Summary

In contemporary visions on supporting people with disabilities, their own questions and wishes are determining factors. People with disabilities should (be able to) make their own decisions and have influence on their surroundings. Yet, how can this vision be translated to people with severe multiple disabilities? Are they capable of making their own decisions and having influence? And if they are, how would that take shape? These questions were the reason to carry out this study.

In this dissertation we report on a PhD study on room for self-determination for people with severe multiple disabilities. It has a social-constructivist nature and aims to explore and understand social relations and interactions and their influence on the social constructs of those involved. The book consists of eight chapters. The first two chapters are introductory and explore the subject. In chapter three, we focus on the theoretical concepts concerning self-determination, and in chapter four we describe the research methodology. Then, in chapters five, six and seven we report on the results of the study. Finally, chapter eight contains the conclusions and recommendations.

In chapter 1, we describe the changing societal and governmental context in the Netherlands. We discuss the problematic relationship between severe multiple disabilities and self-determination. This difficulty has various aspects. To begin with, policy makers struggle with people’s right to self-determination on the one side, and their right to receive care on the other. People with severe multiple disabilities were at first thought incapable to achieve self-determination over their lives, while policy makers later realized that self-determination might be possible after all, albeit on different terms. Additionally, self-determination as part of one’s quality of life is, for this target group, only sporadically studied or specified. Against the background of on the one hand the dominant discourse of autonomy and self-determination, and on the other hand the problematic reality of severe multiple disabilities, this study focuses on how (important) others – formal care givers, family members and neighbors – perceive and discuss self-determination. The central question is: How do professional care givers, family members and neighbors talk about self-determination for people with severe multiple disabilities?

In chapter 2, we further explore the situation and the characteristics of people with severe multiple disabilities in The Netherlands. The Netherlands has an average of 10.000 citizens with both severe mental disabilities and additional motorial and sensory limitations in various combinations and degrees of severity (Reinders et al., 2011). The seriousness of the disabilities relates directly to a person’s capabilities to communicate, which often occurs on a pre- or protosymbolic level through physical expression (Vos et al., 2010; Velthauz, 1987; Roemer et al., 2014). Additionally, severe disabilities also cause social-emotional problems. People with severe multiple disabilities generally have little opportunity to participate in social settings and are faced with stigma and prejudices (Maes et al., 2007; Reinders, 2010, Nakken, 2011, Fornefeld, 2008). In the past, and even still in current days, the question whether a life with such severe disabilities can be seen as worth living, would often arise (Metz, 1972; Mans, 1998).

Due to the severity of their disabilities, people with severe multiple disabilities need support in every aspect of their lives. Over the years, the way this support takes shape has aligned itself with the way the vision on people with severe multiple disabilities has developed from a medical orientation
through a focus on personal development, towards participation in society as the main goal. Several studies show that people with severe multiple disabilities have barely benefitted from developments in the field of care for the mentally handicapped, such as the increased focus on participation and inclusion. The same applies to the current discourse on being able to make your own decisions and take your own actions. When translated to people with severe multiple disabilities, expecting them to make their own decisions can even be seen as paradoxical and uncharitable. After all, to what extent are they actually free to decide who they want to be and to experience self-determination (Reinders, 2010; Baart & Carbo, 2013)?

In chapter 3, we pay attention to theoretical concepts which are relevant to this study on selfdetermination for people with severe multiple disabilities. We introduce empowerment as overarching framework, and subsequently elaborate on the concept of Quality of Life, in which selfdetermination is one of the domains. We go into the three approaches towards Quality of Life: objective, subjective and interactive. In this study, we mainly focus on the interactive, also known as the dialogical, approach to Quality of Life (Maes et al., 2000). This entails searching for a person’s desires and possibilities to improve his or her quality of life, through dialogue.

