Responding to otherness. About encounters between people with and without intellectual disabilities in ‘reversed integration’ settings

Summary

In the current Dutch chronic care and social welfare sector, participation and inclusion are in the spotlights, at the same time raising all kinds of questions and debate: What does it mean if we would want people with intellectual disabilities to participate in our society? What does this participation demand from both civilians with and without intellectual disabilities? Can we truly encounter one another? And by doing so, how do we deal with mutual differences?

In this book I present my PhD-research about what happens during encounters in ‘reversed integration’ settings – formerly sheltered institutional sites where people without intellectual disabilities become neighbours of people with intellectual disabilities – and the meanings the people concerned attach to what they experience during those encounters.

In chapter 1 I map the research context, research locations, and my research question. Therefore I start with sketching the background of ‘reversed integration’: the Dutch normalization and communalization policies ['vermaatschappelijks beleid'] that started to influence the care and support services for people with disabilities since the early 1990’s. This ‘Community care’ is the result of the cooperation between critical parents and other advocates of the ‘citizenship movement’ ['burgerbeweging'] who collaborated with the Ministry of Health and Social Affairs ['Ministerie van VWS'] in an attempt to grant people with disabilities a valued place in our society – as full-fledged citizens. They considered deinstitutionalization a first and important step: the dismantling of the many large-scale institutions which, due to their existence as alternative societies, at a great distance of the living environment of people without intellectual disabilities, facilitated exclusion and marginalization. Instead of those independent, remote, large-scale, intramural services, care providers should invest in small-scale living and care facilities within the community.

This kind of ‘physical integration’ could give the initial impetus to ‘full-fledged citizenship’ of people with intellectual disabilities and could also facilitate encounters between people with and without intellectual disabilities. However, not everyone agreed on the intended dismantling of the intramural care facilities. A group of concerned parents of people with intellectual disabilities took a stand against this movement, together with a large share of the institutions them-
selves. According to these opponents of deinstitutionalization, the disappearance of sheltered living arrangements would negatively impact the freedom of movement and safety of their children, respectively, among whom many persons with severe intellectual or multiple disabilities and/or behavioral problems and/or psychiatric problems. A small number of service providers developed, often times in close collaboration with the parents of their clients, reversed integration plans. Reversed integration stands for a movement from regular society to the institutional site: people without intellectual disabilities come to live (or work or recreate) in the vicinity of people with intellectual disabilities, instead of the other way around. The institutional policymakers expected that reversed integration could unite the best of two worlds: the freedom of movement, safety, and support services of an intramural care facility, and the excitement and interaction of an ordinary Dutch neighbourhood.

I conducted my research in four reversed integration settings. In the municipality of Monster I investigated what happened in the residential area Polanen (service provider ‘s Heeren Loo Het Westerhorn), in Veldhoven I conducted research in de neighbourhoods de Berkt and Akkereind (service provider Sevennus), in Huis ter Heide in the neighbourhood Sterrenberg (service provider Abrona) and in Apeldoorn, last but not least, in de new housing estate Groot Zonnehoeve (service provider ‘s Heeren Loo Groot-Schuylenburg). In the second part of chapter 1 I describe how the four service providers involved, shaped and drew up reversed integration policies, and I provide a description of the situation which I found when I visited the research locations for the first time.

The aim of my research was – in line with the principles of ‘responsive evaluation’ (Stake, 1975; Guba & Lincoln, 1989, Abma, 1996, 2006) – not so much to evaluate the data collection techniques that helped in my search for answers to my research question rather broad and unrestricted: the data collection techniques that helped in my search for answers to my research question rather broad and unrestricted: to the people directly concerned, i.e. neighbours with and without intellectual disabilities, respectively clients, among whom many persons with intellectual disabilities and/or multiple disabilities and/or psychiatric problems. A small number of service providers developed, often times in close collaboration with the parents of their clients, reversed integration plans. Reversed integration stands for a movement from regular society to the institutional site: people without intellectual disabilities come to live (or work or recreate) in the vicinity of people with intellectual disabilities, instead of the other way around. The institutional policymakers expected that reversed integration could unite the best of two worlds: the freedom of movement, safety, and support services of an intramural care facility, and the excitement and interaction of an ordinary Dutch neighbourhood.

