involvement of the researcher. Photos were discussed during an interview.	12	0
C	Male	38	Guided photovoice: participant took photos together with the researcher. After this stage he lost his camera. No interview took place. The guided photovoice transcript was analysed.	?	?
D	Male	53	Guided photovoice: researcher took photos. Photos were discussed during an interview.	6	2
E	Male	48	Guided photovoice: researcher took photos. Photos were discussed during an interview.	10	2
F	Female	54	Guided photovoice: researcher took photos. Photos were discussed during an interview.	11	0
G	Female	64	Guided photovoice: researcher took photos. Photos were discussed during an interview.	12	0
H	Male	61	Guided photovoice: researcher took photos. Photos were discussed during an interview.	12	0
I	Female	48	Guided photovoice: researcher took photos. Photos were discussed during an interview.	14	1
J	Male	42	Guided photovoice: researcher took photos. Photos were discussed during an interview.	15	0
K	Female	30	Guided photovoice: researcher took photos. Photos were discussed during an interview.	20	3
L	Male	51	Guided photovoice: researcher took photos. Photos were discussed during an interview.	12	1
M	Female	47	Guided photovoice: researcher took photos. Photos were discussed during an interview.	4	0
N	Female	42	Guided photovoice: researcher took photos. Photos were discussed during an interview.	6	0

Plan for the analysis of the approach used in this research project

To analyse the effectiveness of our approach in revealing the voice of people with intellectual disabilities, each step of our approach was planned thoroughly for each participant. This evaluation concerned the observations and interpretations of the researchers (who were involved in each stage for each individual participant).

We started with the preparation stage, in which we evaluated the (dis)advantages of extra involvement of the researcher. First we explored whether our formulated selection criteria were helpful in selecting the most appropriate participants for the project. This particularly meant evaluating the participants' understanding of the process. Next, we evaluated the individual meeting in which information was given on the purpose of the research and the training procedures and the consent procedure. Because there was no involvement of peers and staff we were particularly curious how participants would respond.

Then we related the information provided by the participants during the guided photovoice and the written field notes to the interview transcripts. We particularly wanted to evaluate the decision not to involve staff but instead introduce an independent researcher who was guided by the participant during the process of taking the photos. We focused on the field notes. How did we use these field notes in preparing our interviews and was there an added value in doing so? Finally, we wanted to evaluate the use of a digital camera.

All interviews were recorded and transcribed. ATLAS.ti was used to code the interview transcripts. We searched for text fragments in the interview data that showed how participants related to other residents and staff members, in order to obtain information about our decisions to conduct an individual interview instead of a group interview and for staff members to be absent. To evaluate the intervention of asking about photos not taken, and using the specific follow-up questions mentioned above, we used the technique of process coding, followed by an evaluative analysis (Saldana, 2013). We focused on the interaction process between the interviewer and the participant. To explore the significance of the techniques, we coded the responses to the follow-up question 'photos not taken' and the 'example' questions and to 'active listening' which was aimed at encouraging the participant to tell his or her story.

In the post interview stage, we compared the content of the photos with the stories of the participants. This comparison provided information about the (im) possibility of interpreting photos without a story. Next, we compared the evaluation of the guided photovoice with the analysis of the interview transcripts, to see if this could replace a member check procedure. Lastly, we evaluated the need for aftercare by coding our transcripts based on two questions: did our participants need aftercare and what kind of care was provided?

Results

Stage 1: preparation

In the recruitment procedure, we encountered some difficulties because staff members wanted to decide for us whether or not their residents with intellectual disabilities were able or willing to participate in our project. They tended to think that their residents were too occupied, or incapable of understanding the procedure. For this reasons, the first author paid extra visits to some group homes to discuss the selection criteria with the staff members. Providing this extra information to staff members created enthusiasm and a better understanding of the research project. This enthusiasm helped with the recruitment of their residents. In one group home, the first author visited a group meeting and provided information to potential participants. This direct contact made it easier to recruit participants because the people with intellectual disabilities and their staff gained more understanding about the research project. Eventually, fourteen participants from four care organizations were involved in our research project (for their characteristics see table 3.1). During the recruitment procedure, two participants dropped out of our study. The reason for this was related to the subject of the research project. These two participants experienced difficulties participating in the neighbourhood and did not feel safe enough to walk around and take photos.

All participants were informed and trained individually. The consent procedure was discussed with each participant. In some cases, the interviewer left the form with the participants, so, they could talk it over with family or a staff member if they wished to do so. All participants signed the consent form, and provided information in such a way that it was clear that they understood the procedure. In two cases, a participant explicitly asked to participate in the project together with another person living in the same group home. However, we insisted that they would participate individually because we wanted to avoid mutual influencing.

Stage 2: taking the photos

Table 3.3 shows how the photovoice procedure was conducted with each participant. Eleven out of twelve participants were guided by the interviewer during the photographing stage. Two of the participants took their own photos and during nine guided walks the interviewer took the photos. During the guided walk participants were encouraged to point out people and locations in their neighbourhood that were important to them. One participant hesitated to participate but finally went for a walk with the researcher. After taking one photo, he got really enthusiastic and showed a lot more spots he considered important for him in his neighbourhood. Two other participants were quite silent during the walk but guided the interviewer

to people who were important to them and who lived in their neighbourhood. In meeting these people, the participants opened up and told more about their relationships in the neighbourhood. One participant took her own photos with her mobile phone and sent the photos by WhatsApp. Because it was difficult to plan a meeting with her to take the photos, this approach worked well in her case. Another participant took his own photos during the walk, but lost his camera. The photos were not printed and no interview took place. Only in this case, the recording of the guided photovoice walk was used. On average, almost thirteen photos were taken per participant, ranging from 4 to 24 photos. The amount of photos with people depicted was limited (see table 3.3) but the stories behind other photos often involved people.

Directly after every guided photovoice walk, field notes were taken. These field notes were used as input for every interview. The interviewer made a small summary of the experiences during the guided photovoice walk and wrote down what was observed and where this was located. For example whether participants were recognized by a lot of people in the neighbourhood, whether participants smiled when they saw a neighbour, showed signs of 'happiness' walking around the marketplace or whether participants showed signals of anger when talking about some residents. These field notes were used as a member check and were in some cases helpful in formulating follow-up questions during the interview.

In all cases a digital camera was used. All participants who took the photos themselves were able to operate the camera.

Stage 3: the interview

An individual interview was conducted with thirteen participants. In every interview the relationships with staff members and other residents of the group home was topic of discussion. In three interviews, a difficult relationship with one or more staff members was mentioned; it was stressed that this information was not to be shared with their professional caregivers. According to five participants in our study, the relationships with other residents were also troublesome (for example when someone's privacy is constantly invaded). Two participants were interviewed in a joint room and when another resident walked in, they felt uncomfortable and stopped telling their story.

In twelve interviews, follow-up questions were used frequently (more than five times during the interview). Participants were asked to tell more about the site or the person depicted. These follow-up questions were often combined with an active listening style, encouraging participants to tell more. Aspects of active listening were, for example, saying uhuh or yes. Part of the follow-up questions was asking for examples about activities they had undertaken at a certain spot or with a person

in the photo. The responses to the questions differed for each participant. Eight participants told extensive stories and provided detailed information, whereas four participants had difficulty answering these questions. They remained quiet, kept saying yes or no or were not able to provide more in-depth information. These participants had said more during the guided photovoice walk. This information was used for follow-up questions during the interview.

At the end of each interview, participants were asked about photos not taken or important places and persons they had missed during the guided photovoice walk. Seven participants provided extra information and five participants answered with 'no' or 'don't know' (one participant was not interviewed). This extra information was about concrete spots, like a shop but, also about abstract themes, like loneliness. The question about the photos not taken and the last question "is there anything else you would like to tell", provided extra information and were therefore valuable. At the end of each interview, the photos were handed over to the participant. During the interviews, the field notes taken after the guided photovoice walks were used as a member check which we needed in the post interview stage.

Stage 4: post interview

During the coding process – after the interview – it became clear that photos were often used as a catalyst to tell a story about a topic or about relationships with friends and family. These stories related to the picture but in a lot of cases the pictures could not be interpreted by themselves. For example, a picture showing a building which was experienced as an unsafe place or a picture of a bar which led to a story about relationships with family members. In some cases, a participant had more stories to tell about one picture, for example because there was more than one interesting spot visible in the photo.

It is most common to conduct a separate member check after the interview, but we recommended in our approach to do the member check within interview stage. During eight interviews, the interviewer explicitly referred to the guided photovoice walk. In all interviews the walk was implicitly referred to, for example when the interviewer recalled information heard during the guided photovoice walk and this information was repeated during the interview. All eight participants confirmed this information after it was referred to. Combining the guided photovoice process with the interview was useful as a member check.

Four participants indicated problems that needed after care. The interviewer stressed that they could discuss these issues with staff members and they confirmed they would do so or had already done so. In one case, the interviewer discussed the issue – on the participant's request – with a staff member.

Discussion

The aim of this article is to investigate how the photovoice process could be most useful in enabling participants with intellectual disabilities to express their opinions in research studies. We analysed the existing literature, introduced a more standardized (guided) photovoice approach and conducted a research project to test important methodological decisions. We will reflect on all of this along the stages of the research process.

Stage 1: preparation

In the research project on neighbourhood involvement, the personal involvement of the researcher in the preparation stage, which we recommended, created among the participants and staff more understanding and enthusiasm about the research aim and the recruitment procedures. It became a joint process, in which more participants were involved in the research project. During this stage, a researcher should be aware of his or her own role and should be as objective as possible, maintain a neutral presence and apply no pressure.

In the photovoice approach it is essential to be able to reflect on the photos. Our study showed that even verbal participants had difficulties answering questions during the interview. This supports our recommendation to exclude nonverbal participants. Excluding nonverbal participants does not mean we do not consider it important to involve these people in research, but that photovoice may not be the ideal method to give them a voice.

During the recruitment procedure, we noticed that some residents influenced each other's decisions on whether or not to participate in the study and this stresses the importance of an individual approach.

Stage 2: taking the photos

In the photographing stage, we added a new option to our approach: guided photovoice. Participants could take pictures of their neighbourhood together with the researcher. This mode made photovoice more accessible for participants who had difficulties in for example operating a camera or walking around in the neighbourhood. Sometimes, the guided photovoice procedure helped participants to overcome psychological barriers.

The results of our project support our recommendation to use a digital camera.

Stage 3: the interview

In accordance with our recommendations, it turned out that the field notes were useful as input for the interview stage. These field notes were valuable for confirming information provided during the interview and for formulating follow-up questions. The recommendation to conduct interviews individually and unassisted led to unexpected information about how participants perceived their relationships with staff members and other residents.

As expected, using follow-up questions, asking for examples and active listening all resulted in in-depth information about how participants felt in their neighbourhood and in what way facilities, activities and people contributed to this feeling. Walking around provided participants with an opportunity to tell their story in a well-known context and when meeting friends and family in the neighbourhood they were encouraged to tell more. The recommendation to exclude nonverbal participants from involvement in photovoice projects was supported by the outcome in our project that six of our participants faced difficulties in answering questions during their interviews. In some cases this prompted unwanted interviewer assistance and showed that there are indeed limitations to the involvement of people with limited verbal capacities in a (guided) photovoice research project. An extensive guided photovoice walk (and talk) could perhaps serve as an alternative to the interview.

The results of our neighbourhood research project show that the question about the photos not taken and the final question on whether or not there are more issues to be addressed are important to complete the stories of the participants.

Stage 4: post interview

As expected, we found that the stories which were revealed during the interviews often could not be deduced from the photos alone. This underpins the recommendation not to interpret the photos separate from the interview transcripts.

The more standardized (guided) photovoice procedure makes the special member check redundant. It is replaced by the recommended interview procedure. During the stages before the interview, a lot of information is exchanged that can be used as a member check.

After care proved necessary and should always be considered when conducting a photovoice project.

Reflecting on the strategies of the guided photovoice

There seems to be a paradox in the use of photovoice. Photovoice is often used to include people who have difficulties with direct communication and are disadvantaged on a cognitive and conceptual level (Jurkowski, 2008). But during the interview, the participants often have difficulty reflecting on the photos they have taken. How

realistic is this interviewing? And do these interviews reveal the information we are looking for? Our study showed that some participants benefit from a guided photovoice walk and talk, but that the subsequent interview did not provide us with extra information. In these cases, the face-to-face interview could be excluded from the research process. Literature focusing on walking interviews confirms our findings that respondents find it easier to verbalize attitudes and feelings when 'in place'. This way of gathering information produces richer data (Aldridge, 2007; Evans & Jones, 2011; Garcia et al., 2012). Kusenbach (2003) states that the walking interview is primarily relevant in research that focuses on environmental perceptions, special practices, biographies, social architecture and social realms. Sensitive topics might be more difficult to address; participants could feel uncomfortable by the presence of a researcher in their natural habitat. This uncomfortable feeling might also occur when walking with certain people with intellectual disabilities, depending on the research topic and the needs of the participants. We would recommend further research on 'guided photovoice' in research involving people with intellectual disabilities.

For two people involved in our research project the guided photovoice walk led to renewed contacts in their neighbourhood. These participants took the initiative to visit people they met during the guided photovoice walk. This 'by-catch' of guided photovoice relates to the other aim of photovoice projects, i.e. empowering people and changing their current situation. In our study, this may lead to social inclusion in the neighbourhood. We would recommend care organizations to consider using guided photovoice walks as a method for empowering their residents and providing them with opportunities for change.

Digital tools and photovoice

One participant in our study took her own photos and provided them via Whatsapp. She was perfectly able to explain the photos she took. For participants who have a limited amount of time and who have the ability to take their own photos, it would be recommendable to further explore the use of Whatsapp. Using Whatsapp prevents from difficulties as losing a camera or lacking the development of photos by participants. If participants are clearly guided in this procedure, it can offer opportunities in applying a relative fast and cheap photovoice procedure.

Looking ahead, more new and existing digital techniques are becoming available to support photovoice interviews. For example, geolocation could be added to the interview material to include a spatial analysis. By linking the locations of pictures taken by different participants, themes and shared concerns relating to specific locations could be identified (Jones & Evans, 2012; Paulus et al., 2014). We also mentioned the use of tablets for displaying the pictures. In the near future, a review

of such techniques and their use in photovoice interviews would be useful to the research and support people with intellectual disabilities living in the community.

Our study shows that clear methodological decisions during the photovoice process helped to design a method that elicits rich stories of participants. Within this approach it is important to cater to the needs and capabilities of each participant.

This chapter is based on:
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of people with intellectual disabilities: relevant themes
identified with the use of photovoice.

Submitted.

Chapter 4

Neighbourhood social inclusion from the perspective of people with intellectual disabilities: relevant themes identified with the use of photovoice



Abstract

Background

Earlier studies show that to gain more understanding of the concept of social inclusion, subjective measuring is needed. The aim of this study was to investigate people with intellectual disabilities' perspective on social inclusion in the neighbourhood.

Method

We carried out a photovoice study with eighteen people with intellectual disabilities in three neighbourhoods in the Netherlands. Participants took photos in their neighbourhood they considered relevant, and these photos were discussed during an interview.

Results

Six themes emerged from qualitative analysis: attractiveness of the neighbourhood, social contacts in the neighbourhood, activities in the neighbourhood, social roles in the neighbourhood, independence and public familiarity.

Conclusions

As regards neighbourhood social inclusion, participants were often focused on small and informal activities and situations. Public familiarity proved very important. For further study of the meaning of social inclusion from different perspectives, we recommend research from the perspective of neighbours.

Introduction

The Netherlands has a long tradition of institutional care for people with intellectual disabilities. People with intellectual disabilities were placed in large institutions often separated from society (Schuurman, 2002). From the 1950s onwards, models of social care were developed and social inclusion of people with intellectual disabilities has become a focus of care organizations and policy makers in many Western countries (Beadle-Brown et al., 2007; Overmars-Marx et al., 2014). In the Netherlands, this development has been encouraged by government policy since the 1990s (Ministry of Health Welfare and Sports, 1995). The large institutions, which were separate from society, were closed and care provision increasingly became organized around small-scale group homes situated in ordinary neighbourhoods (Nieboer, Pijpers, and Strating, 2011). Despite these developments, people with intellectual disabilities still feel isolated, shut out from regular activities and enjoy less contacts with neighbours than people without disabilities (e.g. Cummins & Lau, 2003; Cobigo & Stuart, 2010; Hall, 2005; Hall, 2016). These findings show that physical integration does not automatically lead to social inclusion (e.g. Nieboer et al., 2011).

Social research points to the fact that interactions in the neighbourhood, and social relationships between neighbours, have a significant effect on health and well-being (e.g. Forrest & Kearns, 2001; Unger & Wandersman, 1985; Völker, Flap, & Lindenberg, 2007; Van Alphen et al., 2009). Earlier studies show that people with intellectual disabilities have fewer contacts with neighbours and therefore may benefit less from local social interactions. In-depth information about their, possibly special, position in the neighbourhood is lacking. Our study was aimed at gathering the views and experiences of people with intellectual disabilities and their neighbours on social inclusion in the neighbourhood to investigate if and how people with intellectual disabilities are part of neighbourly relations.