Initially, self-determination was seen to be an individual competence. Partly influenced by sociological theories, this view slowly evolved towards the idea that competencies exist in a social context, and that it is necessary to pay attention to people’s dependency on social relations and their need for an inclusive environment. This changed vision in part influenced views on self-determination in general, and on selfdetermination for people with severe multiple disabilities in particular. Self-determination theories also focus on possibilities to develop and evolve, such as learning new skills, increasing knowledge, and experiencing new life events. The general conviction is that society should enable people in an underprivileged position, such as people with severe multiple disabilities, to escape from repression. However, when certain qualities, such as the ability to develop oneself, are dominant in a vision on selfdetermination, they can disqualify people with severe multiple disabilities since the impact of their limitations seems to be too comprehensive (Nussbaum, 2011; Reinders, 2010). In these cases, conversations about self-determination seem to focus mainly on the way ‘important others’ view and judge the life of a person with severe multiple disabilities. Whether a person is given the chance to experience enriching life events that contribute to the development of his or her self-determination seems to depend on the convictions of members of their social network. How do they perceive their own lives and the lives of others, in this case a person with severe multiple disabilities? These perceptions concern meaning and sense-making, and more specifically themes such as freedom (decision-making, autonomy), capabilities (independence, self-reliance) and friendship (relationships and social ties) (Reinders, 2010). A interesting theoretically based hypothesis is that an inclusive context, and the dominant perceptions within this context, influence the extent to which a person with severe multiple disabilities is given space to develop and evolve, and the extent to which he or she has the possibilities to influence (aspects of) his or her own life (Deci & Ryan, 2006). Since self-determination appears to have both an individual and a social, interactive component, aspects of power and power differences should also be taken into account as an influencing, or even determining, factor. Part of self-determination is the ability to resist other people’s influence by offering some kind of counterweight. This thought might evoke discussions concerning the meaning of power when talking about people with severe multiple disabilities, and how and by whom this power is exercised.
Chapter 4 contains a description of the methodology of the study. It has a social-constructivist nature and aims to explore and understand social relations and interactions and their influence on the social constructs of those involved. We explore how informants, individually and in contact with each other, construct their own reality – using interpretation, reflection, and conscious and targeted action – by giving meaning to events taking place around them (Flybjerg, 2001; Goodley, 2011; Korzilius, 2010). The (symbolic) interactionist research tradition claims that these meanings are subject to change, influenced by values, norms, roles and status (Blumer, 1954). These interpretations take shape through negotiation in interaction, and are accepted as self-evident phenomena which have certain consequences. For this study, we included both the interpretation of texts and stories, and the background of these stories. The use of stories stems from the narrative tradition, in which stories are seldom used in a declaratory but more in a descriptive way. This fits well with the exploratory nature of this study (Soools, 2012; Meininger, 2007; Bryman, 2004; Lange et al., 2010). Language is an important tool to gain knowledge on the way social realities are constructed. It can provide insight in social relations, identities, informal ways of communication, and the possible implications.

The general research question of this study is: how do care givers, family members and neighbors discuss self-determination for people with severe multiple disabilities? To answer this question, we included three stakeholder groups: formal care givers, family members and neighbors. We formulated three sub questions: 1. What do formal care givers and family members mean by self-determination for people with severe multiple disabilities? 2. What kind of interaction do neighbors have with people with severe multiple disabilities, and how do they experience this interaction? 3. What are the implications of the answers to the first two questions for people with severe multiple disabilities and their self-determination?

We used several sources (also called a multi-perspective approach). To begin with, we studied daily reports, written by formal care givers, searching for segments touching on influence and self-determination. Secondly, we conducted reflexive interviews with formal care givers and family members, based on video images in which a person with severe multiple disabilities showed initiative or took control. Finally, many short interviews were held with neighbors, which resulted in seventy stories about encounters, about what it means to live together in the same neighborhood, and about changes of ideas and perceptions about human beings in general, and about people with severe multiple disabilities in particular, over time.

All the data were analyzed using the software program MaxQda11. We also paid attention to the quality criteria for empirical research, specifically within the social-constructivist research tradition (Guba & Lincoln, 1994). Two of those criteria are recognizability and credibility, which were strengthened by applying a multi-perspective approach and carrying out collegial checks in both the scientific and the practical field.