I conducted my research in four reversed integration settings. In the municipality of Monster I investigated what happened in the residential area Polanen (service provider ‘s Heeren Loo Het Westerhorn), in Veldhoven I conducted research in de neighbourhoods de Berkt and Akkereind (service provider Sevennus), in Huis ter Heide in the neighbourhood Sterrenberg (service provider Abrona) and in Apeldoorn, last but not least, in de new housing estate Groot Zonnehoeve (service provider ‘s Heeren Loo Groot-Schuylenburg). In the second part of chapter 1 I describe how the four service providers involved, shaped and drew up reversed integration policies, and I provide a description of the situation which I found when I visited the research locations for the first time.

The aim of my research was – in line with the principles of ‘responsive evaluation’ (Stake, 1975; Guba & Lincoln, 1989, Abma, 1996, 2006) – not so much to evaluate the assumptions and goals of the policymakers concerned, but first and foremost to gain insight in that which mattered most in reversed integration settings according to the people directly concerned, i.e. neighbours with and without intellectual disabilities, family members, and care and support staff. Therefore I kept my initial research question rather broad and unrestricted:

What happens between stakeholders with and without intellectual disabilities in reversed integration settings, and which meanings do they attach to those events?

In chapter 2 I discuss the epistemological and methodological starting points and the data collection techniques that helped in my search for answers to my research question. In epistemological aspect, I agree with a mixture of ‘social constructivism’ and ‘enactivism’ (see respectively Gergen, 1985, 2012 and Niessen, 2007). Therefore, I consider 1. each individual as a meaning giving agent, who, in a constant dynamic between his own interpretations and representations and those of others, gives form, interpretation and meaning to the world around him, and 2. the knowledge that each individual gains as a result of action and interaction. In other words: we acquire insights in and beliefs about the surrounding reality by relating ourselves to it with our body, our experiences and our thoughts. Subsequently, I consider conducting participatory research in reversed integration settings as a complex, multiple and collective knowledge production process. That which the participants and the researcher share with each other, is dependent on to which extent they – with their words, attitude, behaviour, thoughts and body – are receptive to each other’s appearance, demeanor, behaviour and perspectives, and are willing to attempt to connect. In line with this relational notion of gathering knowledge, it is logical that I did not restrict myself with one research method at the beginning of my data collection, but I let my choices depend on what I experienced during the interactions with the various stakeholders. The aforementioned responsive research method – which focuses on a horizontal, open dialogue between as many different stakeholders as possible – fits well here, because of the starting point that the research design develops through the dialogue with participants. By performing participant observation and semi-structured interviews (e.g. Davies, 1998/2008, O’Reilly, 2005) I attempted to gain insight into the issues from stakeholders with and without intellectual disabilities. What was especially of interest in reversed integration settings, according to them? How did they experience each other’s presence? What were the most important issues and concerns, according to them? The goal of this all was to stimulate an open dialogue between the perspectives of the various stakeholders, a dialogue that would lead to more personal insight and mutual understanding. Because I was aspired to enlarge the social equality and justice through my research, I paid special attention to the contrasts and controversies between the stakeholders’ stories, while collecting issues. The vast majority of the gathered data consisted of field notes, interview transcripts and conversation reports. At various moments and in different ways I aspired to discuss the issue selection with the research participants. (I describe the quality criteria of this procedure also in this chapter). The most important result of this dialogical data selection process was that the interaction with uneasy and confusing otherness became the central research theme. Because as a responsive researcher I contributed my own perspective and I co-constructed the stories of the research participants, I obviously had to reflect critically on my own position, beliefs and motives related to the research and this research theme. Why did I conduct this research? What did I want to achieve? And why was I personally so fascinated by the confusing otherness of so many stakeholders with intellectual disabilities? In chapter 2 I show that (and how), by way of autoethnography, I reflected systematically on my own position and engagement (see Hayano, 1979, Ellis, 2004).

