

# Parent initiatives: the next step in deinstitutionalisation?

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A COMPARISON OF SMALL SCALE CARE FACILITIES FOR PEOPLE WITH MENTAL DISABILITIES.

Thesis Research Master in Public Administration and Organisational Science  
Utrecht School of Governance

Margot Hermus  
[mmjhermus@gmail.com](mailto:mmjhermus@gmail.com)  
Student number : 4172655

First supervisor: Margo Trappenburg  
Second supervisor: Paul 't Hart  
Utrecht, 25-01-2016



To my dear friend Marieke

*“On ne découvre pas de terre nouvelle sans consentir à perdre de vue, d’abord et longtemps,  
tout rivage”*

*- André Gide (1925), Les faux-monnayeurs*



## FOREWORD AND ACKNOWLEDGMENTS

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Autonomy and self-reliance are important themes in this thesis. According to our government, citizens of the Netherlands are now living in a participation society. This means that, now more than ever, we are put in charge of our own lives and our surroundings. On the one hand, this opens up many new opportunities to make our own choices. On the other hand, it places us for many new challenges and difficulties. This is not only true for the residents, parents and professionals central to this thesis, but also for me as student, researcher and writer of this thesis.

This thesis, more than ever before, presented me with the opportunities to set up my own research, make my own choices and put everything I have learned in my studies so far in to practice. Although writing a thesis is often a solitary process, I could have never done it alone. I would like to use this opportunity to thank everyone who contributed to this research project.

First of all, I would like to thank my thesis supervisor, Margo Trappenburg, for her advice, guidance and patience. What started with a tutorial, became a long term cooperation, which I very much enjoy. I have learned a lot from you. I thank Paul 't Hart, my second supervisor, for his constructive feedback, that brought this thesis to a higher level.

Rob Jansen, chairman of RPSW de Sleutel, brought me into contact with the community of parent initiatives in Noord Brabant. Rob, your enthusiasm is inspiring and infectious. And last, but certainly not least, I thank the parents, professionals and residents of the parent initiatives and regular care facilities who took time out of their day to talk to me. They told me about their accomplishments, success and happiness as well as their worries, challenges and struggles. I thank all of you for your openness and honesty. Your stories form the heart of this thesis.

Margot Hermus

January 2016



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# CHAPTER 1: INTRODUCTION

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## 1.1 RESEARCH QUESTION AND PURPOSE

Care for psychiatric patients and people with intellectual disabilities has changed significantly over the last 50 years. Patients have been transferred from large institutions into mainstream society. The introduction of new antipsychotic drugs, and the rise of the civil rights movement gave way to the idea that it is possible and desirable to provide care for these patients in the community instead of housing them in asylums outside of the community (Yohanna 2013). This deinstitutionalization movement has a lot of consequences for the patients, their families, the professionals and organizations that provide their care and the community at large.

One of these consequences is the development of different types of living arrangements in the community. Most of them are small scale residential facilities, set up by care organizations (Stainton et al. 2011). In the Netherlands, this diversification is strengthened by health care policies that stimulate self-reliance, designed to facilitate government retrenchment. The government, faced by ever increasing health care costs, is looking to transfer some of its responsibilities onto citizens. This development is called the participation society, which means that citizens are involved in, and even co-owners of public facilities. The government adapts its care facilities to complement the care that can be provided by society - and not the other way around, as has happened over the last few decades: people have become too dependent on the government.<sup>1</sup>

The consequences of this development can also be seen in the care for people with mental disabilities in The Netherlands. New care facilities have emerged, alongside the residential homes provided by traditional care organizations. These facilities are founded by parents that consider the living facilities provided by the government not suitable for their children. Thus far, no systematic research has been done to identify differences between these types of residential settings. The question central to this research is: is there a difference in quality of

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<sup>1</sup> TK, 2014-2015, Kamerstukken, 29 538, nr. 173

care between facilities designed and managed by care organizations or by family members and if so: what causes the difference?

As the participation society gradually takes shape, this question becomes more and more relevant. If the ideal of the government is to include parents, or other citizens, in the caregiving of people with mental disabilities, it is useful to study the different ways they can be involved: participating in small scale facilities that are founded and managed by care organizations or the government (top down), or by setting up and running their own facilities (bottom up). This study provides an insight into the differences between these forms of participation and what this means for the quality of care, the residents, the professionals working in both types of facilities and the parents themselves. On the one hand sociological theory suggests that bottom up initiatives might fare better because people feel ownership towards them and can really mould them according to their own preferences. On the other hand it is difficult and time consuming to establish a care organization and keep it afloat over the years as the founding fathers and mothers of the initiative age and die (Newman and Tonkens 2011; Tonkens and Verhoeven 2012). If care facilities set up and managed by parents turn out to deliver superior care it is important to study whether these parents were extraordinary citizens (e.g. in terms of income, education and resources) so as to find out if this form of participation is available to all citizens and whether it should be seen as a new standard in care provision.