Cobigo et al. (2012) conceptualize social inclusion as opportunities to (1) access to public goods and services, (2) experience valued and expected social roles of one's choosing based on his/her age, gender and culture, (3) be recognized as a competent individual and trusted to perform social roles in the community, and (4) belonging to a social network within which one receives and contributes social support. Cobigo et al. (2012) state that further work is required to develop a consensus on the meaning of social inclusion. Part of this work should focus on including subjective measures (see also Cummins & Lau, 2003). Each actor in a neighbourhood has their own position and perspective on the environment, and may therefore also have different perspectives on the social inclusion of people with intellectual disabilities. There may be differences in how people view the nature and the degree of social inclusion. This may in turn affect their behaviour regarding the

social inclusion of people with intellectual disabilities. This knowledge can be helpful to enhance social inclusion.

In this paper we present the views of people with intellectual disabilities. Because social inclusion concerns the people with intellectual disabilities, it is of fundamental importance to understand their view first. The few studies that have been conducted (e.g. Abbott & McConkey, 2006; Hall, 2005; Van Alphen et al., 2009) lack in-depth information about the facilitating and obstructing factors to feeling included in the neighbourhood. The aim of our study is to gain a better understanding of the perspective of people with intellectual disabilities on social inclusion in the neighbourhood.

Methods

Dutch context: care for people with intellectual disabilities

Long-term care in the Netherlands was reformed comprehensively in 2015 and is now regulated by three acts of law. The first, the Long-term Care Act (*Wet langdurige zorg*), regulates care in institutions (residential care) and in the community (home care) for people who need 24-hour supervision. Home nursing care and personal care are regulated by the Health Insurance Act (*Zorgverzekeringswet*) and funded via health insurers. Other support for people living at home is regulated by the Social Support Act (*Wet Maatschappelijke Ondersteuning*) which places the responsibility for the implementation with the municipality (Kroneman et al., 2016). Our study includes people with mild to moderate intellectual disabilities (93% of the people with intellectual disabilities in the Netherlands). People with intellectual disabilities experience difficulties on a cognitive and conceptual level but also in social skills. As in many other Western countries, the view on people with intellectual disabilities has changed as a result of the normalization movement (Wolfensberger, 1983), and they are seen as part of society. Society, in the current opinion, should provide people with intellectual disabilities with the opportunities to live as normal citizens (Oliver, 1996). In the current situation, people with mild to moderate intellectual disabilities either live in group homes in the community where they receive 24-hour residential care or they are supported in their homes under the responsibility of the municipality (which is referred to as ambulant care in the Netherlands). This study includes both people with intellectual disabilities living in group homes and people receiving support at home. On average, the group homes included in our study house fifteen people with intellectual disabilities.

Recruitment and selection of participants

Eighteen participants with intellectual disabilities were included in our study. All participants live in three neighbourhoods in small towns in the eastern part of The Netherlands. Two of the neighbourhoods are situated in small towns with approximately 15,000 to 20,000 inhabitants in low-urbanized areas. The third neighbourhood is a suburb of a small town with a population of 55,000 inhabitants. The neighbourhoods and group homes were selected by the first author in cooperation with the four service providers involved in the research project. The selection criteria were representation of the four service providers and variation in neighbourhoods. The researchers also aimed for variation in the types of disabilities among the residents in the care of group home staff members.

Thirteen participants were living in group homes and five participants were living independently and received support at home (ambulant care). Participants were asked to participate in our study by staff members from the group homes involved in our study. They were selected on the criteria of being able to understand the informed consent, the instruction of the method and the nature of the assignment. This meant being able to take the pictures together and verbally reflect on the content of the pictures. Ages ranged from 24 to 65. Nine participants had been living in the specific neighbourhood for over five years. Six participants were born and raised in the area in which they still lived (table 1). According to staff, all participants had a mild to moderate intellectual disability.

Data collection

Involving people with intellectual disabilities in research is not without difficulties. Therefore, it is important to consider which method would be most suitable for involving people with intellectual disabilities in research. Booth and Booth (2013) suggest that photovoice might be useful in conducting research with vulnerable populations because it does not presuppose the ability to read or write. One of the main goals of photovoice is to give participants the opportunity to record and reflect on their own lives (Wang & Burris, 1994; 1997). It enables participants to share their story and reveal their voice, supported by photos they took themselves. The method was originally developed by Wang and Burris (1994, 1997) to gain more insight into the perspectives of rural women in China on their health. Photovoice allows scientists to include people in research who for example have difficulties with direct communication (Jurkowski, 2008; Finlay & Lyons, 2002; Sigstad, 2014). To include people with intellectual disabilities, we used the (guided) photovoice approach developed in the study of Overmars-Marx, Thomése, and Moonen (2017). Our research was conducted in four stages:

1. Preparation stage

Each participant was provided with written information and was invited for an individual meeting with the researcher. During this meeting, participants were informed about the nature and procedure of the research. We informed the participants about the confidentiality of the study and the anonymization of data. This involved an instruction and an information exchange between the researcher and the participants. All participants signed the written consent form in the presence of the researcher. The consent form contained information about the nature of the research, the use of photos, and the anonymization of the outcomes. In four cases, the preparation stage was partly integrated in the picture taking stage. In these cases, the informed consent procedure and taking the pictures were combined into one session.

2. Taking the pictures

During the (guided) photovoice walk, participants had the option to take pictures themselves or to instruct the researcher to take photos for them. This could also prevent problems such as not being able to handle the camera, being unwilling to return the camera or taking too many photos. The option of taking pictures

Table 4.1 – Participants

	Sex	Age	Town	Group home or ambulant care	History in the neighbourhood
A	Male	65	Town A	Group home	3,5 years in this group home, born and raised in Town A
B	Female	48	Town A	Group home	7 years in this neighbourhood
C	Male	38	Town A	Group home	7 years in this group home, born and raised in Town A
D	Male	53	Town B	Group home	13 years in this group home, born and raised in Town B
E	Male	48	Town B	Group home	7 years in this group home, born and raised in Town B
F	Female	54	Town B	Group home	7 years in this neighbourhood
G	Female	64	Town B	Group home	2 years in this group home, before in another group home in Town B
H	Male	61	Town A	Group home	6 years in this group home, born and raised in Town A
I	Female	48	Town A	Group home	5 years in this neighbourhood
J	Male	42	Town A	Group home	3 years in this neighbourhood, lived in Town A before
K	Female	30	Town A	Group home	11 years in this group home, born and raised in Town A
L	Male	51	Town B	Ambulant care	2 years in this neighbourhood
M	Female	47	Town C	Group home	4 years in this group home, 5 years in Town C
N	Female	42	Town C	Group home	1 year in this neighbourhood, lived in Town C since she moved to the Netherlands
O	Female	65	Town B	Ambulant care	1 year in this neighbourhood
P	Male	24	Town B	Ambulant care	1 year in this neighbourhood
Q	Female	33	Town C	Ambulant care	1,5 years in this neighbourhood
R	Female	64	Town A	Ambulant care	7 years in this neighbourhood

without the presence of the researcher was also available. Participants were asked to photograph important places and people in their neighbourhood; i.e. places where they felt (un)comfortable and people who were important to them. In other words, people or places which had a positive or negative impact on how they felt in their neighbourhood. Only one participant took pictures without the presence of the researcher. The participants or the researcher took photos of important spots and people in their neighbourhood with a digital camera. On average, this resulted in approximately fourteen pictures of a variety of pleasant or frightening places and important people in the neighbourhood. There were a limited number of people in the pictures. All pictures were printed by the researcher. The photos were also stored on the computer.

3. Individual interview

To limit the influence of staff member or peers, with each of the seventeen participants an individual interview was conducted. An individual interview provides the opportunity to tell your own story without the influence of others. One participant dropped out before the interview. For this participant, the information gained during the guided walk was used in the analysis. During the interview, participants were asked to describe what was on the picture and why they took this picture. Open-ended questions were used during the interview. To encourage participants to tell more, we used follow-up questions or we asked for examples. At the end of each interview, we asked participants if there were any photos they might have wanted to take but didn't take and whether they wanted to say more about the neighbourhood. If, during the interview, a participant expressed the need for a change in care provision, we asked if aftercare should be provided. In these cases, staff members were already aware of the participant's special needs.

4. Data analysis

All interviews were recorded and transcribed verbatim. The interview transcripts were content analysed using ATLAS.ti software (Scientific Software Development GmbH Berlin, Germany). The coding process was based on elements of the grounded theory techniques (Strauss & Corbin, 1990). Our approach was aimed at providing thorough descriptions and interpretations of social inclusion in the neighbourhood from the perspective of people with intellectual disabilities. The first stage was open coding (Glaser & Strauss, 1967). During the coding process, we engaged with the material by reading the transcripts over and over again. During the next stage we performed axial coding (Strauss, 1987) and classified the codes into categories, or subthemes. The coding process was an iterative process: categories were adjusted during the process by comparing them within and across different

transcripts. After the axial coding, the codes were grouped into broader themes. A sample of interviews was analysed by a second researcher. While analysing the interview transcripts we continuously reflected on the process and the findings obtained (Yanow, 2003). By classifying the data, creating concepts based on this classification and connecting these concepts, we achieved rich descriptions of social inclusion in the neighbourhood (Dey, 1993).

Results

We identified six themes related to neighbourhood social inclusion: attractiveness of the neighbourhood, social contacts in the neighbourhood, activities in the neighbourhood, social roles in the neighbourhood, independence, and public familiarity (see table 2). All participants narrated stories about the attractiveness of the neighbourhood and social contacts in the neighbourhood. Activities in the neighbourhood were also mentioned by most participants. More than half of the participants told stories about social roles in the neighbourhood and independent living. Half of the participants stressed the importance of ‘public familiarity’. Blokland and Nast (2014) define public familiarity as the implicit relationships that contribute to recognizing others and being recognized by others in public spaces. The themes are described separately but the correlations between the identified themes is also addressed in the separate descriptions.

Table 4.2 – Overview of themes and codes relevant to social inclusion in the neighbourhood

	Theme	Codes
	Attractiveness of the neighbourhood	Level of facilities Green spaces/parks
	Social contacts in the neighbourhood	Intensity of contact with family, acquaintances/friends, neighbours, other residents and staff members
Neighbourhood social inclusion	Activities in the neighbourhood	General activities in the neighbourhood: sport, funfair, lunch club Activities focused on meeting neighbours: barbecue, drinking coffee Activities involving people with intellectual disabilities
	Social roles in the neighbourhood	Regular, sheltered and voluntary work in the neighbourhood Small tasks in the neighbourhood
	Independence	Facilities nearby Own room
	Public familiarity	Meeting people in the neighbourhood – being recognized Social contacts related to the interaction with shops assistants, performance in social roles and attendance at neighbourhood activities

Attractiveness of the neighbourhood

The participants in our study emphasized the importance of the atmosphere in the neighbourhood. This atmosphere was created by e.g. the presence of a nice park nearby, but also by the presence of shops, pubs and restaurants. Half of the participants explicitly mentioned the presence of a park, a petting zoo or benches to sit on. Participants like to walk through the park or sit on a bench to watch other people. *'It is nice. My son likes it. We go there for a walk. It is nice and quiet.'* (Participant Q from town C), *'We go for a walk to the petting zoo and look after the animals even it is raining.'* (Participant G from town B) Other participants also told positive stories about their walks To the shopping area, for example. *'Sometimes, when I am not working, I just walk around. I go to the shopping centre to visit some shops and buy groceries.'* (Participant N from town C)

All participants but one took pictures of shops or restaurants/bars. They are familiar with the people who work in the shops, bars or restaurants and like to chat with them. Sometimes they know these employees from their shop visits and in other cases they have met them in another context. *'He is behind the counter. He is nice.'* (Participant I from town A) *'When the funfair is in town, I go to the cafeteria. It's nice. An acquaintance of my brother's works there.'* (Participant K from town A)

A participant from town B is an exception. He doesn't like the atmosphere in the neighbourhood and misses his old one. His experiences with shop assistants are quite negative: *'When I ask for something, they just point at the product and then I must take it myself. This is strange because I don't know the shop.'* (Participant L from town B)

Social contacts in the neighbourhood

Participants hardly took any pictures of people but during the interview, all of them told stories about social contacts in the neighbourhood. Social contacts are important in providing participants a positive feeling about the neighbourhood. For example, meeting someone in the street and having a chat or being able to visit a family member nearby and spending time together make participants feel at home in the neighbourhood. Social contacts in the neighbourhood vary among participants in 1) the kind of relationship with the other person and 2) the intensity of the contact. Stories were told about family members, but also about the contact with shop assistants. And these contacts have a wide range of intensity, from superficial to extensive contact. In this section, we make a distinction between social contacts with family members who live in the neighbourhood, with acquaintances and friends in the neighbourhood, with neighbours, with other residents and with staff members from the group home.

Some participants have a lot of family members living nearby whereas other participants have lived in this neighbourhood for only one year, and do not have any contacts close to home. Two participants from town B with a moderate intellectual disability had a lot of support from members of their family, who lived a couple of blocks away. They undertake activities together, such as shopping, and visit them often. *'My brother asked me to be a referee at the football club. I see him often, which is nice.'* (Participant D from town B)

Also, four participants from town A were born and raised in their neighbourhood. They have family and acquaintances in the neighbourhood. Three of these participants mentioned joint activities like shopping, visiting each other or celebrating anniversaries together in a restaurant. Spending time together in their neighbourhood gave them a positive feeling. *'This is my brother's house. Our contact is nice. We drink coffee and watch television.'* (Participant K from town A)

Participants hardly mentioned any friends in the neighbourhood. Some participants have acquaintances whom they know from their past, through their family or work. One participant made a friend in the neighbourhood. Her friend's husband was the owner of the pub next to the group home: *'...Yes, at one time she had a holiday and also came to visit the pub. He introduced her to me: 'This is my wife'. She loved my dog ...'* (Participant B from town A) The same participant demonstrated that having a lot of contacts does not automatically mean that there is no need for more contacts. She told stories about the contacts she had in the neighbourhood; with neighbours, with her boss, with her contacts through voluntary work, but she still missed a person to, for example, go to a bar with or to go shopping together with. She had taken a photo of a community centre in the neighbourhood, where she followed a course, *'I know you'*, to extend her social network. This is what she said about it: *'For a course assignment, I organized a high tea at my place. Someone from the course helped me. That was nice. We met a couple of times afterwards but since September there's no more contact. I don't know what happened'.*

Ten participants told stories about their contacts with neighbours. Apart from the friendship with a neighbour mentioned above, contact with neighbours is limited to greeting or having a small chat. Two participants from town B attended a barbecue where they met neighbours but both mentioned that these contacts did not continue after the barbecue. One participant from town A also mentioned contact through a barbecue meeting. Another participant from town A meets her neighbours during joint activities in the apartment building. *'On Wednesdays, there is a gym activity and on Mondays we drink coffee together. If there is a communal activity we have contact and when we meet we say hi. We don't visit each other, but I don't feel the need to.'* (Participant R from town A)

Two participants from town C live in a flat and their contact with neighbours is limited. During the interview, one participant mainly focused on not having any problems with neighbours and the other participant mentioned the talks she has with her neighbours. *'My neighbour is sweet. First there was no contact but now if she sees me, she asks how I'm doing and how things were at work.'* (Participant N from town C)

Fifteen participants told stories about other residents with intellectual disabilities in the group or the apartment complex. There were both positive and negative stories. Most of the participants maintain good relations with the other residents. They have meals together and sometimes undertake joint activities, such as shopping, going to the gym or visiting the theatre: *'Yesterday we were together in the communal living room (...) We have lunch together on Saturdays.'* (Participant G from town B).

Two participants mentioned a close friendship with another resident and one participant has an intimate relationship with another resident from the same group home: *'...Yes, a really close friendship. Staff members also say: you two get along very well.'* (Participant A from town A)

Three participants brought up negative situations with other residents: *'We (me and my dog) were once physically assaulted by one of the other residents. That's why I want to move (...) I don't feel safe here.'* (Participant B from town A). One participant from town B uttered his disappointment about the fact that in contacts with other residents, most of the time he had to take the initiative.

Finally, thirteen participants told stories about their contact with staff members. Only two of them were negative about staff. In both cases, the issue is a lack of trust. One story concerned the assault mentioned above; the other participant disliked the fact that personal information she provided was available to all staff members. In general, participants were positive about the relationship they have with staff members. Sometimes staff members come along when they go shopping or drink coffee with them. Staff members were seen as important to tell your story to. *'If I have a problem, they come immediately. (...) I can tell my story to her (...) This is nice (...) she understands me.'* (Participant N from town C)

Activities in the neighbourhood

Nearly all participants are involved in various activities in the neighbourhood. Five participants mentioned sports activities in the neighbourhood, such as fitness and swimming. Going to a gym also leads to more contacts, for example with the sport instructor. Four participants mentioned the neighbourhood barbecue. They were all

enthusiastic about the event: *'...Nice, this year the neighbours organize the barbecue.'* (Participant P from town B)

Two participants from town A and one from town B are involved in activities in their apartment complex together with older people. They drink coffee together, attend church services, go to gym classes, do creative activities or listen to choir performances. One of the participants mentioned that if there were no activities like these, she might get lonely. The other two also mentioned feeling positive about these activities.