At the end of the second chapter, I also introduce the ‘thinking with theory’ approach from Alecia Jackson and Lisa Mazzei (2013), by which I added a continuation to the dialogical conception of knowledge production. By interpreting the issues that touched on the central research theme – the interaction with uneasy
and confusing otherness – through the application of three meta-theories about human interaction on my data collection, I attempted to gain more insight into what happened during encounters between stakeholders with and without intellectual disabilities.

In chapter 3 I present the three theories that I ‘assembled’ to my data, as to produce more knowledge about the interaction with uneasy and confusing otherness. With this I show, by means of a fragment from my field notes, how the assemblage of theory and data works, and how this produces a wealth of (reflexive) questions. The three meta-theories I used were from the Canadian sociologist Erving Goffman (1959/1983), the Dutch sociologist and philosopher Harry Kunneman (1996) and the German phenomenologist Bernhard Waldenfels (1990/2013, 2004).

Goffman, to start out with, describes everyday human interaction as if it takes place in a theatre. I use his ‘dramaturgical perspective’ to interpret what was observable and – often without words – expressed when people with and without intellectual disabilities met each other in reversed integration settings. On the one hand, I performed this to get more insight into the symbolic content of our actions during said encounters, on the other hand because Goffman’s provoking point of view challenges critical reflection on the underlying motives in motives our attitude and actions during these interactions.

Additionally, I use the work of Kunneman who claims that a growing number of encounters in current care settings take place in a fluid, hardly crystallized field of force where two fundamentally different logics appear: Kunneman calls the colliding exchange between the two conflicting logics ‘interference’. The ‘interference zone’ exists on the one hand of the objectified thinking models and protocols of the care organization, and on the other the personal and localized experiential knowledge and motives of individual stakeholders. With the help of Kunneman’s ‘interference perspective’ I researched how and to what extent objectified ‘care provider logic’ and subjective ‘communicative logic’ determines what happens in everyday encounters in reverse integration settings, and what meanings the participants attribute to these occurrences.

Thirdly, I applied various insights of Waldenfels, who states that every encounter is about a predetermined, bodily response to the strangeness that we experience while observing the other, and afterwards – consciously – attach to our observation and response. With the help of Waldenfels’ ‘responsive perspective’ I aimed to work out and interpret the reflexive knowledge of the people involved about their personal bodily restrained experiences during encounters in reversed integration settings. I did that especially to gain more insight into the extent and manner in which the original and the new residents (and some family members and care facility representatives) refer to the experience of strangeness in their stories about interactions.

By ‘thinking with the theories’ of Goffman, Kunneman and Waldenfels about the (in dialogue with the research participants) selected data, my initial broad, rather unrestricted twofold research question transformed into a more focused, theoretically charged, threefold variant:

What happens during encounters on reversed integration stages, which logics do participants use to give meanings to those encounters, and to what extent do they refer to strangeness?

In the fourth, fifth and sixth chapter, I present the empirical findings, after which each paragraph has a block of theoretical reflections. In chapter 4 I focus on bodily encounters between the new and original residents. I do that especially by describing and analyzing what happens when residents without intellectual disabilities meet (one of) the residents with intellectual disabilities, whether or not in the company of a representative of the care facility or a family member: How do they move and behave in such situations? To what extent do they remove themselves, keep their distance, approach each other or stand together? Additionally, I describe and analyze also some of my personal experiences while meeting a person with intellectual disabilities.

First of all, it seems that in everyday life, residents with intellectual disabilities are on the street quite infrequently – and most of them never without guidance. If we suppose – with Goffman – that the entourage, the stage and our public have a big influence on the role we perform, then we can conclude that the fact of being outdoors adds very little to the fact that many participants with intellectual disabilities show stereotypical, bored or lethargic behaviour.