## **1.2 APPROACH**

As the foregoing section has already shown, the care for the mentally disabled has changed a great deal. An illustration of this can be seen in table 1. Two developments can be seen: the move from asylums to community care (deinstitutionalization - arrow 1). These are both public care facilities, the change is in the scale: from large asylums to small group homes in the community. The second arrow signals the development of a new type of community care that is founded not by care organizations but by parents. Both developments will be discussed in this thesis.

*Table 1: Developments in the care for people with mental disabilities*

Type of organization	Scale	Large	Small
Top-down		Asylums	Group homes in community
Bottom-up		---	Parent initiatives in community

Deinstitutionalization, the first arrow, has been studied intensively. In order to provide an overview of all the insights gained by previous studies, a systematic literature review is conducted in this thesis. This review sheds light on the consequences of this development. All studies, published between 2004 and 2014, that discuss the deinstitutionalization of care for the mentally disabled are analysed, in order to identify consequences of this development in terms of quality of life and quality and costs of care. The literature study will also provide insight in the consequences of these changes for the families of the disabled and for society at large. The results of this systematic review can be found in chapter 2.

The second development, the emergence of parent initiatives, has not been studied before. Therefore, this development is the focus of the empirical part of this study. By conducting interviews with parents, professionals and residents from three parent initiatives and three regular small scale facilities for people with intellectual disabilities and/or autism, I provide an insight in the differences between those two types of facilities. In order to do so, I used a theoretical framework, that is presented in chapter 3. Chapter 4 explains the methodological choices made in this thesis. Chapter 5, in turn, provides the findings of my empirical study and chapter 6 presents the overall conclusion of this thesis.

## CHAPTER 2: DEINSTITUTIONALISATION: A SYSTEMATIC LITERATURE REVIEW

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### 2.1 INTRODUCTION

As the introduction in chapter 1 has shown, this thesis discusses two developments - presented in table 1. This chapter is concerned with the first arrow in the table. It provides a systematic review of the scientific literature on deinstitutionalisation in order to answer the following question: What are the positive and negative effects of deinstitutionalisation? I included studies about people with psychiatric conditions and/or intellectual disabilities and I identify not just outcomes for these vulnerable groups themselves but also for their social environment: families, caregivers and the community at large.

In the second half of the 20th century, and more particularly in the last decade of that century, Western psychiatry underwent a significant change. For the most of the 19th century and the first half of the 20th century, the number of patients with psychiatric illnesses and mental retardation that were institutionalized increased rapidly. Partly because the incidence and prevalence of psychiatric disorders increased, partly because the available treatments left little room for patients to function in society (Ravelli 2006: 1). This changed in the 1950s with the emergence of the deinstitutionalisation movement. This movement started in England, the USA and Italy and spread rapidly to the remainder of continental Europe, Scandinavia and the Antipodes (Novella 2010). Deinstitutionalisation means that disabled persons no longer live in institutions, but are included in mainstream society. They reside in ordinary neighbourhoods, in sheltered living facilities if necessary, and integrate in society as much as possible (Bouras and Ikkos 2013; Hamden et al. 2011)

Multiple causes of this significant change in mental health care have been identified in the literature. The first is the development of effective psychotropic drugs in the 1950s (Becker and Kilian 2006: 9). These enable patients to live a relatively normal life in the community, supported by outpatient care facilities. The second cause was the emergence of a civil rights paradigm for people with disabilities. It states that people with disabilities should be treated

in the least restrictive environment possible. That is, if possible, individuals should be supported to be included in the community. This is also described as the normalization principle. This principle is affirmed by the United Nations member states in the United Nations Convention on the Rights of Persons with Disabilities (Chow and Priebe 2013; Overmars-Marx et al. 2014). Large institutions are supposed to cause a high degree of dependency among their patients. Patients who receive long-term care in institutions become hospitalized and thus unable to take control of their own lives, which precludes social integration (Novella 2010: 223; Trappenburg 2013: 3).

In addition, the dynamics of institutionalized care create an environment where patients are at risk for (sexual) abuse: they are not only vulnerable, but become completely dependent on staff, isolated from the outside world and lack credibility. Staff members are in charge of defining the rules in an institution, and their dependency makes patients even more sensitive to reinforcement strategies (Crossmaker 1991). Thus, the secluded environment, with clear structures and routines and many support for patients who have difficulty controlling their lives in the community, could provide security, but also includes additional risks of abuse for an already vulnerable group. Community psychiatry, on the other hand, supposedly emphasizes recovery and rehabilitation, thus furthering the social integration of patients (Novella 2010; Bouras et al. 2013). A third cause of deinstitutionalisation is cost reduction. The high costs of institutional care are considered too high to bear for society (Parker 2014; Chow and Priebe 2013; Yohanna 2013).