Some participants visit annual events in their neighbourhood, such as the funfair, markets or the flower parade. One participant from town B who has joined a lunch club organized by the local welfare organization. He lunches with three older ladies. He enjoys having lunch together and this led to a more frequent contact with one of the older ladies: *'It's nice. Those people around me. (...) Having a chat together.'* (Participant I from town B)

Apart from participating in regular activities, nine participants told stories about activities with people with intellectual disabilities. Once a week, the welfare organization opens its doors for a coffee get-together. Two participants in ambulant care visit this open door moment. Participants are also involved in cooking, creative clubs, and sports for people with intellectual disabilities. The contacts they have during these activities are considered valuable.

Two participants from town C are not involved in any activities in the neighbourhood. One of them mentioned she would like to participate in a card club or a floral arrangement course. However, she does not have enough time and is not familiar with the opportunities in the neighbourhood.

Social roles in the neighbourhood

Two participants from town A have regular work in the neighbourhood. One of them has a close relationship with her boss and his family and the other participant works in the market, which makes him a well-known figure in the neighbourhood. In both cases, regular work makes them feel at home in the neighbourhood, because of the social contacts it brings with it. How important this is, was also illustrated by another participant, who used to work at the market on Saturdays. Because of health problems he couldn't do this anymore. During the interview, he repeatedly said how he missed this work and the contact with customers and colleagues. Also, participants talked about their jobs with pride: *'...We used this coffee machine during the flower parade here in town A. The mayor was also there.'* (Participant B from town A)

One participant working in the neighbourhood also volunteers at the church. This voluntary work is very valuable to her. Another participant will become a

volunteer after his retirement. He is looking forward to this. He is going to distribute meals with his car.

Six participants perform sheltered work in the neighbourhood. In this job, contacts are limited to other people with intellectual disabilities and these contacts usually do not extend beyond the sheltered work setting.

Some participants mentioned that, apart from being active in regular, voluntary or sheltered work, they perform small tasks in their neighbourhood. They perform social roles, for example babysitting for a friend (who lives in another neighbourhood in the same town), helping in a bar, working as a DJ (in the past), raising the Dutch flag or serving as an assistant referee on the soccer field. 'I like to serve coffee, wear nice clothes. (...) I can play the waiter. (...) I really want that.' (Participant D from town B). These relatively small social roles give participants a 'feeling of pride' and also create opportunities to extend their social network. Two participants also referred to tasks within the group home: returning empty bottles to the supermarket and posting letters.

Independence

The pictures participants made of their own apartments, the streets where they walk, and the shops they visit also represent their independence. In fifteen interviews, the topic of independence was discussed. Independence was related to visiting shops on their own, joining a cooking course, being able to withdraw to your own apartment/room whenever you feel the need. Participants who can ride a bicycle or walk safely in traffic, can easily visit shops or family nearby. Two participants from town B need support in traffic. One of them mentioned that he would like to visit his family on his own. The presence of shops nearby is helpful for participants' independence: they can easily visit the shops without any assistance of staff members. *'It is important to learn to go shopping. It is going pretty well. I need to ask the receipt and give it to the staff members.'* (Participant E from town B)

Most of the participants enjoy having their own apartment. They do their own housekeeping and some of them even manage their own accounts. But most important to them is having a place of your own where you can be on your own whenever you like. Participants mentioned the possibility to have meals on your own, listen to music or watch television. It is also a place where you can be alone, away from the other residents. *'My neighbour resident always walked in. I don't want that. Now I lock the door.'* (Participant I from town A)

One participant from town C told a story about not feeling comfortable in her own apartment. The apartment is at the top floor and she hears noises from outside. This apartment was the only one available at the time. She brought up her feelings with staff members but they said they couldn't do anything. She feels like she has no choice. She is not happy with this situation.

Public familiarity

During the interviews, half of the participants explicitly mentioned the importance of being known in the neighbourhood. Some participants know many people in the neighbourhood and are often recognized. *'Everybody knows everybody. It is very important because I live here. On Saturdays, there is market and I like it.'* (Participant H from town A) A third of the participants was born and raised in the area they still live in and link public familiarity to having a lot of family and acquaintances nearby. This public familiarity provides participants a feeling of being at home in the neighbourhood.

A long history with the neighbourhood contributes to public familiarity, but performing social roles, for example working at the market or being a volunteer at the church, can also help. *'I know some people in the shops and they know me from the market. Having a chat is very important during my work.'* (Participant C from town A) Other factors that can contribute to public familiarity in the neighbourhood are visiting shops, bars and restaurants or participating in neighbourhood activities. Participants told stories about how they developed social contacts while visiting shops or while attending an activity in the neighbourhood. Participants experienced these social contacts as valuable. This is best illustrated by one participant, who took photographs of all the shops she visits, including all shop assistants.

Two participants, who live in the suburb of town C, do not experience much public familiarity in their neighbourhood. Both of them have been living in the neighbourhood less than five years, do not participate in any activities, and have limited contact with neighbours. One of them mentioned that it is nice when a neighbour greets you in the street. They feel safe in the neighbourhood but, compared to other participants from town A and town B, their work and family contacts are mainly outside the neighbourhood.

Discussion

The aim of this study was to gain a better understanding of the perspective of people with intellectual disabilities on social inclusion in the neighbourhood. Using photovoice, we were able to identify six themes linked to neighbourhood social inclusion: attractiveness of the neighbourhood, social contacts in the neighbourhood, activities in the neighbourhood, social roles in the neighbourhood, independence, and public familiarity. The identified themes largely correspond with the conceptualization of Cobigo et al. (2012), as they also emphasize the importance of social roles and a social network in creating social inclusion. However, the perspective of people with intellectual disabilities brought up some more detailed aspects of neighbourhood

social inclusion. Where Cobigo et al. (2012) focus on the broader and extensive aspects of social inclusion, such as having access to public goods and services, or having a social network focused on social support, our participants particularly attached importance to the small and more informal activities and situations in the neighbourhood, which create the seemingly superficial social contacts, which we called public familiarity. These aspects were not explicitly outlined in the work of Cobigo et al. (2012). Our participants specifically valued opportunities to 1) visit shops independently, 2) perform (small) social roles, 3) attend neighbourhood activities and 4) meet family and acquaintances in the street. These aspects of social inclusion provided them with an opportunity to create and maintain social contacts in the neighbourhood. According to the stories of our participants, these social contacts, linked to public familiarity, contributed to a feeling of being at home in the neighbourhood. In cases where public familiarity was absent, participants felt less connected to their neighbourhood. These findings suggest that public familiarity could be identified as a significant aspect of neighbourhood social inclusion from the perspective of people with intellectual disabilities (e.g. Van Alphen et al., 2009; Blokland & Nast, 2014; Bredewold et al., 2016). In this section, we will further elaborate on the aspects we see as important for realizing public familiarity, reflect on our study, and provide some implications for future research.

Besides being born and raised in the neighbourhood, and consequently having a lot family and acquaintances nearby, there are other aspects which increase the opportunity of meeting people in the street and having a small chat. Our participants narrated stories about the valuable contacts they have with shop assistants in local shops. This finding is in line with the studies of Wiesel, Bigby, and Carling-Jenkins (2013) and Bredewold et al. (2016), who found local shops to be of great importance to the people with intellectual disabilities, because they provide recognition and thus contribute to public familiarity (Blokland & Nast, 2014). This recognition is also gained by performing social roles in the neighbourhood. These social roles varied from occasionally assisting in a pub to having a full-time job in the neighbourhood. All kinds of social roles provided opportunities for creating social contacts and contributed to public familiarity. Lastly, in some cases, participating in neighbourhood activities led to valuable social contacts. Attending neighbourhood activities offered opportunities for meeting neighbours and contributed to public familiarity (see also Wiesel & Bigby, 2014).

The apparent significance of public familiarity raises the importance of the location of services for people with intellectual disabilities. The physical layout of a neighbourhood can provide opportunities for social interactions (Skjaeveland & Garling, 1997; Van Alphen et al., 2009). These aspects should be considered in the planning of the location of services for people with intellectual disabilities. In response

to the findings of our study, service providers could think about characteristics such as the presence of meeting areas, and opportunities to visit shops and other facilities independently. Besides these physical aspects of the neighbourhood, we recommend service providers pay attention to residents' needs and locate them close to their significant social contacts, since living in close proximity to family and acquaintances proved to be important for feeling at home in the neighbourhood.

Our participants benefitted from spending time in public spaces, for example by performing (small) social roles or attending neighbourhood activities. Staff members play a crucial role in the lives of people with intellectual disabilities, also when it comes to issues related to the neighbourhood (e.g. Van Alphen et al., 2009). Most participants were positive about their relationship with staff members and staff might seize this positive relationship as an opportunity to encourage social inclusion in the neighbourhood. Staff members could, for example, create opportunities for their residents to perform (small) social roles and to attend activities in the neighbourhood.

Reflection on our study and implications for future research

In this study, people with intellectual disabilities expressed their needs and perceptions regarding neighbourhood social inclusion, but their neighbours might have a different viewpoint. A next step would be to research the perspective and experiences of neighbours. Some studies focus on the encounters between neighbours with and without intellectual disabilities (Van Alphen et al., 2010; Bredewold et al., 2015; Wiesel & Bigby, 2014) but little is known about how neighbourly relations with people with intellectual disabilities differ from other neighbourly relations (Van Alphen et al., 2010). Therefore, we would recommend further exploration of the perspectives of individual neighbours, to create opportunities to advance social inclusion in the neighbourhood.

Participants in our study were mostly positive about their neighbourhood. This seems remarkable, given the fact that other studies show that people with intellectual disabilities still encounter discrimination and rejection (Cobigo & Stuart, 2010; Hall, 2005). This could be explained by the selection of our participants. In most cases, participants were selected by a staff member. Staff members may have had the tendency to select participants who feel comfortable in their neighbourhood. We also had an experience with two participants who initially wanted to cooperate but, after the aim of the project was discussed, said walking through their neighbourhood felt too uncomfortable because of previous experiences and refused to participate in the research project. Another explanation might be that people with intellectual disabilities living in small towns experience less 'big city issues' and that small towns provide more opportunities for public familiarity. Wiesel and Bigby (2014), for

example, found more contact between neighbours with and without intellectual disabilities in country towns in comparison with metropolitan suburbs. Relationships between neighbours might be more intensive and more focused on assistance, compared to other neighbourhoods (Van Alphen et al., 2010). We would recommend further research from the perspective of people with intellectual disabilities in more urbanized areas.

The use of photovoice provided participants with intellectual disabilities a platform to have their voices heard. Supported by photographs, they could tell their stories about the neighbourhood. Although in most cases this worked out well, in some cases it was difficult to obtain more insight into participants' situation and experiences. In these cases, even follow-up questions did not result in more detailed information. Despite these challenges, we would definitely recommend the use of photovoice in future studies. It gives participants an active role in the research process and encourages participants to be open and tell stories (e.g. Overmars-Marx et al., 2017).

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(or) together: neighbours' views and experiences on their
relationships with neighbours with and without intellectual
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Chapter 5

Living apart (or) together: neighbours' views and experiences on their relationships with neighbours with and without intellectual disabilities



Abstract

Background

Neighbours play an important role in the social inclusion of people with intellectual disabilities. Neighbouring in general might help understand the social interactions between neighbours with and without intellectual disabilities. Our study focuses on gaining insight into neighbouring patterns and how people with intellectual disabilities fit in them.

Method

We conducted 26 interviews with 29 neighbours of people with intellectual disabilities on their norms and behaviours towards neighbours with and without disabilities.

Results

We identified four patterns: feeling an outsider, fleeting contacts, individualized neighbourliness, and sense of community.

Discussion

Participants perceived neighbours with intellectual disabilities as different: they are difficult to approach and show inappropriate behaviour. The groups shared most general perceptions, but there were differences. The first two groups mostly had fleeting encounters whereas the last groups seemed more open to communal activities and assisting neighbours. In enhancing social inclusion, staff should be aware of these neighbouring patterns.

Introduction

Since the 1980s, growing numbers of people with intellectual disabilities have started living in ordinary neighbourhoods (Beadle Brown et al., 2007). However, they do not automatically feel included when living in the general community (Cummins & Lau, 2003; Hall, 2005; Cobigo & Hall, 2009; Overmars-Marx et al., 2014). Social inclusion in the neighbourhood is not only determined by the personal characteristics of the people with intellectual disabilities themselves, but also by the way neighbours respond to them (Cobigo et al., 2012; Simplican-Clifford, Leader, Kosciulek, & Leahy, 2015). Studies into the relationships between neighbours with and without intellectual disabilities identify a variety of facilitating and obstructing factors for the interaction between the two groups of neighbours (e.g. Van Alphen et al., 2010; Bredewold et al., 2015; Wiesel & Bigby, 2014). Studies identify the following barriers: people with intellectual disabilities invading the privacy of neighbours; unconventional and unexpected behaviour; neighbours perceptions of the group homes; and the idea that the residents of the homes need more care than neighbours without intellectual disabilities were willing to provide. Neighbours without intellectual disabilities also considered themselves lacking the skills to interact with people with intellectual disabilities. Positive experiences were greeting and engaging in small talk (Bredewold et al., 2015; Wiesel & Bigby, 2014).

The studies mentioned above provide information on isolated factors affecting the relationship between neighbours with and without intellectual disabilities. However, relationships between people with and without intellectual disabilities are part of local neighbouring patterns, which are embedded in urban and non-urban contexts (e.g. Keane, 1991; Thomése, 1998). Citing Henning and Lieberg (1996, p. 6), Mollenhorst (2015) characterizes neighbourhood relations as 'unpretentious everyday contacts': interaction is usually limited to relatively impersonal contacts and exchange of instrumental support. Still, it is a typical role-relationship, and normative expectations about the way neighbours should behave inform actual interactions between neighbours (Auhagen & Hinder, 1997). Despite many suggestions that neighbourhood communities are declining (Wellman, 1979), research suggests that neighbour relations are still important in the daily lives of residents (Mollenhorst 2015). However, neighbouring has individualized; neighbour relations are less defined by collective structures and norms, are more guided by individual norms (Linders, 2010), and have become embedded in personal networks (Wellman, 1979).

Several social norms may inform neighbour relations (Stokoe & Wallwork, 2003; Ajzen, 2005; Kusenbach, 2006; Linders, 2010). The first is friendly recognition, which demands that neighbours greet one another and sometimes engage in small talk (Kusenbach, 2006), so people are familiar with one another (Blokland & Nast,

2014). At the same time, neighbours find it important to maintain their privacy. Wilmott (1986 in Crow et al., 2002) calls this the norm of friendly distance. Second, neighbourhood relations usually involve an obligation to help each other, as and when this is necessary (Bayertz, 1999). Bayertz (1999) argues that this norm of solidarity originates from bonds between people, based on e.g. shared history or interest. Related to solidarity is the norm of generalized reciprocity: I'll do this for you without immediately expecting anything in return, confident that down the road you or someone else will return the favour (Gouldner, 1960; Putnam, 2000).

We propose to contribute to the literature in two ways. First, we will strengthen the small body of literature (e.g. Linders, 2010) which differentiates neighbour relations in the same neighbourhood. Most studies generalize relationships within a neighbourhood (Forrest and Kearns, 2001) or only focus on individuals' networks (Völker et al., 2007). The question what types of neighbour relations (co-)exist within the same local area remains unanswered. Second, we know of no studies which link general neighbouring patterns to the relationships between neighbours with and without intellectual disabilities. Do neighbours see people with intellectual disabilities as part of their neighbourhood and their neighbouring patterns or as a separate group? And does this vary with different types of neighbour relations? Information on how neighbours relate to people with intellectual disabilities may offer insights into opportunities for social inclusion. We aim to make recommendations to group home staff members to use the identified neighbouring patterns in enhancing social inclusion.

The following questions will be addressed:

- Which neighbouring patterns can be identified?
- How do neighbours with intellectual disabilities fit into these patterns?
- How can group home staff members use their awareness of neighbouring patterns to enhance social inclusion in the neighbourhood?

To answer these questions we conducted a study among neighbours of people with intellectual disabilities living in group homes. Focusing on people with intellectual disabilities living in group homes increases the chance that neighbours are aware of the presence of people with intellectual disabilities. and we could rely on actual experiences of neighbours with residents of the group homes. When people with intellectual disabilities are supported in their individual home situation, neighbours might not be aware of their status as having an intellectual disability.

Method

Research settings

The study was conducted in two neighbourhoods in the eastern part of The Netherlands, where eight group homes for on average 15 people with intellectual disabilities were located in different parts of the neighbourhood. The group homes included in our study locate people diagnosed with mild to moderate intellectual disabilities. In one group home, there were residents who also have mental health problems and in four of the homes there were a few residents with an increased need of physical care. Two of the group homes also provided care to people with more severe intellectual disabilities. The group homes employed full-time staff that support their residents 24 hours per day.