If people with intellectual disabilities do come outside, then we notice that the residents without intellectual disabilities avoid or ignore them frequently, or stage their own play during interactions with them. Through the dialogue with Goffman’s dramaturgical perspective, we learn to consider these avoiding movements with regard to the uneasy and confusing otherness of participants with intellectual disabilities, as a general human need to keep everyday interactions supple and light, and therefore to avoid displeasure and conflict. As a consequence of this typical human need, various people with intellectual disabilities receive the role of a ‘non-person’ in the public space. According to Goffman, somebody who is attributed the role of non-person, is indeed present during the interaction, but other people do not pay attention to his performance, and stage their own play. They perform as if the other is not there – not really because he has less value, but more often because it is unclear how to interact with him. Goffman states that in the early days especially slaves had to deal with this approach, while in modern western societies especially old people, young children and sick people are attributed the role of non-person.

A third important finding is that various newcomers refer explicitly to the experience of displeasure, unease, confusion, fear, dislike or disgust during an encounter with some residents with intellectual disabilities. Very often their unease and confusion is because they do not know how to communicate with the residents with intellectual disabilities in a satisfying manner. The possibility to communicate
The fifth and last important finding of chapter 4 is that a couple of residents without people, but it conceives form, content and meaning in the relationship between an unjustifiable way: strangeness can never be assigned to the characteristics of individualized approaches dismiss the relational aspects of experiencing the alien in which they experience this unease. From Waldenfels’ responsive perspective, such individualized approaches dismiss the relational aspects of experiencing the alien in an unjustifiable way: strangeness can never be assigned to the characteristics of one person, but it conceives form, content and meaning in the relationship between people.

The fifth and last important finding of chapter 4 is that a couple of residents without intellectual disabilities, that seek contact with their neighbours with intellectual disabilities on a regular basis, emphasize that the ‘how’ and ‘why’ of human interactions is at least as determining for the meanings that we attribute to those interactions as the ‘what’. According to them, this awareness could lead to the fact that new residents in a manner other than verbal or cognitive ways can learn to communicate playfully with their neighbours with intellectual disabilities. Examples of such an approach are jokes, teasing and horsing around (something which a striking amount of caregivers tend to do also in contact with their clients).

Through the dialogue with Kunneman’s interference perspective, I interpret this view as an argument to act more from the standpoint of communicative logic. If residents without intellectual disabilities, in an attempt to facilitate mutual understanding and an equal dialogue, take the non-verbal communicative signals of neighbours with intellectual disabilities more into consideration, then none of them would avoid the last mentioned regularly, nor would they respond to them in an exclusive verbal manner.

The main theme in chapter 5 is the very strong organized and protocol rich approach of otherness. First of all I focus on what happens during an encounter between residents with and without intellectual disabilities when ‘some’ influence the main theme and difficulty of daily interactions as the ‘what’. This is apparent from what Kunneman – following Jurgen Habermas (1981/1995) – typifies as ‘the colonization of the life world through instrumental logic’. Not only many participants with intellectual disabilities experience huge restrictions of movement as a result of the focus on peace and quiet, safety and order and their possibilities to meet new people, also the life world of their neighbours without intellectual disabilities is colonized by these instrumental ‘care provider logic’.

Several newcomers would also enjoy it if support staff would stay more in the background during encounters with their neighbours with intellectual disabilities, and thus take on the role of ‘outsider’ instead of ‘buffer’. At the same time, many of them consider staff to be indispensable, because of their professional knowledge about dealing with people with intellectual disabilities. Some newcomers mirror the attitude and behaviour of caregivers during encounters with the original residents, and think of the interpretations and actions of care professionals as guiding. This also shows the colonization of the life world of residents with and without intellectual disabilities through care organization logic.