Hence there is a clear trend away from institutional care and towards community care both for people with psychiatric conditions and for people with intellectual disabilities (Chow and Priebe 2013; Nicaise et al. 2014; Kunitoh 2013; Novella 2010). Although there are various differences in approach, time of onset and pace of the reforms in different countries, there is a widespread trend of closing large mental hospitals and developing some form of community mental health care (Fakhoury and Priebe 2007; Becker and Kilian 2006). Therefore, it is of great relevance to identify the positive and negative consequences of this development.

Section 2 will describe the methods used for this study. Sections 3 and 4 present the findings: positive and negative consequences will be discussed. Section 5 reflects on these outcomes and thus provides answer to the central question of this chapter: what are positive and negative consequences of deinstitutionalisation?<sup>2</sup>

## 2.2 METHODS

In order to answer the research question, a literature search was conducted. The process is depicted in the flow chart in figure 1. In the first phase, I searched Pubmed and Online Contents using the search terms deinstitutionalisation (3718 hits) and deinstitutionalisation (172 hits). In order to make the amount of articles manageable, the search was limited to the last ten years, i.e. 2004 – 2014 and to articles written in English or Dutch. This limited the total amount of hits to 342 that seemed relevant for our research question. From these articles, titles and abstracts were studied, after which 29 articles remained in the selection. Inclusion criteria were (1) article describes (a) consequence(s) of deinstitutionalisation, (2) in Western cultures and (3) the target group(s) include people with mental illness and/or intellectual disability. In analysing the results, articles focusing on social integration seemed underrepresented. This might be a consequence of the search terms that were used and the databases that were searched.

Thus, in phase 2, I searched the databases Pubmed, Online Contents, Sociological Abstracts and Scopus, using the search terms social inclusion and disabled. The initial search gave 326 results. Limiting the search to English or Dutch articles published between 2004 and 2014 resulted in 203 potentially relevant articles. From those articles, the abstracts were studied using the same inclusion criteria as mentioned above and double articles were excluded. 23 Articles remained in the selection. These articles provided relevant information about the social position of people with mental illness or intellectual disorder, but provided little insight in the consequences for the other people in the community. Phase 3 consisted of a search in Scopus, using the search terms community, neighbour, neighbour, disabled and disability (1617 hits). When limited to articles published in English or Dutch between 2004

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<sup>2</sup> This chapter is a result of a cooperative project with Margo Trappenburg and Femmianne Bredewold.

and 2014, 910 hits remained. After studying the abstracts of those articles, using the same inclusion criteria and removing the double hits, 17 relevant articles were included. This resulted in a total amount of 73 articles.. The included articles will be analysed closely in order to determine the consequences of deinstitutionalisation for people with intellectual disability and/or mental illness. An overview of the included articles can be found in table 2.