In chapter 5, we report on the results of the analysis of the daily reports and the interviews with formal care givers. We focus on formal care givers' perceptions of self-determination for their clients with severe multiple disabilities. We saw two different ways in which formal care givers stimulated self-determination: 1) stimulating initiative, and 2) stimulating choice-making by offering two or
more options. When it comes to the first form, stimulating initiative, formal care givers stress the importance of involving people with severe multiple disabilities in daily activities, motivating them to express preferences, and being responsive to their own initiatives. With respect to the second form, stimulating choice making, Both forms require active commitment, in this case by the formal care giver. In the daily reports, formal care givers also describe spontaneous initiatives by the person with severe multiple disabilities. This often involves new, explorative behavior. Self-determination for people with severe multiple disabilities can be seen as the ability to show targeted behavior, but also requires the ability of the ‘important other’ (the formal care giver) to (correctly) interpret this behavior. Both parties are to some extent expected to be alert. This especially stresses the important role of, in this case, the formal care giver, who may interpret behavior as self-determination or as something else. Formal care givers may also inhibit self-determination, consciously or unconsciously. For instance, they may impose limits on an initiative based on the belief that the person cannot oversee the negative results of this behavior. Imposing limits is often done by confronting or physically constraining a person. Another way of imposing limits is by ignoring signals. This behavior can be seen in care givers who experience chaos and commotion and, as a result, lack the necessary patience or the ability to immediately respond adequately. Consequently, the person with severe multiple disabilities is required to wait for the formal care giver’s attention and alertness.

Formal care givers often fail to be explicit about ways in which they interpret the behavior of their clients. In the end, their interpretations are determined by the consequences of that behavior rather than by the observed behavior itself. Formal care givers appear to barely reflect on this, or discuss this with their colleagues.

Chapter 6 contains the results of the reflexive interviews with family members. We focus on reasons why family members stimulate their family members with severe multiple disabilities to reach a higher level of self-determination, or why they choose to refrain from doing so. We also discuss the roles they see for themselves in this respect. Previous studies show the importance of family members in the lives of people with severe multiple disabilities, when it comes to participation, inclusion and belonging (Gennep, 2007; Brown et al., 2009; Bogdan & Taylor, 1989 in: Van Hove, 2014). Family members can offer chances and possibilities, teach skills, or exploit opportunities for development and growth. Teaching people with severe multiple disabilities new skills requires a relationship based on trust and involvement. With this in mind, we were interested in family members’ implicit ideas, assumptions and thoughts concerning selfdetermination, and the implications for the extent to which people with severe multiple disabilities can have some influence on their own lives. The relationship with a child, brother or sister with severe multiple disabilities is typically a long-term care relationship. While our informants generally experience the relationship with their family members with severe multiple disabilities as meaningful, this cannot be taken for granted. They notice a lack of interest from their social environment when it comes to their disabled family member. The result is a fairly isolated and only minimally supportive network. Our respondents experience the relationship with their disabled family member as beautiful and meaningful, while they also see it as their duty to sustain this relationship. When their disabled family member moves to an institution, this also means having to relate to the formal care givers of that institution. From that moment on, family members try to ensure that care and support are offered in an, according to them, acceptable way. In doing so, they mainly focus on physical care and a safe environment. Teaching their disabled family member new skills, and offering him or her new
experiences, become the formal care giver’s task, at least in the eyes of the family members in our study. Formal care givers and family members often have differences of opinion about ways in which this can be done, for example about the tools they apply or the activities they offer. In this respect, family members explicitly distinguish daily decisions from more fundamental choices, thus accentuating that in their view, self-determination for people with severe multiple disabilities has its boundaries.

It appeared to be difficult for family members in our study to talk about self-determination for their disabled relatives. Thinking and talking about their loved one’s limitations evokes feelings of sadness and mourning about these limitations and about the influence this had on their own lives. Therefore, discussing self-determination feels like putting salt in an open wound. As a result, family members tend to translate the concept as self-determination of the entire family system in the process of raising and supporting their disabled family member, and in its relation to the formal care givers involved.