Furthermore, I describe and analyze – as a contrast – what happens when the interpersonal experiential knowledge from the participants dominates. How do the participants establish themselves in relationship to each other when such a communicative logic guides their actions? What are the most important aspects of this way of thinking? And to what extent do new residents (and caregivers) succeed in applying form, content and meaning to their attitude and actions towards stakeholders with intellectual disabilities, without using fixed, objectified, professional frameworks?

Just like in the previous chapter, while presenting the empirical findings of chapter 5, I use fragments of my field notes, interview transcripts and conversation reports. This focus is on encounters between original residents, newcomers and caregivers, although I also describe and analyze a personal experience with the interaction with otherness that is highly organized and has a lot of protocols.

The first important finding of chapter 5 for many caregivers in reversed integration settings is that the maintenance of peace and quiet, safety and order in the life of their clients had a high priority. They are strongly focused on preventing problems and difficulties. Also during everyday encounters between their clients and the new residents the caregivers are focused on what could go wrong. As a result of this risk focus they often come in between interactions with residents with and without intellectual disabilities, preventive as well as reactive.

Secondly, the representatives of the care facilities seem to emphasize during most of the information meeting what could go wrong, and residents without intellectual disabilities are told to be careful. Almost none of the newcomers feel inspired by the facility to seek interaction in daily life. So with this, the guiding and protective presence of care provider representatives often has a restraining effect on the development of concrete interaction between the original residents and newcomers. This approach of otherness in an exclusive verbal manner.

Secondly, the representatives of the care facilities seem to emphasize during most of the information meeting what could go wrong, and residents without intellectual disabilities are told to be careful. Almost none of the newcomers feel inspired by the facility to seek interaction in daily life. So with this, the guiding and protective presence of care provider representatives often has a restraining effect on the development of concrete interaction between the original residents and newcomers. This approach of otherness in an exclusive verbal manner.
In the last part of chapter 5 I illustrate that in reverse integration settings a surprising large amount of space for mutual, pleasurable encounters between people with and without intellectual disabilities often originates. This happens when a newcomer or a caregiver on the basis of his personal convictions and motives (temporarily) dares to challenge the rules of conduct, protocols and routines, which hamper or block the interaction with a person with intellectual disabilities. Such Kunneman’s ‘culturation through communicative logic’ often shows up as the interaction takes place outside the [for the participant with intellectual disabilities familiar and trusted] surroundings of the care facility. This also tends to happen when a representative of the care organization combines his professional attitude and proceedings with non-conspicuous, conspiratory [calming of encouraging] non-verbal signals towards the newcomers.

I present In chapter 6 I focus on the theme ‘difference’, as well as in the Community care policy of the government as in the reverse integration policy from the care providers in question. How much attention and space is there in the policy stories for the difference between people with and without intellectual disabilities? How do the perspectives from the government and the care providers relate to the people directly involved in reversed integration settings – neighbors with and without intellectual disabilities, family members, care workers and middle managers – recounting about their experiences with mutual differences?

With these two questions in the back of my mind, in this chapter around nine sub-themes the most striking statements from former government policy makers, care provider policy makers and those directly involved about how we as a society cope – and should cope – with the differences between people with and without intellectual disabilities.

While writing this chapter, I especially paid attention – in line with the responsive research tradition – to the contrast and controversies between the stories of the members of these groups [formed by me]. Consequently, I constructed a dialogue between the perspectives from people who in their daily life will see each other very little or not at all, a dialogue moreover with a theme that interests them in various ways, and with a variety of intensity.

The starting point of this dialogue about difference was constantly the perspective of the government [as written in policy documents and orally recorded from two former high level civil servants]. I reflected on this government perspective in two steps: first with the help of stories from the institutional policy makers and after that with those of neighbors with and without intellectual disabilities, family members, care workers and middle managers. I chose for this order of presentation, because to me it was both relevant to have as much diversity in the constructed dialogue about difference in government policy, but also that the stakeholders who have the least influence on this current policy would certainly have the final say. Also, I tried to accommodate the intermediate position from institutional policy makers in reverse integration settings, who design their policies in line with the government on the one hand, and on the other take into account the personal stories from stakeholders who do not always agree with these government policies. What is striking in this dialogue is that the government, in her Community care policy in the last twenty years, is mainly focused on strengthening the similarities and solving or bridging the apparent material and social differences between people with and without a disability. This includes pushing back the influence of large-scale intramural institutions and stimulating small-scale integrated living and care facilities. With this, according to care providers and legal representatives in reverse integration settings, they have paid too little attention to non-erasable individual differences between people with and without intellectual disabilities which make the interaction sometimes difficult, problematic and sometimes undesirable.