Figure 1: Flow chart

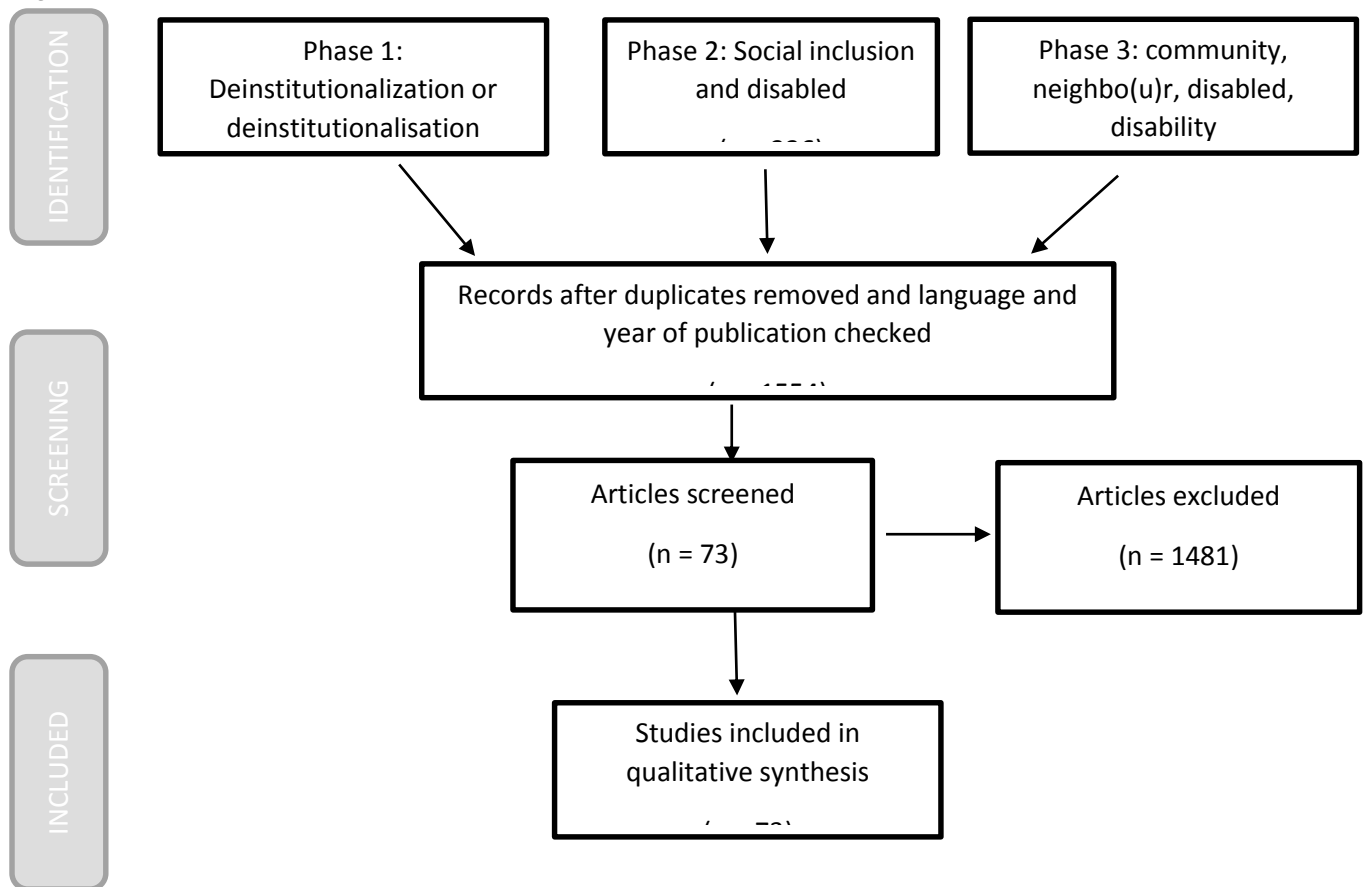


Table 2: Included articles, organised by target group and type of study

	Mentally ill	Intellectual disorder
Empirical study	Basta et al. 2013	Gray et al 2014
Quantitative	Csipke et al. 2013	Bertoli et al. 2011
	Raphael and Stoll 2013	Martinez-Leal et al. 2011
	Short et al. 2013	McConkey & Collins 2010
	Davis et al. 2012	Ouellette-Kuntz et al. 2010
	Forrester-Jones et al. 2012	Slayter 2010
	Killaspy et al. 2012	Bigby 2008
	Sealy 2012	McConkey 2007
	Livingston et al. 2011	Forrester-Jones et al. 2006
	Killaspy et al. 2011	Hall & Hewson 2006
	Saz-Parkinson et al. 2011	Tossebro & Lundebj 2006
	Kramp & Gabrielsen 2009	Young & Ashman 2004a
	Yoon & Abramowitz et al. 2008	
	Nilsson & Logdberg 2008	
	Psarra et al. 2008	
	Picardi et al. 2006	
	Arvidsson & Ericson 2005	
	Heila et al. 2005	
	Kalucy et al. 2005	
	Teplin et al. 2005	
	Sealy & Whitehead 2004	
	Simpson et al. 2004	
	Thiblin et al. 2004	
	Wallace et al. 2004	
Empirical study	Nicaise et al. 2014	Rossow-Kimball & Goodwin 2014
Qualitative	Martinsson et al. 2012	Wiesel & Bigby 2014
	Hamden et al. 2011	Power 2013
	Singh & Castle 2007	Wiesel et al. 2013
	Toib 2006	Hall & McGarrol 2012
		Dusseljee et al. 2011
		Adolfsson et al. 2010
		Van Alphen et al. 2010
Literature study	Parker 2014	Overmars-Marx et al. 2014
	Chow and Priebe 2013	Amado et al. 2013
	Kunitoh 2013	Duggan & Linehan 2013
	Yohanna 2013	Bigby 2012
	Machado et al. 2012	Wang 2012
	Chan 2011	Hamelin et al 2011
	Knapp et al. 2011	Gleeson 2010
	Novella 2010	Kozma et al. 2009



	Bruffaerts et al. 2008 Gostin 2008 Salokangas 2007 Schmetzer 2007 Bigby & Fyffe 2006	Emerson 2004 Young & Ashman 2004b
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The findings from these studies are divided in two ways. A first criterion was whether the study described (a) positive or negative consequence(s). Then, within these groups, articles were categorised by type of consequence. The categories were created inductively; they are not necessarily exhaustive, but provide an overview of the research included in this chapter. The categories can be found in table 3.

*Table 3: Effects of deinstitutionalisation*

Positive effects	Negative effects
Improvement quality of life	Effects on (physical) health and well-being
Social inclusion	Redistribution within target groups
Adaptive behaviour	Criminal behaviour and victimisation
Better quality of care	Increased care burden family members
Economic benefits	Disappointing financial consequences

As becomes clear from this table, several categories are used in this study. These categories are based on the included articles and the topics they discuss. Looking at the table, one can see the following categories: quality of life (including physical health), quality of care, integration in society (and accompanying risks of criminal behaviour and victimisation), the care burden of family members and economic consequences. Deinstitutionalisation is a comprehensive phenomenon, that has consequences on many terrains. In this literature review, I have looked at the terrains discussed by the included articles. This does not rule out that there are any other consequences, both positive and negative, but that would need to be determined by further research.