In chapter 7, we describe our findings concerning the contact between people with severe multiple disabilities and neighbors without such disabilities. We chose to include neighbors in this study because children with severe multiple disabilities increasingly stay at home as long as possible, with a transfer to a small scale facility in a ‘normal’ neighborhood as the next step. This approach is believed to increase and intensify encounters between neighbors with and without disabilities (Overkamp, 2000). The relationship between the two can best be described as one of ‘familiar strangers’. They cross paths on the streets, they see and greet one another. We found that neighbors place importance on people with severe multiple disabilities living in the neighborhood and being visible. According to them, this has educational value for their children and increases their own awareness regarding the vulnerability of life. In general, our informants know little about people with severe multiple disabilities. They tend to compare them with something they do know, such as children and babies, to explain the difference with themselves. To them, people with severe multiple disabilities are pitiful people, unable to act on their own, and they feel sorry for them and their family members. Most of our informants are satisfied with the shallow relationship with their disabled neighbors, and they generally do not feel the need to intensify this relationship. This seems to be partly caused by a self-consciousness because of a lack of knowledge and skills concerning how to interact with people with severe multiple disabilities (Linders, 2010; Bredewold, 2014). Neighbors experience the inability to communicate verbally as an insurmountable problem, it appears to be difficult for them to notice the signals and possibilities to act. Indeed, they assume that people with severe multiple disabilities can barely do anything, let alone show initiative and have some sort of self-determination. Furthermore, they hold family members responsible for sustaining social relations. Obviously, these convictions inhibit more in-depth relationships between neighbors with and without severe multiple disabilities. This is in stark contrast with theoretical convictions stating that social connectedness with a diverse group of people is crucial for experiencing self-determination and control. It is thought that connectedness with other people evokes meaningful and enriching life experiences which contribute to the development of self-determination (Biklen, 2006; Hur, 2006; Barvosa-Carter, 2007; Reinders et al., 2011). In our study, these alleged positive effects were not found, and they seem to be less self-evident when it comes to people with severe multiple disabilities.
Finally, in **chapter 8**, we examine how the results we reported on in the last three chapters relate to each other. We chose three perspectives to look at self-determination (formal care givers, family members and neighbors) because of their differences in genesis, and in the level of involvement in the lives of people with severe multiple disabilities. In the descriptive chapters 5, 6 and 7, we made a vertical analysis per group of informants. In this final chapter, we apply a horizontal analysis, overarching the three informant groups and enabling us to draw some cross-connections.

The theoretical framework for this analysis focuses on the social environment, and on the pedagogical and developmental components of self-determination (Deci & Ryan, 2006). The developmental perspective pays attention to the acquisition and development of skills and capacities as a condition for selfdetermination. The perspective of social connectedness sees a large and diverse social network as an important condition for the development of self-determination. The underlying idea is that the social network knows the person with severe multiple disabilities, and can therefore interpret his or her signals correctly and undertake meaningful activities which might evoke development. The horizontal analysis shows that the network’s reactions depend on the members’ perceptions of people with severe multiple disabilities. Their convictions influence the extent to which they offer the disabled person the possibility to acquire new skills or build new relationships. We found that formal care givers, family members and neighbors mostly talk about self-determination in ways that reflect their perceptions of their own lives, which in turn determine their perceptions of the lives of others, including of persons with severe multiple disabilities (Bogdan & Taylor, 1989). Our study shows that the convictions of these ‘important others’ in fact seem to be the most important determining factor when it comes to the possibilities of selfdetermination for people with severe multiple disabilities.

Self-determination as a concept is rather abstract and cannot easily be shaped within the context of the study. This causes informants to initially declare self-determination to be impossible for the persons with severe multiple disabilities they know. Additionally, neighbors who do not have a personal relationship with the disabled person in their neighborhood, suspect little opportunities for self-determination. We may expect that formal care givers and family members, who are frequently in contact with a person with severe multiple disabilities, have a different view. Our data confirm this. After giving it some thought, formal care givers and family members conclude that, despite some serious limitations, these persons do have skills and capacities to indicate what they need or want. Being able to see and talk about these possibilities requires reflection on one’s own convictions, and people can be invited to do so. Therefore, self-determination for people with severe multiple disabilities seems to primarily be a co-creative process between the person with severe multiple disabilities and the ‘important other’, often the formal care giver. This type of empowerment, the process of increasingly becoming a subject in one’s own life, seems to be in line with the lived reality of people with severe multiple disabilities. When increasingly becoming a subject in one’s life, people gain more room to shape their own lives, together with those around them (Boumans, 2012). Involving other people in this process, however, shows a remarkable dynamic. All the informant groups in this study, including formal care givers, perceive the process of shaping the development of a person with severe multiple disabilities as the formal care giver’s task. Family members mainly see themselves as advocate for the interests of the disabled person, and they feel responsible for making sure that care is provided in a proper way. They focus on good care, preventing pain and discomfort, and avoiding risky situations. This seems to collide with commonly
accepted ideas regarding empowerment, which focus on diminishing dependence, on extending decision-making opportunities (Steenssens & Van Regenmortel, 2007), on gaining control and self-fulfillment (Peterson & Hughey, 2004), and on the process of giving up previous beliefs (Hal, 2012). Empowerment requires the person with severe multiple disabilities and important others to have faith in the formal care givers’ sensitivity and responsiveness when it comes to responsibly taking risks. So, empowerment in this context mainly entails connectedness between a person with severe multiple disabilities and important others, such as family members and formal care givers, and the human dignity and authenticity they allocate to the disabled person. Hence, important conditions for self-determination seem to be: connectedness, a belief in the developmental possibilities of a severely disabled person, and stimulating this development by offering new experiences.