With the help of Waldenfels’ responsive perspective I consider the dominant policy focus on similarities as a futile attempt to alienate the otherness of stakeholders with intellectual disabilities. Because of this attempt many critical stakeholders consider the government’s version of the citizenship ideal as an insufficient policy starting point; in their eyes it does no right to the individuality of the vulnerable (social) position of their child, brother, sister or client. A second striking point of controversy is the meaning of ‘vulnerability’, ‘safety’ and ‘protection’. The government civil servants emphasize especially the potential interfering and marginalizing aspects of a very strong focus on vulnerability and protection of people with intellectual disabilities. They consider this focus as an important symbol for an overwhelming influence of large-scale, intramural care facilities that do not act on behalf of their clients. The government policy makers are for example convinced that there would be no reverse integration settings, if the individual support demands of people with intellectual disabilities would guide the policy of the care providers. Many directors, however, claim that their policy roughly meets the demands of their clients and their legal representatives. In reaction to this, many family members, care professionals and middle managers claim that it is often impossible to gain knowledge of the individual demands or needs of stakeholders with intellectual disabilities. In addition, they report that their focus on vulnerability and protection arises from personal experiences with the concrete threat of the otherness of their family member (or client) by outsiders – for example through indifference, rejection, teasing and aggression.

A third controversial point about difference comes forth from the fact that government and institutional policy makers almost never speak publicly about the significance of room and attention for inevitable unease during interactions between people with and without intellectual disabilities. On the contrary, they focus strongly on the possibilities of bridging the gap between mutual differences. The application of Waldenfels’ perspective shows that they – with good intentions, I presume – in doing so either assimilate or romanticize the otherness of many stakeholders with intellectual disabilities. On the contrary, for family members,
caregivers and new neighbours the experience and recognition of the inerasable and uneasy aspects of difference is inextricably bound to their relationship with people with intellectual disabilities. Various caregivers and family members emphasize that there will only be enough room for the clients (or family members), if the rest of our society is willing to be confronted with unpredictable, uneasy and inerasable otherness more often. However, they are pessimistic about such societal willingness, and think that it will be unlikely that the newcomers in reversed integration settings in everyday life will be open for difficult or confronting interactions with the original residents. According to stakeholders harmony in reversed integration settings is the highest achievable. They advocate an ‘exclusive’ rather than public space from the confronting confusing expressions of people with intellectual disabilities.

The fourth and last empirical finding of chapter 6 is that government civil servants, institutional policy makers as well as people directly involved point to the responsibility that other parties have for stimulating or facilitating encounters and connections between people with and without intellectual disabilities. The government points with (high expectations) to the leading role of city council members and other local executives; the institutional policy makers point (with rather low expectations) to the leading role of their employees; the newcomers point to the institutional policymakers and the caregivers, and family members, finally, emphasize not only the chief role of newcomers, government, institutional policymakers and caregivers, but also the leading role of people with intellectual disabilities.

According to Goffman the persuasiveness of someone’s role during an encounter is strongly dependant on the context where the performance takes place: the more coherence between both, the more the other participants in the encounter would be willing to accommodate their own performance to ours. Looking at it that way, the conclusion seems justified that the government policymakers on the one hand and people directly involved on the other hand would be able to stimulate mutual meaningful encounters if they would try to accommodate their stories – again and together – on the local contexts of reversed integration settings. Said differently: as soon as the people directly involved would contribute to what would be needed to create space for all the above mentioned roles, it would become inevitable to work creatively and detailed on credible, sympathetic ‘story lines’ for a joint performance, wherein everybody flourishes.