In terms of generalizability of the findings of the studies, it is important to acknowledge that most of the included studies are limited in terms of target group, type of residential facility, outcome measure / studied effects and time period. In addition, studies come from a variety

of Western countries. The specific effects mentioned in table 3 are all covered by multiple articles, which allows for some degree of comparison in the extent and direction of the effect. Comparing articles from different categories proves more difficult, especially when studies are limited in geographical location, target group and type of residential facility.

Appendix D provides a more detailed summary table of all included studies. The studies are ordered by the effect they describe. The table attempts to shed light on the evidence that studies provide for their statements, either in term of number of studies cited (in the case of literature studies) or by mentioning the research method and amount of participants (for empirical studies). In addition, the table provides the main findings and conditions to obtain these results.

Even then, it remains difficult to isolate the influence of deinstitutionalization and combine this to a generalized picture of the effects of deinstitutionalization, since the studies are so different in goals, subject, geographical location (which in turn influence care configuration) and research method. This is a limitation of this study. In order to effectively synthesize findings from different studies, it would be necessary to limit the variation of studies, or to do separate reviews on all of the mentioned effects. However, for the purposes of this research, an indication of important themes when studying deinstitutionalization is most important, and this chapter serves that purposes more than adequately.

## **2.3 POSITIVE EFFECTS OF DEINSTITUTIONALISATION**

Table 3 presents an overview of the various effects of deinstitutionalisation. Before discussing the positive consequences into detail, it is necessary to make a general observation. Many of the positive effects that are found, require a well-functioning community care system. For example, Knapp et al. (2011) state that community care is more cost-effective, but only when it is properly set up and managed. Kozma et al. (2009) found that community care generally offered more choice and opportunities for self-determination, but add that staff practices and empowerment are crucial to reach this result. The community care system thus needs to meet certain requirements in order to reach these positive effects. These requirements are for instance in terms of availability and accessibility of care – as to

ensure mentally ill people do not have to go back into institution when they need (more) care – but also in terms of quality of care: e.g. types of support that are needed to facilitate self-determination. The positive effects, mentioned in the following sections, show what the results a good functioning system of community care can have.

### **2.3.1 Improvement of quality of life**

One positive effect of deinstitutionalisation seems to be the improvement of quality of life of people with disabilities. While authors use different definitions of quality of life and various measurement-scales, the following domains are generally used: 1. Physical domain or living conditions 2. Social relationships/social networks 3. Well-being or psychological conditions 4. Community access. I report some of the main outcomes according to these studies.

Picardie et al. (2006) found that the quality of life of people with psychiatric problems, living in residential facilities, is not significantly poorer than their counterparts who live independently or with their families. Many other studies, who compared the situation before and after deinstitutionalisation, found an increase in quality of life. Young & Ashman (2004b) found that deinstitutionalisation improves quality of life, because it improves the standard of residential accommodation, it increased opportunities for life routines and community access and the development of wider social networks. Bigby and Fyffe (2006) found a significant improvement of living conditions after deinstitutionalization. Accommodations improved, which is obvious considering people with mental disabilities moved from large institutions - where they often shared a room - to new, smaller houses, which offer more privacy and space.

Quality of life has not only changed for people who already were in the mental health care system. Sealy (2012) took a broader perspective and looked at the mental health of the whole community in Canada. From 1998/1990 to 2002/2003, individuals with higher levels of psychological distress more often accessed mental health services. Sealy attributes this to deinstitutionalisation, because this led to a greater availability of community-based mental health services. Community-based facilities enable citizens to seek help without significant travel or being separated from their social support network.

### **2.3.2 Social inclusion**

As stated before, deinstitutionalisation is more than the closure of large congregate care facilities for people with disabilities. Social inclusion and participation in the community are central to deinstitutionalisation. The development of an individual's network of informal social relationships is one of the key means of achieving these aims. An informal social network is supposed to meet social, emotional and instrumental needs of people with disabilities. Social networks can be seen as the vehicle through which informal social support might be exchanged (Bigby 2008, p.148).

When it comes to social inclusion of people with disabilities the outcomes, found in this literature review, are varied and ambiguous. Various authors are positive about the social inclusion and conclude on the basis of literature review that people who live in the community have larger social networks and more friends than people in institutions. Their networks should be larger, but also include more members who are not staff, nor family or others with disabilities. They suggest the closer the living arrangements approximate to independent living, the larger and more active the social networks (Kozma et al. 2008, p. 1951; Young and Ashman 2004a p.22; Emerson 2004; Duggan and Linehan 2013; Mc Conkey and Collins 2010a; McConkey et al. 2007).

Despite these reported positive outcomes, other researchers are not so optimistic when it comes to the social networks of people with disabilities. The studies of Duggan and Linehan (2013), Forrester-Jones et al. (2006), Forrester-Jones et al. (2012) and Amado et al. (2013) indicate that people with disabilities tend to have small social networks typically comprising paid caregivers, family members and other people with disabilities. Staff members when included comprise a considerable proportion of the network.