The neighbourhoods were situated in moderately low-urbanized areas and are known as neighbourhoods where neighbourliness traditionally played an important role. The neighbourhoods differed in their level of facilities. Both offered shopping, catering and leisure facilities, but one had a greater availability of the various facilities that attracted people from across the region, while the other had more of a village-like atmosphere. Both neighbourhoods had fairly similar sociodemographic characteristics, with a relatively high percentage of people aged above 65 years (23% and 26%, compared to 17% of the Dutch general population) (Centraal Bureau voor de Statistiek, 2014). The average income of neighbourhood residents was defined as just below the average income of the general Dutch population (€29,500): between €24,400 and €26,600 gross per year. We approach the neighbourhood as “a set of nested zones which subdivide the environment around one's home into sections of distinct spatial, social, and emotional nearness” (Kusenbach, 2008). Using this definition, we studied respondents' subjective perceptions of their neighbourhood. In our study, we focus on the stories of residents about their views and experiences regarding their neighbour relations with people with and without intellectual disabilities.

Recruitment of neighbours

The recruitment of neighbours was carried out by going from door to door. We wanted to increase our chances of recruiting participants who actually had encounters with people with intellectual disabilities and therefore approached people who lived within two blocks from their group homes. We visited each neighbourhood once to recruit potential participants. In the interviewing stage, extra participants were recruited during the day and early evening hours. The person who opened the door was given information about the research. Neighbours who agreed to participate and neighbours who wanted to think it over, were handed a flyer describing the

aim and design of the study. The researchers recorded the personal details of the person they had spoken to. One week later, the researcher called the potential participant to make an appointment for the interview. This resulted in 26 interview appointments.

Interview and topic list

We interviewed 29 neighbours, representing 26 households, who lived close to the group homes for people with intellectual disabilities. Table 5.1 shows the socio-demographic characteristics of our participants.

The interviews were guided by a topic list, which focused on the relationships between neighbours; how do respondents characterize their relationships with neighbours (actual behaviour) and what social norms play a role within these relationships (e.g. expected behaviour related to meeting each other in the street). We also focused on concrete situations to elicit more stories from neighbours; we particularly asked about conflict situations or disturbances. Most participants had limited experience with people with intellectual disabilities. To gain more insight into neighbours' views and experiences regarding their contact with people with intellectual disabilities, we used, when necessary, fictitious scenarios or asked them to expand on their personal experiences within or outside the neighbourhood. In the findings section, we list whether participants responded to a fictitious situation or spoke from personal experience.

Table 5.1 – Participants – socio demographic characteristics

Town A				Town B			
Sex	Age	Household		Sex	Age	Household	
A1	Couple	74 and 66	Married	B1	Male	72	Single
A2	Male	61	Together with partner and resident children	B2	Male	67	Married
A3	Male	37	Single (joint custody)	B3	Male	39	Married with resident children
A4	Female	31	Single	B4	Male	84	Single
A5	Female	70	Single	B5	Female	34	Married with resident children
A6	Female	50	Together with partner and resident children	B6	Female	46	Married with resident children
A7	Female	65	Single	B7	Female	64	Single
A8	Female	36	Single	B8	Female	57	Married with resident children
A9	Female	76	Single	B9	Female	84	Single
A10	Female	75	Married	B10	Female	47	Together with partner
A11	Female	86	Married	B11	Male	60	Married with resident children
A12	Couple	71 and 59	Together with partner	B12	Female	70	Single
				B13	Male	65	Married
				B14	Couple	62 and 64	Married

Data analysis

All interviews were audio taped and transcribed verbatim. We used an inductive approach for analysis, using ATLAS.ti. The first stage of our data analysis was open coding (Strauss & Corbin, 1998). During this stage, which we called first order analysis, little attempt was made to categorize codes (Gioia, Corley, & Hamilton, 2012).

In the second stage of data analysis, we categorized the open codes into more abstract, so-called second order themes (Gioia et al., 2012). Strauss and Corbin (1998) call this stage “axial coding”. Seven themes emerged: perceived neighbourhood identity; perceived opportunities for social contact; chance encounters; the importance of being recognized; pre-arranged social contact and expectations; neighbour assistance; social control versus privacy; and experienced disturbances.

The coding was done by one researcher. During the first and second stage of analysis, four interviews were coded and categorized by two researchers. Discussion of the outcomes led to small adjustments in the labelling of the themes that had emerged.

The third and final stage of our analysis consisted of identifying neighbouring patterns in the second order themes. During this stage, we classified participants on the content of their responses to the seven themes (see also table 2). Combining these responses resulted in the identification of four neighbouring patterns: feeling an outsider; fleeting contacts; individualized neighbourliness; and sense of community. These neighbouring patterns were discussed with three researchers involved in the study. All participants could be categorized into one of the identified patterns. Five participants reported social norms and behaviour classifying them in two different neighbouring patterns.

The steps of our analysis are visualized in figure 5.1.

Findings

In the first part of this section, we present the seven themes which emerged from our second order analysis and discuss participants' social norms and/or behaviour regarding neighbouring in general and their neighbours with intellectual disabilities. After a description of the themes, the four neighbouring patterns are explained.

Perceived neighbourhood identity

In the first theme, participants described how their perception of neighbourhood identity related to the traditional form of neighbourliness (*noaberschap*) and how people with intellectual disabilities fit into this neighbourhood identity.

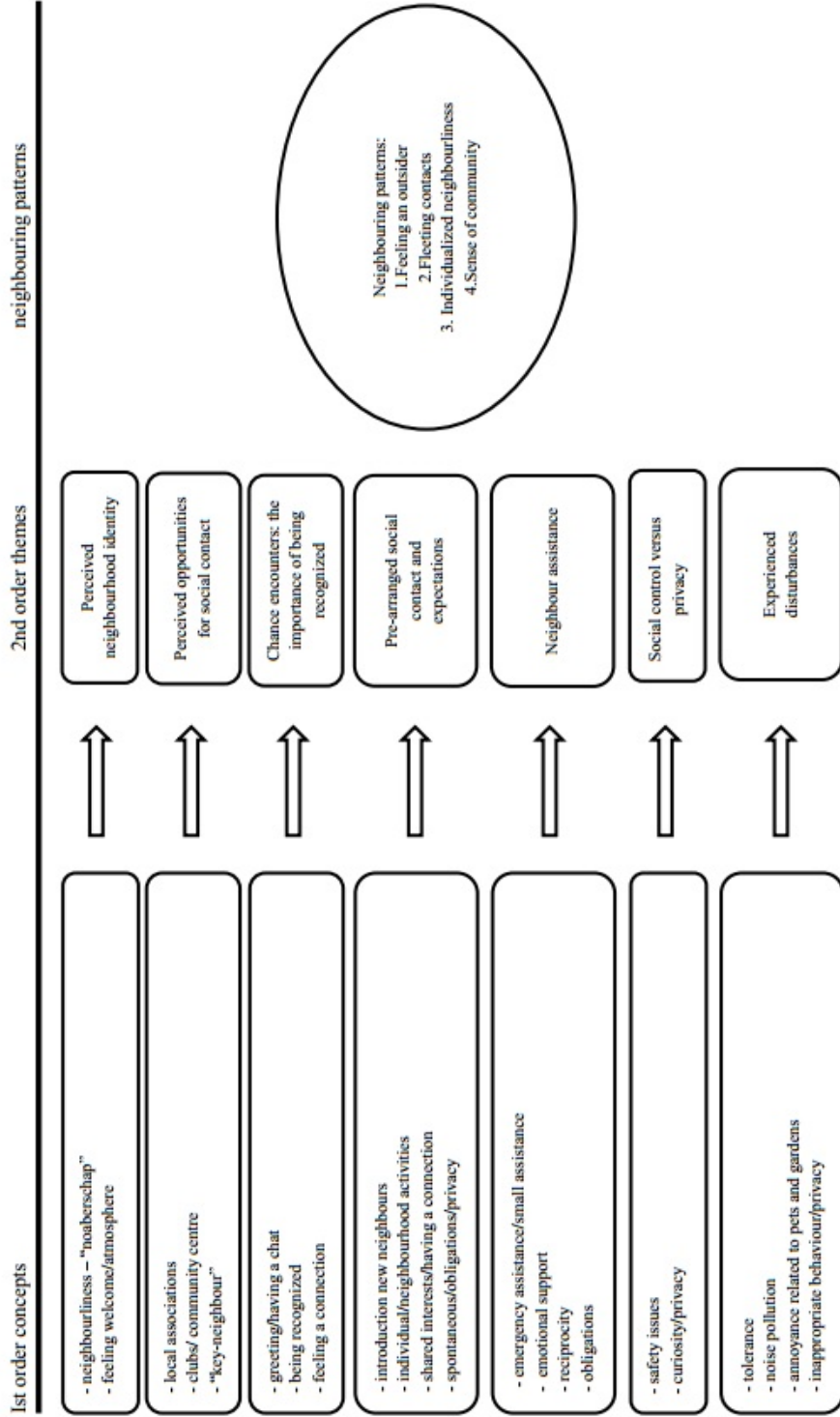


Figure 5.1 – Data structure

Many participants refer to the traditional neighbourliness typical of this area (*noaberschap*). Participants defined *noaberschap* as the obligation to help each other if necessary. In connection with *noaberschap*, participants mentioned a traditional custom which is called *buurtmaken* (making community). This starts with inviting your neighbours over for a drink when you move into a neighbourhood.

Based on the stories of participants, *noaberschap* is perceived in three different ways. The first group of participants has a (strong) sense of neighbourliness. They feel obliged to help neighbours and in some cases also refer to the importance of *buurtmaken*:

'In this street "buurtmaken" is normal. Inviting everyone over when you are new. If you don't, it's rather strange.' (Participant B6) *'A lot of neighbours come from the small hamlets where the customs that have to do with "buurtmaken" are normal. Women visit each other on birthdays, and when someone dies, neighbours go to the house.'* (Participant B11).

The second group of participants stressed that there is still a sense of neighbourliness, but that the traditional form of *noaberschap* is in decline, because of the arrival of people from outside the region. This new form of neighbourliness was described as helping each other in cases of emergency but participants call this kind of help normal and do not attribute this to a sense of community.

The third group of participants are the newcomers mentioned by the second group. This group feels they are outsiders and report they have difficulty making real contact with the existing residents: *'I know everyone but still feel an outsider. You can't make real contact.'* (participant A9).

All participants see the presence of people with intellectual disabilities as normal. As one participant puts it: *'These two people have intellectual disabilities but somehow they are completely settled in our village.'* (participant A6).

They run into neighbours with intellectual disabilities in the street and in shops and see this as positive: *'You run into people with intellectual disabilities, because they work in shops or help out in a pub, which is good.'* (participants A4).

Perceived opportunities for social contact

The second theme covers the stories in which participants refer to meeting areas that provide opportunities to establish and maintain social contact with neighbours.

Participants mentioned associations, sport clubs and a community centre as important in establishing and maintaining social contacts. Apart from these more organized opportunities, participants also approached a key person in the neighbourhood as an opportunity to connect to neighbours.

Associations, clubs and societies, which are locally organized and not on the neighbourhood level, play an important role for most participants. Participants told

stories about e.g. the carnival society, annual festivals and other specific associations (“De Schutterij”). Annual festivals are also perceived as meeting opportunities: *‘It is a tradition where people come together.’* (Participant A2).

Nearly half the participants mentioned their membership of different clubs, involving sports, music or card games, as important for initiating and maintaining social contacts. Seven participants from one neighbourhood described how they meet neighbours at the community centre and drink coffee and how their children play together.

About a quarter of participants mentioned neighbours who had a pivotal role in the neighbourhood. Such a person organizes activities with neighbours, e.g. activities for children or drinking coffee together. This person can also be important when new neighbours move into the neighbourhood. In some cases, activities or contacts stopped when the key person moved out of the neighbourhood: *‘He was the “mayor” of the street. Since he has died, there are less activities in the street.’* (participant B3).

People with intellectual disabilities were not mentioned in the context of local associations, clubs or the community centre. Participants said they were not visible in these contexts but some did have concrete experiences with them in shops and restaurants, as a fellow customer or as an employee or voluntary worker, e.g. a waiter, which participants valued as positive.

Chance encounters: the importance of being recognized

The third theme covers participants' stories about their encounters in the street.

Greeting neighbours, with or without intellectual disabilities, is considered normal in the neighbourhoods and villages where participants live: *‘Greeting costs nothing and it gives people a good feeling.’* (participant A5). Four participants mentioned feeling bad when ignored by neighbours: *‘I am unhappy if I meet and recognize a neighbour and he or she says nothing.’* (participant B6). Some participants expressed indifference at not being greeted: *‘It’s their decision’*; *‘It doesn’t bother me’*.

When asked how they would feel if the person who ignored them was a neighbour with intellectual disabilities and limited social skills, participants reported they would not experience any negative feelings towards a “non-greeting neighbour”.

Most participants are open to a chat in the street. Sometimes, these chats turn into more extended conversations. Participants report feeling uncomfortable when such a conversation takes a turn into unwanted curiosity or an invasion of privacy. One participant said: *‘Every time I left the house, he was there. I was not always in the mood for a chat but I didn’t want to offend him because he’s my neighbour. Now I tell him I’m in hurry and that works fine.’* (participant B7).

Extended conversations with people with intellectual disabilities were not mentioned. About one third of participants have chats with neighbours with

intellectual disabilities: *'The people are usually very spontaneous. They like it if I stop for a chat.'* (participant A9). One participant mentioned always being greeted by a number of people with intellectual disabilities when they get off the bus *'but I don't think you can have a normal conversation with them'*. And when people with intellectual disabilities walk by in a group, this creates a barrier for having a chat or even greeting each other, according to participants (see also Van Alphen et al., 2010).

Pre-arranged social contact and expectations

Participants not only told stories about chance encounters in the street, but also about pre-arranged social contact (theme four). This theme of pre-arranged contact both covers views on how to introduce yourself when you move into a neighbourhood and organized activities on an individual, small group or neighbourhood level. According to four participants, new neighbours are expected to invite their neighbours over when they move into the neighbourhood. Some participants mentioned the traditional form of neighbourliness and saw inviting your neighbours over as part of the customs within the neighbourhoods involved. There were also participants who were not explicit about how the first introduction has to take place. Both parties involved can take the initiative and it doesn't have to be arranged but can also come about by meeting each other in the street.

Regarding the introduction of neighbours with intellectual disabilities living in group homes, participants would appreciate an introductory meeting arranged by the group homes. This would create a better understanding and it would be reassuring and sometimes useful to know the neighbours with intellectual disabilities: *'Then you know what's going on, what kind of people live there and you get to know the people.'* (participant A7).

Pre-arranged social contact between neighbours also takes place in communal neighbourhood activities. Two types of neighbour activities can be distinguished: neighbourhood activities organized for all neighbours and neighbour activities involving only one or a small number of neighbours.

Activities organized for all neighbours are for instance a barbecue, a drink, "burendag" (Neighbours' Day) or activities like playing bridge, organized within the apartment block. The impact of this kind of activities on the social contacts between neighbours is significant, according to some participants. They provide an opportunity to catch up with neighbours or meet (new) neighbours: *'By having communal afternoons, we all know each other in the apartment block.'* (participant A10).

In general, people with intellectual disabilities are not involved in general neighbourhood activities but they are welcome. Since they are present in the neighbourhood they should be invited, just like other neighbours: *'If you invite the neighbourhood, you invite everyone.'* (participant B10). But this opinion does not always

correspond with the actual situation, as one participant puts it: *'I've never thought about it. They invited us over for a barbecue but we didn't invite them. I don't know the reasoning behind it.'* (participant B13). Other participants mentioned that the group home is not in their street and therefore the people with intellectual disabilities are not invited to neighbour activities. When participants were asked, in the context of a fictitious situation, about the importance of group home staff being present during activities, about one fifth of participants answered they would appreciate their presence. They thought staff members would be able to recognize problems sooner, as they are aware of the needs and capabilities of their residents. Two participants had previous experiences with neighbours with intellectual disabilities who had an active role during the activity, e.g. tapping beer. People with intellectual disabilities enjoyed these roles: they contributed to a sense of pride, according to participants. Taking the initiative in organizing an activity would be highly appreciated by more than half of the participants. These kinds of meetings create opportunities for getting to know one another. One participant put it as follows: *'If they become more open, this might give neighbours a taste for more.'* (participant A3).

Seven participants are involved in activities with one or a small number of neighbours, sometimes as a spin-off from general neighbourhood activities. An important condition for these contacts is feeling a connection. These activities can be of a structural or incidental nature: *'Sometimes I go for a walk with my neighbour. I send her a message through Whatsapp, "do you feel like having a walk together?"'* (participant B6). Most participants emphasize the importance of spontaneous contact and don't want to feel any obligations. If the contact is not spontaneous, too frequent or unwanted, it feels like an invasion of their privacy.