In the dialogue that I constructed with the perspectives from the [government] policymakers and the people directly involved, there is very little agreement about the storyline along which the interactions between all parties could take place. The big question is then which shared storyline – one that is adjusted to the personal characteristics of all the protagonists and the contextual features of the reversed integration stages – would be able to transform this.

Finally, in chapter 7, I discuss and interpret the most important findings of my research. Based upon these findings, I make several suggestions for future research and improvements of care and support practice.

This is not written in a traditional form with conclusions and recommendations, but I present my findings as an ‘agenda for negotiation’ (Guba & Lincoln, 1989 p. 218; see also Abma, 1996, p. 97) I present in this agenda for negotiation controversial items from my data collection, with which the people concerned with reversed integration settings can continue to talk and reflect together. After all, as a responsive researcher I do not have the last word about issues surrounding the research participants, but I want to start and facilitate individual and collective learning processes through connecting their personal stories and interpretations.

The crux of my research is that regarding encounters in reversed integration settings, we tend to shy away from confrontations with uneasy and unavoidable difference. Avoiding, ignoring and steering away from discussions regarding uneasy and confusing otherness of those people with intellectual disabilities does not only occur on a micro level (direct encounters between individuals), but also on a meso level (influence of the care facility) and macro level (government policies).

From the dialogue with Goffman’s dramaturgical perspective we can learn to see that it is a sign of inability and – in a lesser sense – of good will, that the stakeholders without intellectual disabilities avoid the confrontation with the otherness of persons with intellectual disabilities in daily life. Most of the time they do this, after all, because they do not know how to react in an alternative, mutual pleasurable and constructive manner on the displeasure they experience through these interactions. Looking at it from the epistemological perspective of ‘knowledge-construction’ between the original and new neighbours, there is a lot to gain if care facility representatives would allow, encourage or assist this, for example by offering personal communication tips. Remarkable many care facility representatives and also various newcomers report however, that they do not feel challenged and facilitated by a clear, convincing policy from their organization and the government.

Furthermore, the dialogue with Kunnenmans still shows that care workers and newcomers can put aside routines and suffocating protocols by application of individual commitment, initiatives, creativity and courage, and as a result of this, a surprising amount of room is created for interpersonal ‘knowledge production’ and connections. The contemporary realization of the citizenship ideal has limited relevance, because this realization does not facilitate the interaction with the large degree of independence, vulnerability and unpredictability i.e. that which the instrumental logic of the care facility is so busy with each day.

The dialogue with Waldenfels’ responsive perspective (1990/2013, 1997/2013, 2004) stresses that it is impossible not to react to another person’s otherness. This otherness calls our attention before we can help ourselves, and the way we react to the other should be regarded as a reaction to their otherness. From Waldenfels we can also get to know the two most occurring reactions to uneasy and confusing otherness: assimilation or romanticizing. In both cases, we do not think about the fact that our experience with strangeness during the encounter with others, especially...
we can attempt to find fitting answers to the non-erasable and unknowable other by acknowledging that difference, otherness and strangeness are relational concepts, and that this experience does not teach us about the other person. Only after we tell our own stories, express opinions, preferences, strong and weak points, perspectives, lived experience and knowledge of the people directly involved.

This knowledge was essentially dependent on personal, situational, social and cultural influences. In line with Balagangadharat (1994/2005, 2012) and Renders (2012), I conclude that we as social scientists can only gain fundamental knowledge about otherness and difference if we 1. acknowledge the limits of our own occidental thought frameworks and descriptions, and 2. compare these with other personally, societal and culturally influenced perspectives about otherness and difference. Finally, I suggest that field researchers in the sector of care and support for people with intellectual disabilities should employ people with severe intellectual disabilities more often as a benchmark for their research, and I give several examples of ways we could perform this.