Bigby (2008) found that some of the deinstitutionalized patients did not have any living family members left. Friendships with non-co-resident friends or people without intellectual disabilities decreased over-time and the initial increase in informal network size and family contact after the relocation was not sustained. However, a small portion of people with ID

managed to form new friendships in the community. Another small group had a key informal person in their network who kept in touch and actively checked their well-being.

Dusseljee et al. (2011) investigated the variation in community participation in the domains work, social contacts and leisure activities among people with intellectual disabilities in the Netherlands. A number of categories of people with ID were distinguished including accommodation type. With respect to accommodation type they suggest that people that lived in campus settings had a much lower percentage on 'having paid work' and social contacts with neighbours with ID compared with people that live in non-campus settings (p.14). This seems to be positive, but might be explained by the fact that more people with moderate ID lived in a campus setting compared with people with mild ID.

As it has been argued that an important determinant of the success of community living efforts is the attitude of the public towards individuals with intellectual disability and their presence and involvement in the community, Ouellette-Kuntz et al. (2010) measured the social distance of adults in Ontario Canada towards people with intellectual disabilities. Social distance is defined as the distance between people that accounts for sympathetic understanding. A large social distance is the result of less emotional intimacy or of the presence of social prejudice. The results of the study indicate that, overall, participants seemed to hold remarkably positive attitudes towards individuals with intellectual disability; meaning that social distance could be limited, which in turn increases chances for social integration of people with intellectual disabilities.

Several demographic characteristics of participants predicted a tendency to desire greater social distance from persons with intellectual disability. Older and less educated participants held attitudes that reflected greater social distance. Participants who had a close family member with an intellectual disability and those who perceived the average level of disability to be mild expressed less social distance. This could indicate that as people become more familiar with people with intellectual disabilities, they could also hold more positive attitudes, meaning that deinstitutionalisation could diminish social distance, thus possibly improving the position and social inclusion of people with ID in the community.

### **2.3.3 Adaptive behaviour**

Living in society requires certain skills like self-care, independent functioning, taking responsibility, self-direction, and social skills. Several authors studied the improvement of adaptive behaviour of people with disabilities after their relocation (Kozma et al 2009, Chow and Priebe 2013; Kunitoh, 2013; Young et al, 2014b). Kunitoh (2014) reviewed recent literature, in order to understand the influence of deinstitutionalisation on discharged long-stay psychiatric patients. His study found that people who received rehabilitation training, improved on social functioning. Deinstitutionalized patients who did not receive any training, did not improve. Kozma et al. (2009) had similar findings, and found in addition that people who remained in institutions or other congregate settings were more likely to experience a decline, whereas movers maintained or improved their abilities – depending on the quality and characteristics of the facilities they live in.

Young and Ashman (2004b) followed people with an intellectual disability over a two year period as the institution in which they had lived was closed. The outcome of this research shows initial increases in adaptive behaviour. But after two years these are beginning to plateau in some areas, namely at the domains economic activity, domestic activity, responsibility. That's why they conclude there has been no increase in adaptive skills that encourage independence and self-reliance. Young et al. (2004b) suggest that this is caused by the over-controlling or bad functioning of staff (p.39-40): although people learn new skills, the opportunities to use them, or to develop further, are limited by the staff either out of protection or because of inadequate capabilities or resources.

This aspect of over-controlling off staff is also coming up in the study of Chow and Priebe (2013). They suggest according to their literature review, that adaptive behaviour to services can also be found in specialized community care services. There people with disabilities, can also remain to rules and restrictions imposed by staff as if contained in old fashioned asylums. They also point that some patients flourish in hospital setting, due to the isolated nature (Chow and Priebe 2013: 10-11). In short, it seems that deinstitutionalisation can result in better adaptive behaviour, if the residential facilities and care programs are designed to support this goal.

#### **2.3.4 Better quality of care**

While in various articles authors do consider that the quality of care (better therapeutic environment, treatments and interventions, social interface, self-management and autonomy, living environment, human rights, recovery based practice) is improving for people with disabilities after their discharge to community (Singh & Castle 2007; Parker 2014) I only found two studies in which the quality of care is measured (Killaspy et al. 2012; Young and Ashman 2004b) . Both conclude that care in community facilities was better than in hospital units. The difference is mostly explained by the fact that community facilities provide more space for autonomy and choice-making. Killaspy et al. (2012) state there is a direct link between the quality of an institution and its service user's experiences of care and autonomy.