About one third of participants are open to individual activities involving people with intellectual disabilities. Some participants had experience with these kinds of activities and are still willing to, for example, drink coffee or play a game together. These participants find it important to feel a connection and they do not appreciate too frequent or unwanted contact. Just as in the relationship with other neighbours, participants do not want to feel obliged to engage in a structural, e.g. weekly, activity. Sometimes, fear of "claiming behaviour" is based on warnings by staff members. This creates a barrier to inviting neighbours with intellectual disabilities. One participant mentioned it would be a shame if contact ends because of this behaviour. This participant had the experience that being clear and direct helps to maintain a healthy relationship. In response to fictitious situations, some participants mentioned the importance of information by staff about how to cope with certain behaviours (psycho-education), such as claiming behaviour, but also making noises or an epileptic seizure. 'Feeling like a staff member or volunteer', is mentioned as a barrier for individual activities with people with intellectual disabilities.

Neighbour assistance

Participants told stories about the assistance they exchanged with neighbours, why this was important and the significance of reciprocity. These are combined in the fifth theme.

All participants stressed the importance of helping out in the case of an emergency. This is what characterizes a good atmosphere in the neighbourhood, according to some participants. Other types of assistance participants mentioned were borrowing goods, moving a new washing machine or putting out the rubbish for a neighbour. Participants saw this kind of assistance as normal: *'I was raised with the idea that it is normal to help each other out.'* (participant B12).

Around three-quarters of participants told stories about more extensive support received from or given to neighbours. In most cases, this kind of support was only exchanged with one or a small number of neighbours. Five participants exchanged more extensive support with more neighbours, sometimes the entire street. More extensive support consists of e.g. cooking for each other, taking someone to the hospital, shopping for groceries or taking care of each other's pets. These kinds of assistance are related to the traditional form of neighbourliness.

Over half the participants who told stories about reciprocity were very clear: there is no direct need for a favour in return: *'If worst comes to worst you can rely on your neighbours. Knowing that is enough.'* (participant B3). Some participants even explicitly mentioned they would rather give than receive support.

When it comes to providing help to people with intellectual disabilities, most participants are willing. One participant mentioned that the 24 hours support provided by staff members gives the impression that no further assistance from outsiders is needed. In most cases, this assistance is not a reality at present, but the willingness to help was expressed within the context of a fictitious situation. A few neighbours had experience assisting people with intellectual disabilities. Their stories largely correspond with the stories about assistance between neighbours in general. Fifteen participants were willing to provide help with shopping or other minor tasks. All of them mentioned they did not want to feel any obligation and that assistance should not be structural. Four participants stressed that the boundary between occasional help and voluntary work should be clear. Five participants said they only wanted to assist neighbours in the case of an emergency or spontaneously in the street, e.g. if someone has a problem with his bicycle. Receiving help from people with intellectual disabilities did not come up in participants' stories. Participants made clear that reciprocity would not be important to them when assisting people with intellectual disabilities. Participants stated that if you can make someone feel happy that's enough. The social contact is more important than a favour in return.

Social control versus privacy

The sixth theme covers the stories of participants which focus on the trade-off between social control and privacy.

During the interviews, almost all participants expressed their desire for a certain degree of social control. Over half the participants mentioned alertness about safety issues and uncommon situations. *As one participant puts it: 'If someone touches my property, enough neighbours notice this.'* (participant B3).

Participants perceive this kind of social control as normal. The actual form social control takes, deliberate or incidental, varies among participants.

Half the stories of participants on social control extended beyond security concerns and also dealt with minor issues like leaving the key in the door or forgetting to turn off the car lights. Moreover, neighbours' alertness can extend to social issues as well: noticing that someone is ill or being aware of family problems. In most cases, participants perceive this kind of social control as pleasant. Some participants mentioned they feel uncomfortable when social control turns into curiosity and invades their privacy. Gossip and neighbours knowing all the ins and out of their private life is not appreciated: *'He doesn't have to know where I was at three in the morning, just because he saw my car wasn't there.'* (participant B7).

Three participants told stories about experiences with social control in relation to the group homes where people with intellectual disabilities live. Participants appreciate being informed about what's happening in the group home, e.g. if there has been a burglary or if there are problems with residents.

Experienced disturbances

The final theme focuses on participants' stories about disturbances they have experienced.

Over half the participants had experienced some kind of disturbance in their neighbourhood and about one third of participants had never dealt with any kind of disturbance. The latter group reported that either there really wasn't anything to it or that they did not want to make a fuss. The degree of tolerance varies among participants and depends on their relationship with neighbours.

In general, participants did not experience serious disturbances from people with intellectual disabilities living in the group homes. Only one participant mentioned he avoids two residents because of drug use, but he did not experience any other disturbance. Some other incidents were discussed, e.g. yelling outside, noise pollution, and throwing stones in gardens. These incidents were usually resolved in a satisfying way. In this kind of situations, the support of staff members is welcomed. Short lines of communication with staff members are appreciated. In some cases, certain behaviour is perceived as unremarkable: *'One resident always leaves the bus yelling, that has become normal. It doesn't surprise me anymore.'* (participant B3).

Table 5.2 – Composition of the neighbouring patterns

Themes → Neighbouring patterns ↓	Perceived neighbourhood identity	Perceived opportunities for social contact	Chance encounters: the importance of being recognized	Pre-arranged social contact and expectations	Neighbour assistance	Social control versus privacy	Experienced disturbances	View on neighbours with intellectual disabilities
Feeling an outsider	Feeling an outsider.	Not or limited involvement in associations/ community centre/ clubs.	Greeting and small chat – important.	Not present or selective – desire for more neighbour contact.	Emergency and minor assistance.	Social control related to safety.	Some experiences – importance of communication.	Limited contact – willing to help but not structural.
Fleeting contacts	Diminishing nooberschap.	Not involved in associations/ community centre. Some involvement in clubs.	Greeting and small chat – important.	Limited present – only spontaneous, no obligations – satisfied with superficial contact.	Emergency and small assistance.	Social control related to safety.	Some experiences – live and let live.	Limited contact – willing to help but not structural – no obligations.
Individualized neighbourliness	Positive neighbourliness, diminishing nooberschap.	Not or limited involvement in associations/ community centre. Some involvement in clubs.	Greeting and small chat – important.	Focus on communal activities - spontaneous and no obligations.	Individual support. Direct reciprocity not important.	Social control mostly related to safety – limited alertness.	Some experiences – show neighbours some courtesy.	Limited contact – open for activities and help.
Sense of community	Community sense related to (diminishing) nooberschap.	Some involvement in associations/ clubs/ community centre.	Greeting and small chat – important.	Focus on communal activities with group of neighbours.	Individual and community support. Direct reciprocity not important.	High level of social control.	Disturbance – seeking for a solution together.	Limited contact – open for activities – feeling a connection but no obligations.

Participants have different ways of coping with disturbances caused by people with intellectual disabilities. Some participants would discuss their irritations with the people involved, but most would turn to a staff member to help them out. Some participants expect staff members to warn group home residents not to cause any kind of disturbance. One participant, who works with people with intellectual disabilities, would have difficulties with noise and screaming from residents: *'I tell you honestly. We once discussed this among colleagues. Residents who shout and make loud noises; we wouldn't want to have them living next-door to us. Integration is a two-way process. You have to know which people you place in an ordinary neighbourhood.'* (participant B7).

Neighbouring patterns

In the third stage of the analysis we identified four neighbouring patterns: feeling an outsider, fleeting contacts, individualized neighbourliness and sense of community (see table 5.2).

1. **Feeling an outsider.** This group of participants would like to have more contact with neighbours, but contact stays limited to greeting and an occasional chat. Four participants mentioned having difficulties connecting with the original residents of the neighbourhoods and surrounding area. Most participants within this group would appreciate assistance in emergency situations and minor assistance. Social control is expected on safety issues.

These participants accept the presence of people with intellectual disabilities. They would appreciate an open day organized by the group home to get acquainted with the home and its residents. Their contact with people with intellectual disabilities is limited to greeting. In most cases, participants do not feel the need to have more contact. Participants are open to offering assistance but not on a structural basis.

2. **Fleeting contacts.** The neighbourly relations of half the participants primarily consisted of fleeting encounters in the street. This kind of contact is often limited to greeting each other and small talk. The norm of friendly recognition (Kusenbach, 2006) is felt strongly within this group. Participants have positive feelings towards their neighbours. In most cases, they are satisfied with the more superficial contacts. Regarding assistance and social control, this group's attitudes are similar to the first group's. Assistance is often limited to helping in cases of emergency or minor assistance, e.g. accepting a parcel for a neighbour. In several cases, participants have one or two neighbours they can rely on for more intensive support if the need arises. Social control is mainly focused on safety issues. Participants do have some experiences with disturbances, but in most cases these experiences didn't have much impact. In general, participants favour the idea of "live and let live".

Like the group considering themselves outsiders, these participants welcome an open day organized by the group home. Participants are open to contact with neighbours with intellectual disabilities in the street, but contact should be spontaneous. Participants are willing to provide incidental assistance, just as the first group of participants.

3. **Individualized neighbourliness.** About one quarter of participants consider social activities with neighbours and helping each out important aspects of neighbourly relations. Participants undertake activities with neighbours, which vary from drinking tea together to activities on the neighbourhood level. However, contact with neighbours is more selective than the neighbourly relations described in the fleeting contact pattern. Participants within this group are dedicated to helping, although in practice this often only amounts to minor assistance, such as lending something out or taking out the rubbish. In some cases, help consists of driving someone to hospital or being present when someone dies. This help is based on individual relationships and not embedded in any collective form of solidarity. This is line with Linders' study (2010). Participants stated that direct reciprocity was not important). They are confident that when they need assistance, neighbours will return the favour (Putnam, 2000). Social control is mostly focused on emergency situations, as in the first two groups. Regarding disturbances, participants generally feel it is important to show your neighbours some courtesy.

According to this group of participants, people with intellectual disabilities are welcome in the neighbourhood. They sometimes actively engage with them. Some participants had visited an open day of the group home, and had experienced this as positive. Participants do not object to people with intellectual disabilities being involved in neighbourhood activities and most participants show willingness to undertake a joint activity or to help. In most cases, however, participants object when it comes to structural activities and assistance.

4. **Sense of community.** Four participants feel they are part of a community within their neighbourhood. This sense of community resembles *modern noaberschap* as described by Abbas and Commandeur (2012). Social gatherings are important in their contact with neighbours. These participants are strongly involved with their neighbours as a community, and helping each other is not based on an individual relationship but support is provided to everyone who is considered part of this community. The norm of solidarity (Bayertz, 1999) plays an important role in this group. As with individual neighbourliness, direct reciprocity is not an issue (see also Putnam, 2000). Participants perceive their street or block as an integrated whole and all its residents as part of their community. The way in which participants express their sense of community varies. Participants mentioned traditional customs, e.g. gathering when someone dies, communal group activities, and social

support. Assisting and supporting neighbours is seen as obvious, even more so than in the third group. Participants report a higher level of social control than in the other patterns: neighbours take action when they notice someone has not left the house for a couple of days or watch each other's house during the holidays. Some participants reported that when there was a disturbance, neighbours tried to solve the problem together.

All participants stated that people with intellectual disabilities were welcome at neighbourhood activities and generally they were open to individual contact, or even had experiences with it. However, participants did stress that it was important to feel a connection.

Discussion

Our study shows that various social norms and behaviours related to neighbouring can be grouped in different patterns, the act of grouping provides further insight into the concept of neighbouring. Apart from minor differences, all patterns show that neighbours feel they should be able to rely on each other. How this reliance is shaped varies among the patterns. Differences in neighbouring style not only result from individual characteristics but also from situational context, e.g. moving into a new neighbourhood or the departure of a neighbour who held the neighbourhood together.

Within the same context, various neighbouring patterns were found. Neighbours with a strong sense of community, those with individualized neighbourliness and those with fleeting encounters live together in the same neighbourhoods. This new knowledge on neighbouring patterns might be useful to gain more understanding about how people with intellectual disabilities can be part of a neighbourhood. Contact is generally limited to friendly recognition at the most (Kusenbach, 2006; Wiesel & Bigby, 2014). Neighbours included in our study experience these fleeting encounters as normal, and find it important to recognize and be recognized by their neighbours. In the case of fleeting encounters they do not seem to make a distinction between their neighbours with or without intellectual disabilities. Several studies show that, besides neighbours, people with intellectual disabilities also benefit from this recognition in the street (e.g. Van Alphen et al., 2009; Blokland & Nast, 2014; Bredewold et al., 2016).

However, concerning more intense forms of neighbouring people with intellectual disabilities seem to be assigned an exceptional position in the neighbouring patterns. People with intellectual disabilities are not mentioned in relation to (minor) neighbour assistance and social control. This can be considered an implicit form of exclusion, since it effectively bars them from more involved types of neighbouring. We have

no information on the reasons for this exclusion. It may have something to do with the perception neighbours have of people with intellectual disabilities: participants mentioned that people living in the group homes do not need help because there is staff present. Participants also expressed fears people with intellectual disabilities might invade their privacy and supposed one cannot have a normal conversation with them. These assumptions may be influenced by various contextual factors, such as the fact neighbours see them walking by in groups, accompanied by staff members and the relative isolation of the group homes. Walking by in groups in the presence of staff members creates a certain distance between them and the neighbourhood. Participants in our study might not be inclined to provide individual help or invite people with intellectual disabilities to a neighbourhood activity, because they perceive the group home as a unit separate from the neighbourhood, which can take care of itself. These results seem to be in line with earlier studies that show that neighbours respond differently towards individuals with intellectual disabilities than towards the group home where people with intellectual disabilities are located (Hudson-Allez & Barret, 1996; Schwartz & Rabinovitz, 2010; Van Alphen et al., 2010).

Beyond these shared general perceptions of people with intellectual disabilities, the four neighbouring patterns show subtle differences in the opportunities for social contact they offer. Participants within the first two patterns focus on the limited contact resulting from fleeting encounters. They accept the presence of people with intellectual disabilities and are open to spontaneous contact in the street. Participants focusing on individualized neighbourliness and who have a sense of community welcome people with intellectual disabilities to join neighbourhood activities and would visit activities initiated by the group home. These participants are also the most willing to help out or participate in an individual or group activity with people with intellectual disabilities. These findings suggest there are opportunities to enhance social inclusion.

Our study shows staff members can either hinder or facilitate the contact between neighbours with and without intellectual disabilities (see also Abbott & McConkey, 2006; Van Alphen et al., 2009). Although our participants do not make a distinction between their neighbours with or without intellectual disabilities when it concerns fleeting encounters, they did experience walking by in groups as a barrier for initiating for example a chat in the street. It would be useful to investigate if and how group home staff members can play a role in facilitating these fleeting encounters based on the needs of both people with intellectual disabilities and their neighbours (see also Wiesel et al., 2013).

A more open attitude of staff members would be appreciated by the participants in our study. Participants are willing to visit activities initiated by the group homes.

These activities provide opportunities for getting to know each other on an individual level, which might constitute a basis for positive encounters in the street. These minor contacts might also act as a stepping stone to create a sustained contact. Staff members have a role in encouraging these contacts based on mutual interests. Participants mentioned their desire for psycho-education and the regulation of deviant behaviour, e.g. invasion of privacy and disturbance issues.

Performing social roles in the neighbourhood might not only facilitate minor neighbourly contacts, it could also help change the perceptions neighbours have about people with intellectual disabilities. Participants were positive about examples of these social roles (waiting tables in a bar or tapping beer during an activity) and, from the viewpoint of people with intellectual disabilities, social roles are an important aspect of social inclusion (Cobigo et al., 2012; Wolfensberger, 2000). Staff could offer support by finding opportunities to perform social roles in the neighbourhood.

Also, participants mentioned the importance of being a neighbour and not a volunteer. We recommend to aim for neighbourly contacts that start out small but might (or might not) spontaneously lead to more intensive contact. Bredewold et al. (2015) argue that positive contact between neighbours with and without intellectual disabilities is often characterized by built-in boundaries: the rules are clear. Fixed roles and structures are helpful. Support of staff members is needed in setting out rules, ensuring compliance to these rules, and clarifying roles in individual contacts between people with intellectual disabilities and neighbours.

To approach the four groups of participants with distinctive neighbouring patterns, different strategies are needed. The first two groups focus on fleeting encounters. Creating an open atmosphere and opportunities for individual encounters in the street catalyses more contact corresponding to their needs. People with intellectual disabilities benefit from encounters in the street; being recognized gives people a feeling of belonging (Blokland & Nast, 2014; Wiesel & Bigby, 2014). The third group of participants focuses on social activities and support on an individual level. These participants welcome people with intellectual disabilities and are open to more individual contact or offering some assistance. This group seems most promising for enhancing social inclusion. Staff members should be aware of these opportunities and of the obstacles regarding structural contact and obligations. It is important to cater to the needs of neighbours. Focusing on mutual interest is part of this. An individual approach is preferable. The fourth group of participants, who feel part of the community, are open to contact with people with intellectual disabilities. To reach this group, staff might benefit from using a different strategy than the individual approach. It is important to establish the group home as part of the neighbourhood and not as a separate unit. Becoming part of the neighbourhood and being present at neighbourhood activities might also lead to more individual contact based on mutual interest.

