

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 Historical references show that during the Middle Ages, people with intellectual disabilities were banished from the cities if, for example, they displayed behaviour considered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, Verdonschot,

& 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 Nations 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; Verdonschot et al., 2009a, 2009b; Overmars-Marx et al., 2014). Meinger (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 neighbourhood patterns and how people with intellectual disabilities are incorporated in these neighbourhood 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.