#### **2.3.5 Economic benefits of deinstitutionalisation**

While it was believed that grouping people together in large numbers with qualified staff was the also the most cost-effective way to provide treatment and support, research of Knapp et al. (2011) suggests that this is not the case - when they related the costs to the quality of care both types of facilities deliver. Knapp et al. (2011) conducted a systematic literature review, collecting empirical data on the consequences of deinstitutionalisation in the UK, Germany and Italy, and supplemented these findings with interviews with experts from all three countries. Subsequently, they compare five categories of studies: (1) studies that compare hospital and community settings at a specific point in time; (2) studies that follow the transition of patients from mental hospitals to community facilities; (3) studies that identify differences between types of provider (state or non-state), (4) studies of service models that aim to decrease hospital admission and stimulate care in the community and (5) studies of cost variations.

Their conclusion is that "community based models of care are not inherently more costly than institutions, once account is taken of individuals needs and the quality of care. The new community-based care arrangements could be more expensive than long-stay hospital care but may still be seen as more cost-effective because when properly set up and managed, they deliver better outcomes" (Knapp et al. 2011: 113). They also state that low-cost institutional services are always delivering low-quality care. Most empirical, economic studies used in

this research are English. There was very little economic research on mental health care before the late 1980's - but by then, most psychiatric hospitals in Italy had already closed. However, experts from Italy and Germany saw no reason to believe that the conclusion from UK evidence are not relevant for their countries (Ibidem: 122). Since these countries have different care systems and socio-cultural backgrounds, findings can be cautiously applied to other countries. This is also supported by other studies presented in this chapter: in order to reach the positive outcomes described above, community care needs to be of good quality and provide various types of support. This fits with the idea that it might do more costly, but also produce better quality of care.

## **2.4 NEGATIVE EFFECTS OF DEINSTITUTIONALISATION**

Deinstitutionalisation does not work miracles and it seems to come with unintended side effects. This literature review showed six categories of negative findings: negative health or well-being effects among the target group; redistributional effects within the target groups (i.e. better outcomes for part of the group go to the detriment of others within the same group); negative aspects for family members; criminal behaviour among the target group; victimization of members of the target group and disappointing financial outcomes.

### **2.4.1 Negative health or well-being effects**

Salonkangas et al. (2007) did a review of studies into the physical health of deinstitutionalized schizophrenia patients. They found that physical illnesses among them are highly prevalent and often remain undetected. Schmetzer (2007) found an increase in the prevalence of HIV and hepatitis among patients with a psychiatric diagnosis. According to Bertoli et al (2011) and Yohanna (2013) health needs among people with mental disabilities are not being met.

Two studies (Slayter 2010; Schmetzer 2007) found an increased chance of substance abuse among deinstitutionalized mentally ill patients. Other studies report an increasing number of visits to emergency care (Kalucy et al. 2005) or emergency psychiatric care facilities (Bruffaerts et al. 2008; Saz-Parkinson et al 2011). According to Machado et al. (2012) who did a review study into readmissions to hospitals of deinstitutionalized schizophrenic psychiatric patients turn into revolving door patients: patients that leave a psychiatric



hospital only to return shortly thereafter and live alternately in mental hospitals and in the community. Livingston et al. (2011), however, who did an empirical study with 335 psychiatric patients in Canada, found that most patients remained in community care, suggesting that the revolving door phenomenon could be related to the configuration of community care. Four studies (Yoon and Bruckner 2009; Heila et al. 2005; Matheson et al. 2005) report increasing suicide numbers, especially among schizophrenic patients, or a slight increase in the number of isolated deaths (Thiblin et al. 2004).

Four studies found social isolation among deinstitutionalized patients: Nilsson and Lögdberg (2008) looked at the fate of schizophrenic patients in Sweden and found that they were prone to substance abuse and social isolation. Martinsson et al. (2012) did a small scale, in depth research on the well-being of elderly people with intellectual disabilities in Sweden. They found that their elderly respondents felt powerless, vulnerable and disrespected at times. Hall and Hewson (2006) did a longitudinal study among people with intellectual disabilities in the UK. Shortly after leaving residential care they were an isolated group. Ten years later the researchers found no significant improvement.

#### **2.4.2 Redistribution within target groups**

Several studies conclude that community care is less suitable for the most severely affected members of the target groups. Novella (2010) and Davis et al. (2012) found that community care is mostly beneficial for the less severely afflicted. According to Davis et al. who investigated the fate of former residents after deinstitutionalisation seriously mental ill patients are often reinstitutionalized in less suitable institutions such as prisons and nursing homes. Arvidsson et al. (2005) studied psychiatric care use after deinstitutionalisation in one Swedish district. They report that good care for schizophrenic patients was accompanied by a decrease in care for patients with other psychiatric needs. Csipke et al. (2013) found a market deterioration of inpatient care during fifty years of deinstitutionalisation in the UK. Possibly deinstitutionalisation of patients goes to the detriment of those remaining in residential care who were offered less activities than their predecessors fifty years ago.