Limitations

Although our participants live close to the group homes for people with intellectual disabilities, they had limited experiences with residents. Contact mostly consists of greeting and sometimes having a chat. For this reason, we used fictitious situations (vignettes) in some interviews, to gain more insight into the views of participants about people with intellectual disabilities. Responses to fictitious situations do not always represent how participants would react in real life. Despite these limitations, the vignettes helped us gain more understanding of participants' views on neighbouring in relation to people with intellectual disabilities.

Neighbours in our study did not make a distinction based on the severity or complexity of disability but they did report barriers related to certain behaviours of people with intellectual disabilities. Our study focused on people with mild to moderate intellectual disabilities, where such behaviours are less prominent. The willingness of neighbours to engage with people with behaviour problems related to more severe intellectual disabilities might be different (e.g. Van Alphen, Dijkster, Bos, Van Den Borne, & Curfs, 2012).

It might be that neighbours willing to participate in our study have a more positive view on people with intellectual disabilities compared to neighbours who refused to be included in our study. However, we did not find indications for such a bias because neighbours also referred to experiences of other neighbours and the neighbourhood in general. Next, we also interviewed neighbours with little to no (recent) experiences with people with intellectual disabilities and neighbours that shared their negative experiences and perceptions related to people with intellectual disabilities as well.

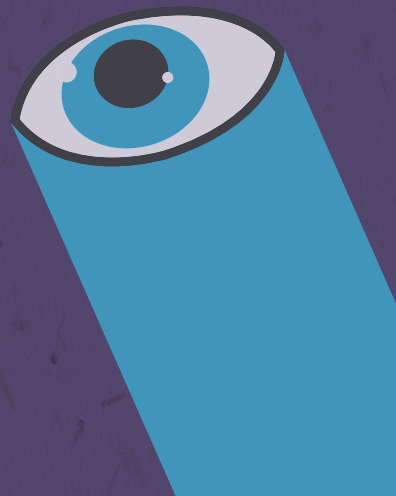
The two neighbourhoods involved have some unique features regarding neighbourliness. Traditional *noaberschap* still plays a role in the contacts between neighbours. Relationships between neighbours might be more intensive and more focused on assistance compared to other neighbourhoods (Van Alphen et al., 2010). In addition, most participants in our study are familiar with people with intellectual disabilities in their neighbourhood, which might be different in other neighbourhoods and could also explain the fact that anxiety around risk and protection appeared to play a limited role. Wiesel and Bigby (2014) found more contact between neighbours with and without intellectual disabilities in country towns in comparison with metropolitan suburbs. We recommend further research on the differences between neighbourhoods in small villages or country towns and metropolitan suburbs.

This chapter is based on:

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Chapter 6

Social inclusion in the neighbourhood and the professional role identity of group home staff members: views and experiences of staff regarding neighbourhood social inclusion of people with intellectual disabilities



Abstract

Background

During the last decades, people with intellectual disabilities have moved to ordinary neighbourhoods and policies have incorporated goals related to social inclusion. However, people with intellectual disabilities are still experiencing social isolation. We investigated the role of group home staff members, on the assumption that neighbourhood social inclusion cannot be considered a standard element of their professional role identity. The aim of our study was to gain insight into the individual perceptions of staff and the institutional environment in relation to staff's professional role identity in dealing with neighbourhood social inclusion.

Method

We conducted semi-structured group interviews with staff from nine group homes in three neighbourhoods in The Netherlands.

Results

Our analysis yielded five themes: (1) staff perceptions of residents' neighbourhood contacts: positive and negative experiences (2) staff perceptions of residents' needs and capabilities, (3) staff perceptions of neighbours and neighbourhood, (4) staff perceived role in social inclusion in the neighbourhood, and (5) staff perceived role of service provider.

Conclusions

Our study showed that individual perceptions of a professional role identity primarily focused on care tasks and the (lack of) experienced support from service providers hinder staff in creating opportunities for social inclusion in the neighbourhood. To enhance social inclusion in the neighbourhood we recommend service providers invest in supporting staff in acquiring the necessary skills.

Introduction

Over the last decades social inclusion of people with intellectual disabilities has become an important goal of policy makers. Historically, the Netherlands has a long tradition of institutional care for people with intellectual disabilities. People with intellectual disabilities were placed in large institutions, often separated from society (Schuurman, 2002). These institutions aimed to provide a safe and secure environment which was not ensured in society (Mans, 1998). From the 1950s onwards, models of social care were developed. In these social models, people with intellectual disabilities are considered part of society and, as a result, in subsequent decades people with intellectual disabilities became more visible in society. As in many other Western countries, the large institutions were closed, and care provision increasingly became organized through small-scale group homes situated in ordinary neighbourhoods (Beadle Brown et al., 2007; Nieboer et al., 2011). These group homes house people with mild to moderate intellectual disabilities who receive 24-h residential care.

National, local and institutional policies also started to incorporate goals related to social inclusion (e.g. Jones, Ouellette-Kuntz, Vilela, & Brown, 2008). However, there seems to be a large gap between these policies and the realities of daily life people with intellectual disabilities are confronted with. They still experience high levels of social isolation (Forrester-Jones et al., 2006; Jones et al., 2008; Milner & Kelly, 2009; Tøssebro et al., 2012). These findings show that physical integration does not necessarily lead to social inclusion (e.g. Nieboer et al., 2011; Cummins & Lau, 2003; Overmars-Marx et al., 2014).

Our study addresses social inclusion in the neighbourhood. Based on the conceptualization of Cobigo et al. (2012) we define neighbourhood social inclusion as 1) having access to neighbourhood facilities, 2) being able to perform social roles in the neighbourhood, 3) being recognized in these social roles, and 4) having meaningful contacts in the neighbourhood (Overmars-Marx et al., 2014). We stress the importance of neighbourhood social inclusion because relationships between neighbours have a positive effect on health and well-being. Although most interactions between neighbours can be considered as superficial, they are of significance to neighbours. Neighbours are inclined to see each other as possible sources of support they can rely on in times of need (e.g. Forrest & Kearns, 2001; Unger & Wandersman, 1985; Völker, et al., 2007, Van Alphen et al., 2009; 2010). Studies show that people with intellectual disabilities also benefit from encounters with neighbours or other actors in the neighbourhood; being recognized provides people with a feeling of belonging (e.g. Van Alphen et al., 2009; Wiesel & Bigby, 2014; Bredewold et al., 2015).

There are individual differences in the way neighbourhood social inclusion is experienced and perceived, and so the concept must always be considered in relation to the social and institutional setting in which a person functions (Overmars-Marx et al., 2014). This setting can either be supporting or thwarting for social inclusion (Schwartz & Rabinovitz, 2001). Therefore, we consider neighbourhood social inclusion the product of the interaction between a person with intellectual disabilities' individual characteristics and the neighbourhood where he or she is located (e.g. Cobigo et al., 2012). The various actors involved in achieving social inclusion in the neighbourhood, people with intellectual disabilities, neighbours, and the staff members working in group homes (Cobigo et al., 2012; Simplican et al., 2015) all have their own perspective on the neighbourhood and the opportunities for social inclusion it provides.

This study focuses on the role of group home staff members. The attitudes of staff determine a successful implementation of inclusive policies and directly affect the lives of people with intellectual disabilities (Jones et al., 2008). Group home staff members play a pivotal role in enabling and mediating inclusion (e.g. Van Alphen et al., 2009; Overmars-Marx et al., 2014). Such a role requires paying attention to tasks related to social inclusion. For example, staff can facilitate inclusion by supporting residents in developing social contacts in the neighbourhood by being open to neighbours (e.g. Abbot & McConkey, 2006; Van Alphen et al., 2009; Bigby & Wiesel, 2015). However, staff members of group homes for people with intellectual disabilities primarily focus on the provision of personal care to their residents (McConkey & Collins, 2010a). This could be explained by the fact that most staff members have been traditionally educated to care for their residents within these sheltered settings (e.g. Jones et al., 2008). To enhance social inclusion, a shift from 'caring for' to 'supporting' people with intellectual disabilities is necessary (Council for National Health and Care, 2002; Schuurman, 2002; Abbott & McConkey, 2006). To achieve such a shift, in-depth information is needed on all factors relating to the performance of group home staff members in supporting social inclusion.

We use the concept of professional role identity to understand the performance of group home staff members in supporting social inclusion in the neighbourhood. Group home staff's perceived professional role identity determines how they view their role in neighbourhood social inclusion, and the way they act in the neighbourhood and towards neighbours (Pratt et al., 2006; Weick, 1995). This professional identity results from their self-definition as a member of their profession, i.e. whether they consider it part of their professional task to contribute to the process of neighbourhood social inclusion. This professional role identity is influenced by institutional forces (Chreim et al., 2007): professionals adjust the way they express their professional identity to their perception of the organization's

expectations. These expectations are based on the support they perceive in their performance of tasks within their professional role. This support is, for example, reflected in training opportunities related to neighbourhood social inclusion. Service providers can either support or frustrate the development of a professional role identity that supports social inclusion.

Therefore, to understand the performance of group home staff members in promoting their residents' social inclusion in the neighbourhood, we have to focus on the way social inclusion is embedded in 1) their perceptions on whether and how they should contribute to the process of social inclusion, and 2) the expectations concerning social inclusion in their institutional environment and the level of support they experience from this environment in promoting it.

Our study was conducted among staff members in nine group homes in three municipalities in the eastern part of The Netherlands. The staff members are employed by four different service providers that run the group homes. The involved service providers formulated policies towards social inclusion. They work with independent or self-managing teams. Such teams usually consist of about eight staff members and are responsible for organizing and providing the appropriate care and support to their residents. On average, each team has 15 residents in its care. Although these self-managed teams are autonomous in terms of how they manage and carry out their work, they are supported by a manager.

Method

Neighbourhoods, group homes and group interviews

To obtain more insight into the perspective of staff members, we conducted group interviews with nine teams working in group homes located in three different neighbourhoods in three municipalities in the Netherlands. The group homes were selected by the first author in cooperation with the four service providers involved in the research project. The selection criteria were a representation of the four service providers and variation in neighbourhoods in terms of the presence of facilities and the socio-demographic characteristics of inhabitants.

Two of the neighbourhoods were situated in small towns with approximately 15,000 to 20,000 inhabitants in low-urbanized areas. The neighbourhoods differed in their level of facilities. Both offered shopping, catering and leisure facilities, but one had a greater availability of the various facilities that attracted people from across the region, while the other had more of a village-like atmosphere. Both neighbourhoods had fairly similar sociodemographic characteristics, with a relatively high percentage of people aged above 65 years (23% and 26%, compared to 17%

of the Dutch general population) (Centraal Bureau voor de Statistiek, 2014). The average income of neighbourhood residents was defined as just below the average income of the general Dutch population (€29,500): between €24,400 and €26,600 gross per year.

Both neighbourhoods were known as sites neighbourliness traditionally played an important role. Supporting each other and reciprocity are still key elements of this neighbourliness. However, nowadays the obliging character of *noaberschap* is replaced with a mutual sense of responsibility and mutual trust (Abbas & Commandeur, 2012). Both neighbourhoods located four group homes in different streets within the two neighbourhoods.

The third neighbourhood was a suburb of a small town with a population of 55,000 inhabitants. This neighbourhood had high levels of socio-economic deprivation. Neighbourhood residents had an average gross yearly income of €21,200 – below the national average – and a relatively high percentage (47%) of residents were in the 40% of the lowest incomes in the Netherlands (Centraal Bureau voor de Statistiek, 2014). Like the other two neighbourhoods, this neighbourhood contained a relative high percentage of people aged above 65 years (25%). The group home included in our study was situated in an apartment building and residents have their own apartments spread over three blocks of flats.

We also aimed for variation in the types of disabilities among the residents in the care of group home staff members. In general, the staff members included in our study care for residents with mild to moderate intellectual disabilities. In two group homes, there are some residents who also have mental health problems and in nearly half of the homes (four) there are a few residents with an increased need of physical care.

On average, each group interview involved eight staff members, guided by two researchers. The interviews took the form of planned discussions aimed at eliciting diverse viewpoints and experiences. One of the advantages of such a group interview is that informants tend to inspire one another, which increases the richness and scope of the data (Weiber et al., 2016). We tried to create on a non-judgemental atmosphere in which informants could feel confident and secure enough to freely speak their minds (Krueger & Casey, 2009).

To encourage group discussions, a topic list was used. This list was based on the literature cited in our introduction. Questions were asked about contacts residents had in the neighbourhood, staff members' perception of neighbourhood social inclusion and their professional role in promoting it and on how they were supported by their service provider.

Data analysis

All group interviews were audiotaped and transcribed verbatim. The interview transcripts were content analysed by the first author using ATLAS.ti software (Scientific Software Development GmbH Berlin, Germany). The coding process was based on elements of the grounded theory techniques (Strauss & Corbin, 1990). Our approach aimed at providing staff members' perspectives on their professional role in neighbourhood social inclusion. The first stage of our analysis was open coding (Glaser & Strauss, 1967). During the coding process, we engaged with the material by reading the transcripts over and over again. This increased familiarity with the stories of informants and provided a basis for categorizing the data. During the next stage we performed axial coding (Strauss, 1987) and classified the codes into categories, or subthemes. The coding process was an iterative process: categories were adjusted during the process by comparing them within and across different transcripts. After the axial coding, the codes were grouped into broader themes. While analysing the interviews transcripts, the first author continuously reflected on the process and the findings obtained (Yanow, 2003). A sample of the interviews was analysed by a second researcher to test inter-rater reliability. A comparison of the outcomes led to minor adjustments in the labelling of the themes that had emerged.

Results

Five themes emerged from our data analysis: (1) perception of residents' neighbourhood contacts: positive and negative experiences (2) perception of residents' needs and capabilities, (3) perception of neighbours and neighbourhood, (4) perceived role in social inclusion in the neighbourhood, and (5) role of service provider (see table 6.1). The themes are described separately but the links between the themes will be noted in the separate descriptions.

(1) Staff perceptions of residents' neighbourhood contacts: positive and negative experiences

First, informants told stories about the kind of contacts they saw between their residents with intellectual disabilities and neighbours. They told stories about different forms of contact. According to informants from all nine group homes, contact between people with intellectual disabilities and their neighbours is usually limited to greeting each other. Informants from one group home emphasized the importance of shops and shop assistants. They know their residents and therefore residents can visit shops by themselves.

Table 6.1 – Overview of themes and codes relevant to social inclusion in the neighbourhood

	Theme	Codes
Individual perceptions	Perception of residents' neighbourhood contacts: positive and negative experiences	Type of contact between residents and neighbours Joining activities Difficulties experienced in neighbourhood contact
	Perception of residents' needs and capabilities	Perceived needs of residents regarding the neighbourhood Perceived social skills of residents regarding the neighbourhood
	Perception of neighbours and neighbourhood	Possible negative influence of neighbours Perceived characteristics of neighbours and related needs Expectations regarding neighbours Atmosphere in the neighbourhood
	Perceived role in social inclusion in the neighbourhood	Opportunities for social contact with neighbours Intermediary role – disturbance Psycho education Discussing needs with residents Perceived obstacles related to available time and training
		Collaboration with the neighbourhood
Institutional environment	Role of service provider	Perceived support from service providers Experienced available time Perceived training opportunities

Informants noticed some difficulties where more extensive individual contacts and activities were concerned. They related these difficulties to the needs and behaviours of some of their residents. Residents can be unreliable; they do not keep appointments, exhibit claiming behaviour; e.g. stopping by every day, and can become very disappointed if someone does not visit them regularly. However, informants also mentioned positive examples of more extensive individual contacts and (one-on-one) activities: drinking coffee together; going out together; having contact through social media or working as a volunteer at the local soccer club. There were also examples of neighbours who volunteer to drive residents, for example to attend leisure activities.

All informants could provide examples of people with intellectual disabilities joining regular activities and using neighbourhood facilities. Some residents, for example, were active in sports clubs or visited the general practitioner. One informant presented an example of social inclusion in which people with intellectual disabilities participated in a regular activity: *'We joined the toddler gym....so that toddlers could get acquainted with other people on the planet.'* Informants also told stories about taking the initiative in organizing a neighbourhood activity or neighbour contact themselves, in some cases together with residents. In one group home, where residents live in their own apartments, it is standard practice they introduce themselves to neighbours. Also, informants mentioned a barbecue or an

introductory meeting they organized. Two group homes had positive experiences with organizing an activity. In one of them, staff organized 'Neighbours Day' together with the neighbourhood: *'We organized this on a small scale...Neighbours liked it and when we meet them in the shops now, our contact is positive.'* In most cases, neighbours only visited the introductory meeting and showed little interest in the follow-up activities which were organized. Informants did not know the reasons behind this lack of interest but they experienced it as frustrating. In these initiatives, the role of people with intellectual disabilities varies. In some cases, they participate in organizing them, but in most cases staff members play a leading role, according to our informants.