In an inclusive context, a person can feel like he or she belongs there, is part of a community and, to a certain extent, experience social connectedness (Deci & Ryan, 2006). Unfortunately, people with severe multiple disabilities have very limited social networks (Carnaby, 2004; McVilly et al., 2006; Claes et al., 2011). In this study we also found that very few people around a person with severe multiple disabilities know him or her well enough to be able to interpret his or her behavior, and this number even seems to be decreasing. This might cause for the individuality of the person with severe multiple disabilities to only be visible for a few people (Bogdan, 1989). Yet, the respondents in this study do not appear to experience this as a problem, they do not seem to share the idea that social connectedness and a meaningful social network are important conditions for self-determination.

The three groups of informants generally do not communicate with each other when it comes to their interpretations of the behavior of a person with severe multiple disabilities. Subsequently, they cannot adjust their own views based on the other groups’ interpretations. They do, however, base their actions on their own perceptions of what others – people with severe multiple disabilities as well as important others – think, want and feel. They fail to check whether these perceptions are accurate, which means that they do not develop a shared ‘social construct’.

Starting from the theoretical starting point that thoughts and expressions determine actions, we assume that formal care givers’ actions in general will only rarely be consciously focused on detecting, recognizing, stimulating and developing self-determination for people with severe multiple disabilities. Additionally, family members will primarily direct formal care givers towards care and safety (which are also domains of Quality of Life), rather than to the development of autonomy and expressiveness. Family members’ views on care and safety appear to be powerful and incontestable, and overshadow the other Quality of Life domains. So, on the one hand the informants generally believe in the possibility of more self-determination for people with severe multiple disabilities. Yet, on the other hand, they seem to dismiss the necessity of the involved and extended social network that is an important condition for stimulating self-determination. This observation, combined with the dominance of good care and safety over autonomy and decision-making power, leads to the conclusion that the subject of self-determination for people with severe multiple disabilities is more likely to be marginalized even further, than to be addressed and highlighted.

The chapter concludes with a discussion of the insights this study has produced, and of the lessons the field, educators and researchers can learn from it. The recommendations for the field are twofold. On the one hand, they are aimed at restoring and increasing social relations in the broad
sense of the word, with family members but also with neighbors. On the other hand, we make a case for reflection on formal care givers’ and family members’ interpretations, in order to create a more explicit image of the interests and wishes of the person with severe multiple disabilities himself. Additionally, reflection offers formal care givers and family members the possibility to learn from each other. Recommendations for education are focused on raising students’ awareness of their own norms, values, background, interpretation frameworks and visions on what constitutes a good life. Supervision, organized conversation and video coaching can help students to develop new insights and promote their awareness of the impact of their actions on other persons. Also, they offer them the chance to experiment with observing and considering small actions and interactions, and with reflecting on their own actions and on actions of others. Specific recommendations for research aim at drawing attention to the other domains of Quality of Life, such as inclusion, participation and human rights, which are often neglected in research on people with severe multiple disabilities. Additionally, research on extreme, insurmountable differences between people might be interesting, as well as studies on the effect of an extended and involved social network. In this study, we generally saw small and marginally involved social networks, but little is known about the actual added value of qualitatively good social networks on the Quality of Life of people with severe multiple disabilities.