In my suggestions for improvements in practice, I advocate for more time and attention for dialogue between various interested parties, and for pursuit for more room for various ways to cope with differences between people with intellectual disabilities and without. This in the knowledge that this space will always be too small and the encounters with people with intellectual disabilities will always expose doubts, uncertainties and shortcomings. However, it is really about the merit and continuing aspiration to get to know one another and to do right. Care and support staff professionals should be better equipped, either together with their clients, or on their own, to make decisions, to ensure and show that people with intellectual disabilities are more than just clients in a care facility. Additionally, care providers should be expected to be more honest with their policies, and their clients, or on their own, to make decisions, to ensure and show that people with intellectual disabilities are more than just clients in a care facility. Additionally, care providers should be expected to be more honest with their policies, and their choices cannot be dependant solely on financial systems from insurance companies, but especially from a continuing open dialogue with people with intellectual disabilities, family members, care workers and neighbours without intellectual disabilities. Finally, the government should not hold care providers solely accountable to numbers, checklists and the physical location of their living and care facilities, but could also challenge them to show that their policy takes into account specifically the perspectives, lived experience and knowledge of the people directly involved.

Voor alles natuurlijk grote dank aan ’s Heeren Loo Zorggroep, Stichting Abrona en Stichting Severinus voor het financieren en faciliteren van mijn onderzoek. Ik ben heel blij met de mogelijkheden die ik hierdoor heb gekregen om kennis te maken met de wereld van de verstandelijk gehandicaptenzorgsector, in het bijzonder in omgekeerde-integratiesettingen. In de afgelopen vijf jaar ben ik me sterk verbonden gaan voelen met die wereld. Ook bedankt voor het financieren van de vormgeving en uitgave van mijn manuscrit in deze mooie vorm en deze bijzondere reeks.

Veel mensen namen deel aan het kennismakingsproces dat vervlochten is met de totstandkoming van dit boek. Daarvoor ben ik ieder van hen dank verschuldigd. Zonder al die ontmoetingen zou dit boek er simpelweg niet zijn gekomen. Omdat het te vaak om iedere betrokkenen hier persoonlijk te bedanken, volgt hieronder een selectie van diegenen welke een rol hebben gespeeld. Veel mensen namen deel aan het kennismakingsproces dat vervlochten is met de totstandkoming van dit boek. Daarvoor ben ik ieder van hen dank verschuldigd.

**Dankwoord**

Allereerst de personen met een verstandelijke beperking die, zonder dat zij daar veel invloed op konden uitoefenen, een dag, enkele dagen of zelfs een week die ‘participerende onderzoeker’ in huis kregen.

Donny, Fleur, Jochem, Marco, Charmene, Ricky, Jean-Paul en Bas van Veld: ik kwam graag bij jullie, vooral omdat het zo gemakkelijk was om lol met jullie te maken.

Henny, Esmeralda, Bas, Cindy en Jody: bij jullie liet mij me op eigen wijze welkom voelen. Jan Willem, bij jou kostte dit de nodige aarzeling maar dat maakte je uiteindelijke verwelkoming alleen maar meer waar.

Cor, Hans, Annie, José, Carla, Marion en Nellie van Hulst: met jullie heb ik gezellig gedineerd en soaps gekeken. Hans, Annie en José, met jullie bracht ik een bezoek aan een repetitie van het zangkoor. Zoveel verschillende stemmen en bewegingen tijdens één samenzang had ik nog niet eerder meegemaakt, het was indrukwekkend.


Esmeralda, Bas, Cindy en Jody: bij jullie op Kerkkakkerstraat 2 heb ik eerst geluncht en daarna lieten jullie me alleen enthousiast en uitvoerig jullie mooie kamers zien. Met drie van jullie mocht ik ook mee naar jullie dagactiviteiten: de bakkerij, de boerderij en de technische dienst. Dat was leerzaam en gezellig.

Judith, Miranda, Elke en Marian, met jullie at ik mee en speelde ik een paar heerlijk