(2) Staff perceptions of residents' needs and capabilities

The second theme in our analysis relates to the residents supported by the group home staff members. This theme can be divided into two subthemes: informants told stories about the needs of people with intellectual disabilities and they discussed their capabilities.

All informants mentioned the importance of meeting the needs of their residents. In their opinion, some residents do not feel the need for increased contact with neighbours, because they are already busy or have their own contacts. Informants in one group home mentioned that residents have no need for increased contact, because they already have strong relations with family in the neighbourhood. Also, within another team, informants told stories about residents who do not want to be associated with the group home, for example when organizing or participating in an activity. However, according to our informants, many of the residents did explicitly mention the need for individual contact, but this could also be with someone from outside the neighbourhood.

The group home staff members did not only discuss their residents' needs, but also their capabilities. Most informants believed residents do not have sufficient social skills to develop contacts with neighbours. According to our informants, residents have communicational or psychological problems which form an obstacle to social contacts: *'Some residents easily become aggressive...neighbours expectations in social contact are sometimes higher than residents can fulfil, which leads to problems.'* Informants also mentioned residents that are in permanent need of care and cannot go out unaccompanied.

As far as neighbourhood activities were concerned, informants mentioned that people with intellectual disabilities have difficulties visiting these activities on their own and developing social contacts during these activities. In most cases, residents need some support at the outset and, in some cases, they need continuous support during these activities.

(3) Staff perceptions of neighbours and neighbourhood

Whether social interaction between people with intellectual disabilities and their neighbours is encouraged or held off also depends on staff members' perceptions of the neighbours and the neighbourhood. Informants' stories varied from fearing possible negative influences of neighbours (e.g. alcohol abuse) to the idea that neighbours were old and unable to undertake activities with residents. Despite these reservations regarding the neighbourhood, the neighbourhood context is also seen as positive. Informants from two neighbourhoods expressed they feel welcome and neighbours are familiar with the group of people with intellectual disabilities. Residents often feel a connection with the village because they know a lot of people and are well known in the shops. In one neighbourhood the situation is different. Here, residents are less familiar with neighbours and the neighbourhood, which is characterized by a high turnover rate and a very diverse population. However, informants mentioned that residents reported they do feel they fit the character of the neighbourhood.

According to informants, neighbours' expectations of people with intellectual disabilities are sometimes too high, for example in terms of reciprocity. Informants reported that this particularly applied to people with a mild and often invisible disability. Some informants mentioned they had the idea that neighbours generally are not very keen on making contact or find it difficult to interact or socialize with people with intellectual disabilities.

Informants, for their part, also had their own expectations regarding the neighbours' behaviour. This was clear from informants' remarks that they expected neighbours to visit joint meetings and to show some patience while their complaints were being dealt with. On the topic of joint activities, one team stressed that neighbours could also take the initiative to involve the group home in an activity. Within another team, there was disappointment about the fact that residents were not invited to an activity while the neighbours involved were always welcome at group home activities. According to informants, residents were also disappointed. Other informants stressed the importance of neighbours communicating any problems directly to them, instead of complaining to other neighbours: *'Neighbours should come to us personally if there are any complaints, otherwise we might deny a resident contact with neighbours because we anticipate neighbours' needs based on rumours.'*

According to the informants, the neighbourhood context as a whole can also be a factor obstructing social contact with neighbours. Some group homes are located in neighbourhoods in which neighbours generally have little contact with each other and opportunities to make contact are scarce, for example because one hardly sees any neighbours outside the home. In one case, informants mentioned a high

turnover of tenants in the flat where the group home is situated. Two other group homes are located on a main road, so many people who pass by are not neighbours.

(4) Staff perceived role in social inclusion in the neighbourhood inclusion

Most group home staff members have a 'wait-and-see attitude' concerning their role in social inclusion and how they would like to incorporate promoting social inclusion in their daily work. However, in three group homes, one or two informants were actively seeking opportunities to participate in the neighbourhood. Various aspects of group home staff's perceived role in neighbourhood social inclusion are described in this section.

Most informants have limited contact with neighbours. They greet each other and in some cases, there is a short conversation. Some informants are thoughtful and bring neighbours Christmas cards, for example. In some cases, informants explicitly mentioned they find it important to establish contact with neighbours and to develop and maintain good relations, for example by helping older neighbours or making an effort to greet neighbours: *'I use every opportunity to make contact with neighbours. ... I keep saying hello and in some cases this leads to short conversations'*.

Staff members' intermediary role in disturbances caused by residents was an important topic during all group interviews. However, when there is an increasing number of incidents, informants react in different ways. Some stop investing time and energy in neighbours who complain excessively because they do not see any benefit in it, whereas others consider it their professional duty to stay friendly no matter how unreasonable neighbours react: *'You have to stay friendly to neighbours you would not even consider a friend in your private life'*. In some cases, the disturbance is caused by the neighbours themselves, for example when they are drunk, and informants mentioned the importance of protecting their residents in such situations.

The willingness to provide information to neighbours (psycho education) about how to cope with certain behaviours and providing general information about people with intellectual disabilities is mentioned by some informants. However, informants of one team were very clear about their unwillingness to divulge any personal information to neighbours: *'That goes against your oath of secrecy. You do not have the right to inform neighbours about individual residents'*.

In general, all informants take the perceived needs of their residents as their starting point. If residents express a need for social contacts in the neighbourhood, informants support them in their social skills, if necessary. Informants discuss with residents what is appropriate behaviour and neighbours' expectations and explain that it is not desirable to visit a neighbour every day, for example. In most cases, residents must be accompanied, but informants stressed that they often do not have

enough time to do so. However, some informants explicitly mentioned they try to find time for these kinds of activities. Some informants, for example, initiated a collaboration with the local football club, which resulted in one of the residents starting as a volunteer at the club. Informants also explained how they encourage social inclusion during an activity such as shopping together: *'First, the shop assistants asked ME questions. I told them: these are not MY groceries. Now, they do not ask ME anymore.'*

Contact in the neighbourhood is not a standard part of the individual support plans of people with intellectual disabilities, unless residents have stated their needs for contact with the neighbourhood. Informants mentioned that having a social network in general and/or doing volunteer work are aspects of the individual support plan but that there is no direct link with neighbours or the neighbourhood.

During the group interviews, informants were asked to reflect on their role as a team in furthering social inclusion. Informants supported the goal of promoting social inclusion but experienced a lack of time to focus on neighbour relations: *'We have to make contact with them and maintain these contacts. This takes a lot of time, on top of our other tasks...'* Lack of time was mentioned by most informants. Two teams had experiences with a special staff member who could dedicate time to social inclusion. This so-called ambassador could initiate contacts and set up collaborations with local organizations, according to the informants. In one case, the ambassador also lived in the neighbourhood/village where the group home was located. This created extra opportunities because, as informants said, one's personal network has great potential for e.g. the recruitment of volunteers. During one group interview, it emerged that the function of inclusion ambassador had been cancelled because of financial reasons. Informants within this team were obviously disappointed about this decision, because there was not enough time to embed activities related to social inclusion in their regular work processes. The former ambassador would have liked to develop a training for staff members. These training opportunities are currently not available for staff members, according to all informants.

Collaboration with local organizations (for example, local welfare organizations) seemed to be not very common within the interviewed teams. In some cases there was cooperation with a local organization or association, for example when a resident worked there as a volunteer or when people with intellectual disabilities joined an activity. Informants use their own network and engage the service provider of the group homes to look for suitable activities or voluntary work. However, this does not seem to yield satisfactory results because informants stated there is still a need for more individual contact. During some interviews, initiatives to seek cooperation with local organizations were mentioned. These were, for example, visiting a lunch organized by a local partnership that facilitates activities in a community centre, or contacting the local welfare organization to cooperate in buddy projects.

(5) Staff perceived role of service provider

Informants experience little to no involvement of the service providers running the group homes. For urgent matters, for example related to a disturbance, informants can turn to the manager and issues related to resident care can be passed on to an expert team, which includes a psychologist or a remedial teacher. Informants reported that in most cases they solve issues themselves. They work in self-managing teams and organize the care and support of their residents together. Some informants mentioned that although social inclusion was a spearhead goal of their service provider, in practice these policies did not result in any identifiable activities or support. Informants were asked if they were facilitated in any way in their role in furthering social inclusion. Some mentioned that their service provider did encourage them to look for volunteers but that they were not allowed any extra time or means to do so.

Informants experienced a lack of time to develop activities related to social inclusion. In some group homes, there is only one staff member present, so it is not possible to accompany a resident to e.g. a group activity. In some group homes, there are two staff members present, which allows more room for supporting residents.

Not only is there a lack of time, there is also a lack of appropriate training or counselling, or informants are unaware of possibilities for training. Due to this lack of time many informants are not open to (potential) training opportunities. In one team, staff members had followed a training program which had also covered neighbourhood social inclusion. However, informants mentioned that the knowledge they had acquired had largely been forgotten, possibly because it was not embedded in any ongoing training scheme. In another team, cutbacks had led to the cancellation of the ambassador function and this had created problems for embedding social inclusion in the teams, according to the informants.

During half of the team interviews, informants mentioned the unattractive physical environment of the group homes. The group homes are inaccessible and not particularly inviting to neighbours. As one informant stated: *'The building is like a fortress'*.

Discussion

The aim of our study was to gain insight into the individual perceptions and the institutional environment of group home staff and in relation to staff's professional role identity regarding neighbourhood social inclusion. In earlier studies, we did not find any in-depth analysis of the professional role identity of group home staff members

in relation to their individual perceptions and underlying opinions, and the support staff experienced from service providers. On the whole, the stories of our informants show that their individual perceptions and the (lack of) support they experience from service providers do not encourage them to promote social inclusion. Using the concept of role identity, we were able to provide insight into possible reasons for this deficiency, and develop specific recommendations to enhance social inclusion.

Perceptions and professional role identity

Reflecting on the stories of our informants, we found that staff members' perceptions of their residents, the neighbourhood and their own role implicitly create barriers for enhancing social inclusion in the neighbourhood. The neighbourhood is not a standard topic of discussion with residents and they do not seem to view the neighbourhood in terms of opportunities. Group home staff members support the goal of improving social inclusion, but they also want to protect their residents from any harm that may come from the world outside of the institution. Often, this ambivalence results in putting more weight on possible risks and problems than on opportunities and residents' desires for engaging with the neighbourhood. This was illustrated in our study by the dilemma whether or not to share privacy-sensitive information with neighbours when this might provide opportunities for sustainable neighbour contacts. In general, the informants in our study seem to have difficulties coping with the dilemmas they face concerning social inclusion, and therefore often choose not to take the risk their residents might be harmed, which corresponds with their caring role.

The emphasis on protection could be due to the fact that staff are originally trained to provide care, and the larger institutions were developed to protect people from any harm that might befall them in society (Mans, 1998). This caring role is deeply embedded in their professional role identity and in the way they view the needs and capabilities of their residents (see also McConkey & Collins, 2010a; Salmon, Holmes, & Dodd, 2013). Activities to promote social inclusion always involve the risk of being harmed (Jahoda et al., 2010; Bredewold et al., 2016). Striking a balance between the two may pose a considerable ethical dilemma to staff members (e.g. Jenkins & Davies, 2011; Pelleboer-Gunnink et al., 2017). However, the small number of informants that did dare to expose their residents to possible harm and focused on opportunities in the neighbourhood, provided valuable examples of neighbourhood social inclusion. This might suggest that weighing the factors in the ethical dilemma differently could provide opportunities for social inclusion.

Institutional environment and the professional role identity

Although the service providers involved in our study endorse the significance of neighbourhood social inclusion and have developed policies regarding social

inclusion, daily practice shows that group home staff members struggle with creating opportunities for social inclusion in the neighbourhood (see also Forrester-Jones et al., 2006; Tossebro et al., 2012). Staff members in our study are aware of the goal of social inclusion in the policies of their organizations, but in most cases do not experience any active support from the organization in achieving this goal. Our informants experience a lack of time for activities to promote social inclusion, a lack of training opportunities, and in some cases feel that priorities are continuously shifting, for example when the function of inclusion ambassador is discontinued.

Despite the lack of support experienced by all informants, we did find examples of neighbourhood social inclusion in some informants' stories. These staff members seem to make different choices in the dilemma of protecting residents from harm and encouraging involvement in the neighbourhood. Developing a professional role identity in social inclusion requires providing more facilitative, enabling support to residents than in the traditional caring role (e.g. Mansell, 2006). Developing such a role asks for a fundamental change in culture: staff members need to be supported in making different choices regarding the dilemmas they face. To be successful, this fundamental change in the behaviour of staff members must be supported by organizational adjustments and appropriate management (e.g. Salmon et al., 2013).

Apart from the behavioural changes required to enable social inclusion, some of the informants mentioned the physical environment of the group homes. The physical layout is not seen as very inviting to neighbours, for example a building 'that looks like a fortress'. Earlier studies show that some physical features of the group homes, such as a high fence or the absence of a garden, reduce opportunities for social contacts between neighbours and people with intellectual disabilities (e.g. Van Alphen et al., 2010).

Practical implications

We conclude that social inclusion is not a standard element of the professional role identity of group home staff members, and we recommend service providers support staff to encourage neighbourhood social inclusion to become part of their professional behaviour. To create opportunities for neighbourhood social inclusion, staff members need to be supported in developing the necessary skills. Providing training and counselling increases the staff members' commitment to social inclusion (e.g. Meyer & Allen, 1991). We recommend service providers investigate which skills are needed and how these can be acquired.

One promising method could be peer-to-peer coaching. Working in a team is conducive to managing the difficulties inherent in change, removing opposition against change and increasing the motivation to work on a change such as actively promoting social inclusion (Salmon et al., 2013). During the group interviews, we

found that discussing the topic of social inclusion inspires staff members to think about creating and developing opportunities for social inclusion in the neighbourhood. Staff members came up with ideas like adding 'social inclusion' to their annual workprogramme, putting more effort into getting acquainted with neighbours, and discovering the needs of their residents regarding the neighbourhood, as well as ideas such as organizing group activities and inviting neighbours to specific activities. This illustrates that peer-to-peer coaching (including sharing good practices) is helpful in discussing barriers staff experience and suggesting possible ways of encouraging social inclusion. Creating a safe environment is an important condition for discussing these topics and it is therefore important that service providers invest in developing and maintaining strong relations within the teams working in a group home (e.g. Hensel, Hensel, & Dewa, 2015; Hutchison & Kroese, 2015). Team cohesion is a strong determiner for staff members' motivation and greatly influences how staff members perform (e.g. Hutchison & Kroese, 2015).

Offering training opportunities to staff members in shifting from a caring to supporting role seem to be essential. It suggests a change in culture of the professional development of group home staff members supporting people with intellectual disabilities. This implies that not only service providers have to take their role in initiating relevant training but also educational institutions that train professionals should pay attention to this cultural shift. The study of Jones et al. (2008) shows the role of education in how staff members perform their professional role. We would recommend educational institutions to reflect on the content of their curriculum related to social inclusion and to develop modules that focus on social inclusion together with service providers.

The lack of skills experienced by staff was also evident from the fact that neighbourhood social inclusion is not a standard topic of discussion with residents or included in their individual support plans. Group home staff members emphasize the needs of residents as a starting point in their support, but since social inclusion is only a limited part of their professional role identity, the neighbourhood plays hardly any role in their communication with residents. Service providers could encourage staff members to include the neighbourhood in individual support plans. To achieve this, the goal setting method might be useful (McConkey & Collins, 2010b). McConkey and Collins (2010b) found that goal setting can be an effective way to enhance social inclusion. Neighbourhood social inclusion can be translated into well-defined support needs and goals within the individual support plan. This goal setting can be tailored to the needs of residents. Supervision on staff's focus on uncovering and meeting the needs of residents is recommended (e.g. Salmon et al., 2013; Bradshaw, 2000).

Group home staff members mentioned the physical layout of the group home as a barrier for social interaction between residents and neighbours. Therefore, we

suggest that service providers involve neighbours, staff members and (potential) residents in the development of the physical layout of a group home. Many group homes located in the neighbourhood had an unattractive appearance and did not seem very inviting to neighbours. Besides involving all stakeholders in the construction of a group home, service providers could think of ways to transform the existing group homes into more attractive, more inviting buildings by removing fences and creating open spaces where residents and neighbours can see each other (see also Van Alphen et al., 2010).

Limitations and future research

The group interviews proved a rich source of information and created an environment in which informants inspired one another. Possibly, some informants were not able to tell their story freely because they felt unsafe within the group context. Although we have no reason to assume our data lack valuable information, further research using individual interviews might add new perspectives.

Our study was conducted among nine group homes supported by four service providers. Even though these service providers have an inclusion agenda, group home staff members did not experience social inclusion as an important aim in their job. Future research might focus on the interaction between service providers and group home staff members and including a more diverse range of service providers could also be recommended.

As mentioned above, we did not find any earlier studies which focused on the behaviour of staff members vis-à-vis social inclusion in relation to their professional role identity. It is important to realize that the professional role identity of the staff members included in our study is determined by the Dutch context. Our findings corroborate findings from studies conducted in other Western countries, which also point to the importance of a shift from a caring to a supporting role to enhance social inclusion (e.g. Abbott & McConkey, 2006; Hunter & Perry, 2006). However, we have not addressed any cultural differences in the organization of care that may affect individual role perceptions or the institutional context. Therefore, we cannot assure that our findings are directly transferable to other countries.

Finally, we would recommend future research on the role of peer-to-peer coaching in enhancing social inclusion. We cited some literature that shows how team support can help staff members in adopting skills during an evolving situation (e.g. Salmon et al., 2013) but these studies did not specifically focus on a change such as incorporating (neighbourhood) social inclusion. The experiences during the group interviews are in line with these studies but measuring the effect of peer-to-peer training was not an aim of this study. We would recommend further study of its effects and of how service providers can support this kind of training.





Nederlandstalige samenvatting [Summary in Dutch]

Welke sociale en fysieke aspecten van de buurt spelen een rol bij sociale inclusie van mensen met een verstandelijke beperking, onderzocht vanuit het perspectief van deze mensen zelf, hun buurtgenoten en begeleiders in de woonvormen?

Doel van dit onderzoek was om antwoord te geven op bovenstaande vraag. In de afgelopen decennia is er veel veranderd in de zorg. Deze veranderingen hebben er mede toe geleid dat steeds meer mensen met een beperking in reguliere buurten wonen. Ook in de verstandelijk gehandicaptenzorg zijn bewoners op grote schaal verhuisd van de grote instituten naar kleinschalige woonvormen in de samenleving (Overmars-Marx, 2011; Overmars-Marx et al., 2014). Deze ontwikkeling is gebaseerd op het idee dat mensen met een verstandelijke beperking kunnen bijdragen aan de samenleving en dat het wonen in de samenleving een positief effect heeft op hun kwaliteit van leven (Wolfensberger, 1983). Echter, uit onderzoek blijkt dat mensen met een verstandelijke beperking wel fysiek aanwezig zijn in de buurt, maar dat zij hier nog weinig van profiteren (Verdonschot et al., 2009; Cummins & Lau, 2003, Pretty et al. 2002). Het louter plaatsen van mensen in de samenleving betekent dus niet automatisch dat zij er ook in worden opgenomen. In dit onderzoek richten wij ons op aspecten van sociale inclusie in de buurt. Wij beschouwen sociale inclusie in de buurt als het resultaat van de interactie tussen iemand met een verstandelijke beperking en de verschillende actoren in de buurt. We kiezen daarmee voor een ecologische benadering: We zien sociale inclusie als de uitkomst van de interactie tussen het individu en de omgeving waarin hij of zij zich bevindt (Scheidt & Norris-Baker, 2003; Cobigo et al., 2012). Dit uitgangspunt betekent dat we de perspectieven van de verschillende actoren in de buurt in ons onderzoek moesten betrekken. Daarbij stond de vraag centraal welke sociale en fysieke aspecten in de buurt een rol spelen bij sociale inclusie, gezien vanuit de betrokken perspectieven.

Sociale inclusie vanuit meerdere perspectieven

We benadrukken het belang van een multiperspectivische benadering omdat ieder individu zijn eigen positie in de buurt heeft en zijn eigen perspectief op de omgeving. Er kunnen dan ook verschillen zijn in de wijze waarop de diverse actoren aankijken tegen sociale inclusie van mensen met een verstandelijke beperking. Deze verschillende perspectieven op sociale inclusie zijn van invloed op de interactie tussen de omgeving en mensen met een verstandelijke beperking en vervolgens weer op de mate van sociale inclusie. In dit onderzoek richten we ons op drie perspectieven die het meest direct betrokken zijn bij sociale inclusie in de buurt: 1) mensen met een verstandelijke beperking, 2) buurtgenoten en 3) begeleiders in de woonvormen.

Opzet van het onderzoek

Het onderzoek is uitgevoerd in drie buurten in de Achterhoek en in samenwerking met vier zorgorganisaties die actief zijn in de Achterhoek: de Lichtenvoorde, Estinea, Zozijn en Elver. Alle dataverzameling heeft plaatsgevonden binnen de drie buurten. In het onderzoek zijn drie groepen actoren gevraagd naar hun perspectief op sociale inclusie. Zo hebben we achterhaald welke sociale en fysieke aspecten volgens hen een rol spelen bij inclusie in de buurt. Dit heeft geleid tot de volgende deelstudies:

1. Een photovoice studie waarbij 18 mensen met een verstandelijke beperking in de drie buurten foto's hebben genomen van aspecten in de buurt die voor hen belangrijk zijn (positief of negatief). We bespraken deze foto's in interviews met hen.
2. 26 semigestructureerde interviews met 29 burens in twee van de betrokken buurten.
3. Negen groepsinterviews met gemiddeld acht begeleiders van de groepswoningen in de drie buurten. We maakten gebruik van een topiclijst om de groepsdiscussies te stimuleren.

Ieder perspectief is uniek

Belangrijkste resultaat uit ons onderzoek is dat iedere groep actoren zijn eigen unieke perceptie heeft van de sociale en fysieke aspecten in de buurt die belangrijk zijn voor sociale inclusie. Onze studie was een eerste poging om het ecologische model toe te passen op sociale inclusie in de buurt. De bevindingen laten het belang zien van het includeren van de verschillende actoren. De actoren geven zicht op de aspecten die in de buurt bijdragen aan sociale inclusie, maar ook op de factoren die juist belemmerend werken. In de volgende paragrafen geven we aan welke thema's als belangrijk naar voren zijn gekomen. Binnen deze thema's reflecteren we op de percepties van de verschillende actoren in de buurt.

(H)erkenning op straat

De komst van mensen met een verstandelijke beperking in de samenleving betekent dat zij onderdeel zijn van de plekken waar burens elkaar tegenkomen. Uit ons onderzoek blijkt het belang van (h)erkenning op straat, zowel voor mensen met een verstandelijke beperking als voor buurtgenoten. Beide groepen hechten veel waarde aan een groet en een praatje. Het geeft mensen het gevoel erbij te horen en burens benoemen dat zij het vreemd vinden als mensen niet groeten. Burens maken hierbij geen onderscheid tussen mensen met of zonder beperking. Dat zij geen onderscheid maken, betekent echter niet dat zij automatisch contact maken met mensen uit de woonvormen. Zij ervaren hierbij ook belemmeringen, bijvoorbeeld omdat de bewoners van de woonvormen vaak voorbijlopen in groepen. Daardoor

maak je minder makkelijk contact. Het elkaar ontmoeten en (h)erkennen op straat ervaren ze op zichzelf al als heel waardevol en het biedt mogelijkheden voor het ontstaan van verschillende vormen van sociaal contact tussen burens met en zonder een beperking. Voor mensen met een verstandelijke beperking is de buurt een nieuwe relationele ruimte waar contacten met buurtgenoten ontstaan of zich verdiepen.

'Het is leuk om met elkaar een praatje te kunnen maken' [bewoner met een verstandelijke beperking]

Om ontmoetingen tussen mensen met een verstandelijke beperking en de verschillende actoren in de buurt te bevorderen is het van belang inzicht te krijgen in de factoren die bijdragen aan (h)erkenning op straat:

1. Uit ons onderzoek blijkt dat mensen met een verstandelijke beperking die nog wonen in de buurt waar zij zijn geboren en getogen, zich erg thuis voelen in hun woonomgeving. Zij komen met regelmaat bekenden tegen en zij voelen zich er vertrouwd.
2. Naast de contacten op straat, spelen contacten met lokale ondernemers een belangrijke rol. Mensen met een beperking geven aan dat zij het contact met onder andere winkelmedewerkers en ohers in restaurants als waardevol ervaren. Omdat ze deze medewerkers kennen, hebben de mensen met een beperking meer de mogelijkheid om zelfstandig een boodschap te doen of uit eten te gaan.
3. Het deelnemen aan activiteiten in de buurt draagt bij aan sociale contacten in de buurt. Mensen met een beperking benoemen bijvoorbeeld een prettig contact met de fitnesscoach of ze kennen en groeten hun burens na een buurtbarbecue.
4. Ook vervullen mensen met een beperking in sommige gevallen sociale rollen. Dit betreft betaalde arbeid maar ook het incidenteel helpen in een café.
5. Een open houding van begeleiders en het openstellen van de woonvorm is een manier om (h)erkenning te bevorderen. Buurtgenoten geven aan dat zij hier zeker voor open staan en dat ze het ook prettig vinden om te weten wie de bewoners van de woonvorm zijn. Het is een mogelijkheid om elkaar te leren kennen en dit geeft op een later moment aanleiding voor contact op straat.

'Als ze meer open worden, dan smaakt dat wellicht naar meer' [buurtgenoot]

Bij de factoren 3 en 4 gaat het om een kleine groep bewoners met een verstandelijke beperking die een sociale rol vervult of die betrokken is bij buurtactiviteiten.

Andere vormen van burenccontact

Wanneer mensen met een verstandelijke beperking graag het burenccontact zouden willen intensiveren, blijken vanuit het burenperspectief meerdere belemmeringen een rol te spelen. Er is niet of nauwelijks sprake van uitwisseling van hulp tussen buren met en zonder verstandelijke beperking en ook als het gaat om buurtactiviteiten, nemen de mensen met een verstandelijke beperking hier maar weinig aan deel. Belemmeringen die buren ervaren, hebben zowel betrekking op het (gepercipieerde) gedrag van mensen met een verstandelijke beperking als op de ideeën die buurtgenoten hebben over de woonvorm waar de mensen met een verstandelijke beperking wonen.

Buurtbewoners geven aan bang te zijn voor claimend gedrag van mensen met een verstandelijke beperking. Ze vrezen een inbreuk op hun privacy. Net als in relatie met andere buren willen zij niet het gevoel hebben verplicht te worden tot structureel contact. Ook hebben sommige buurtbewoners het idee dat de bewoners van de woonvormen niet in staat zijn een praatje te maken. Deze assumpties en in sommige gevallen ervaringen werken belemmerend voor het aangaan van verder contact. Daarnaast vormt de institutionele context een belemmering voor buren om verder contact met woonvormbewoners aan te gaan. Buren ervaren de woonvormen vaak als een gesloten eenheid en voelen zich niet verbonden met de bewoners. Het voorbijlopen in groepen, de constante aanwezigheid van begeleiders en de fysieke vormgeving van de woonvormen ervaren zij als niet erg uitnodigend voor het aangaan van contact. Buurtgenoten waarderen een open houding van begeleiders bijvoorbeeld in de vorm van een kennismakingsbijeenkomst.

De genoemde belemmeringen betekenen niet dat buren onwelwillend staan tegenover contact met mensen met een verstandelijke beperking. Er zijn zeker buurtgenoten die open staan voor contact met bewoners van de woonvormen, mits dit niet structureel is en is afgestemd op hun eigen interesses. Buren willen graag benaderd worden als buurman of buurvrouw en niet als potentiële vrijwilliger. Daarnaast is niet iedere buur en buurt hetzelfde, en de behoeften verschillen, zowel op buurt- als op individueel niveau. Rekening houdend met deze verschillen zijn er zeker mogelijkheden voor sociale contacten. Buren die meer gericht zijn op een groet en een praatje, kunnen iets betekenen als het gaat om de (h)erkenning op straat terwijl buren die ook waarde hechten aan relaties met andere buren – ofwel gebaseerd op individuele relaties ofwel op gezamenlijke interesses – mogelijkheden bieden voor individueel contact gebaseerd op gezamenlijke interesses of deelname aan algemene buurtactiviteiten.

Sociale inclusie als onderdeel van de zorg

Het bevorderen van sociale inclusie in de buurt vraagt om ondersteuning van begeleiders aan bewoners met een verstandelijke beperking. Bijvoorbeeld bij het aangaan van sociale contacten, het deelnemen aan activiteiten en/of het vervullen van een sociale rol in de buurt. Het onderdeel zijn van de samenleving gaat gepaard met het nemen van risico's. Van oudsher bekleden begeleiders een meer zorgende rol waarin zij geneigd zijn bewoners te beschermen voor deze risico's. Dit zien we ook terug in de groepsinterviews met de begeleiders in ons onderzoek. Ze worstelen met vragen als het gaat om het stimuleren van sociale inclusie. Zij zijn bang voor een negatieve invloed van buurtbewoners, bijvoorbeeld als het gaat om alcoholmisbruik. Ook vragen zij zich af of buurtbewoners wel iets willen of kunnen betekenen voor bewoners. Aan de andere kant is de buurt niet standaard onderwerp van gesprek met bewoners. Hierdoor hebben begeleiders niet altijd een beeld bij wat "hun" bewoners willen en kunnen met sociale contacten in de buurt. Begeleiders steunen de gedachte om te werken aan sociale inclusie, maar er is in de meeste gevallen nog weinig sprake van.

De context van de organisatie

Bovenstaande resultaten maken een kloof zichtbaar: Aan de ene kant vraagt sociale inclusie van begeleiders om mensen met een verstandelijke beperking te ondersteunen in hun deelname aan de samenleving. Aan de andere kant is de professionele rolidentiteit van begeleiders sterk gericht op een zorgende, beschermende rol. Begeleiders lijken moeite te hebben met het vinden van de juiste balans tussen enerzijds het beschermen van bewoners en anderzijds het blootstellen van bewoners aan de mogelijkheden die de buurt hen biedt. Dit vraagt dan ook adequate ondersteuning vanuit de betrokken zorgorganisaties. De begeleiders in onze studie voelen zich beperkt gefaciliteerd. Zij ervaren weinig tijd om te werken aan inclusie en er is geen training of afgestemde begeleiding beschikbaar. Ons onderzoek laat zien dat het van belang is dat organisaties nadenken over waar ze naar toe willen met sociale inclusie en hoe zij medewerkers hierin kunnen ondersteunen.

'Eerst stelde de winkelmedewerker alle vragen aan mij. Ik heb gezegd: "dit zijn niet mijn boodschappen"'. En nu stellen ze de vragen niet meer aan MIJ.' [begeleider van de woonvorm]

Buurtgenoten en begeleiders noemden de fysieke vormgeving van de woonvormen belemmerend in het sociaal contact tussen bewoners van de woonvormen en buurtgenoten. De laatste groep ervaart de woonvormen in veel gevallen als niet

erg uitnodigend; soms wordt er zelfs gesproken van 'een fort'. Organisaties en begeleiders hebben de taak om na te denken over hoe ze bestaande woonvormen aantrekkelijker kunnen maken en uitnodigend voor burens. Hierbij valt bijvoorbeeld te denken aan het creëren van een buitenruimte zonder een hoge heg of het zorgen voor (onbedekte) ramen waardoor bewoners kunnen zwaaien naar burens. De betrokkenheid van burens kan worden vergroot door ze mee te nemen in dit proces. Ook als het gaat om het ontwikkelen van nieuwe woonvormen kan een inclusive design ervoor zorgen dat iedereen in de buurt zich meer betrokken voelt bij de bewoners van de woonvormen.

Tot slot blijkt uit dit onderzoek dat de kleine informele contacten en activiteiten erg waardevol zijn voor mensen met een verstandelijke beperking. Kleine doelen lijken ook het meest haalbaar vanuit het perspectief van buurtgenoten en begeleiders. Daarnaast vraagt sociale inclusie blijvende structurele aandacht. Het proces van sociale inclusie gaat niet over één nacht ijs. Samenhangend met de worsteling van begeleiders, de dynamiek van de buurtcontext en de ontwikkeling in de samenleving zou sociale inclusie in de buurt een terugkomend agendapunt moeten zijn bij de organisaties in de gehandicaptenzorg en in breder verband ook bij beleidsmakers en politici. Het samenspel tussen de verschillende betrokkenen is hierbij van groot belang.

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Curriculum Vitae

Tessa Overmars-Marx was born in Arnhem, the Netherlands, on July 20, 1978. She graduated in 1996 from secondary school (HAVO) at Dorenweerd College in Doorwerth. From 1997 to 2001 she studied for a BSc in Social Work and Services at the Hogeschool van Arnhem en Nijmegen in Arnhem. After graduating, from 2001 to 2004 she studied her Masters in Sociology at the Radboud University in Nijmegen. During this degree she was an intern at the Netherlands Institute for Social Research (SCP) in The Hague, where she was involved in research related to the position of ethnic minority women.

Tessa graduated in 2004 with thesis focusing on the changing role of men in the household and family. She then continued working at SCP. Her work focused on projects related to health care.

In 2006, she started working at the Institute for Applied Sciences at Radboud University in Nijmegen, carrying out research on topics related to special education. She co-authored several publications in this field.

From 2008 to 2014 she worked at Vilans, focusing on her particular improving the quality of life of people in health care. She worked on several national and international projects focusing on a range of issues including work and disability, technology and independent living for older people, neighbourhood-oriented work and social inclusion. The initial ideas for a PhD and the design started during this period at Vilans.

Tessa continued her PhD study at the VU University in 2014, under the supervision of prof. dr. H.P. Meininger and dr. G.C.F. Thomése. This resulted in this thesis, which focuses on different perspectives on neighbourhood social inclusion of people with intellectual disabilities.