### **2.4.3 Criminal behaviour and victimization**

Several studies point out that deinstitutionalisation may lead to, in terms of Gostin (2008), “new places of confinement”. Former patients no longer waste away in residential care but spend a large part of their lives in prison instead. Thus Abramowitz et al. (2008) report a substantial increase of psychiatric treatments in prison after deinstitutionalisation in both Israel and Western Europe. Kramp and Gabrielsen (2009) found a significant correlation between deinstitutionalisation and the rise of crime (notably arson and homicide) in Denmark; they argue that schizophrenic patients are guilty of the crimes for which they are committed but also victims of a deficient system of mental health care. Schmetzer (2007) reports a rise in violence, citing studies that show that the amount of people with mental disabilities in prisons and jails has risen in the United States and that more people with psychiatric disorders, who live in the community are arrested for a crime. Drugs and substance abuse play an important role in these arrests and convictions, and, as stated above, deinstitutionalization has led to increased substance abuse problems of the mentally disabled due to easy access in the community.

Wallace et al. (2004) studied criminal records and found a rising number of convictions among schizophrenics in Australia and Raphael et al. (2013) a high prevalence of mental illness in US prisons. These findings suggest that mentally disabled who live in the community risk ending up in prison or jail instead of receiving treatment which could prevent their crimes. Toib (2006) and Psarra et al. (2008) argue that extra forensic care and police training are necessary so as to take proper care of the mentally ill, since police officers do not always know how to deal with this target group. Before the mentally disabled lived in the community, police officers had less dealings with them. Now, they are more often presented with nuisance complaints or suicide attempts and need additional training to deal with these issues.

Three studies found that people with psychiatric conditions became victims of crime after deinstitutionalisation. Short et al. (2013) compared schizophrenic patients with ordinary citizens in Australia and found that the mentally ill were much more likely to become

victims of crime; similar findings were reported for the US by Teplin et al. (2005). Schmetzer (2007) also points at the possibility of victimization.

#### **2.4.4 The burden of care: family members**

Several studies observe that people with psychiatric conditions and/or intellectual disabilities do not easily integrate in the community. Wiesel et al. (2013) observed encounters between people with intellectual disabilities and others and found no genuine convivial encounters. In another Australian based study Wiesel and Bigby (2014) found that people with intellectual disabilities are often ignored excluded in the social realm. Rossow Kimball and Goodwin (2014) found that 'normal' people in a Canadian leisure centre hosting a Retirement For All program did not feel they should include people with intellectual disabilities in their activities, not even when urged to do so by the centre's staff. Several studies found that people with intellectual disabilities tend to have small networks (Hall & Hewson 2006) consisting of professionals, other people with disabilities and family members (Duggan and Linehan 2013; Van Asselt-Goverts et al. 2013).

Van Alphen et al. (2010) found that 'normal' people have a hard time coping with people with intellectual disabilities as their neighbours. They have to put up with strange behaviour and odd noises; thus do not easily become friends with their neighbours; tolerating them seems taxing enough. Given this lack of enthusiasm for people with disabilities in society at large it seems understandable that family members often resist deinstitutionalisation, as Tossebro et al. (2006) found. Basta et al. (2013) found in a study in Crete (Greece) that when the psychiatric hospital was closed most patients returned home, to their families which significantly increased the burden of care for family members, as a large majority of the former patients did not find any employment. Wang (2012) and Chan (2011) also found an increased burden on family care givers, as did Gray et al. (2014) who specifically researched parents of adults with intellectual disabilities in Australia. They conclude from their findings: "Parents caring for their adult child reported high levels of mental health problems and dissatisfaction with the long-term care arrangements for their child."

#### **2.4.5 Disappointing financial consequences**

A few studies in our data set report slightly negative financial outcomes of deinstitutionalisation. Two studies found that the level of care for people with intellectual disabilities strongly influences their health (Martinez-Leal et al 2011, in a comparative study in Europe) and adaptive behaviour (Hamelin et al. 2011). Knapp et al. (2011) did a systematic review on the economic aspects of deinstitutionalisation and conclude that community care may be better for former residents but does not lead to great savings. Sealy et al (2004) report that decreased spending on hospital care in Canada is equalled by an increase in spending on community care. Power et al. (2013) argue that special places for people with disability are very important and should not be abolished to save costs. Although these are not outright negative results, it is necessary to stress in addition that many studies point out that adequate community care requires additional costs.

### **2.5 CONCLUSION**

In this study, we have attempted to shine a light on both the positive and the negative consequences of the deinstitutionalisation of people with mental illnesses and/or intellectual disabilities. The foregoing sections show that deinstitutionalisation has both positive and negative sides.

Several studies have found that deinstitutionalisation improves quality of life – i.e. quality of living conditions, social relations, well-being and community access - of the mentally disabled. Quality of care has also increased, mostly because community care allows for a higher level of autonomy and choice-making than hospital care. Deinstitutionalisation is however more than a new system of care. It involves a aspiration to incorporate people with mental disabilities into the community.

Locating people with mental disabilities in the community has large implications for them, their families and the community at large. Mentally disabled people who live in the community more often have paid jobs and contact with neighbours. Their social functioning improves. A subgroup even makes new friends in the community. The more their living arrangements approximate independent living, the more chance they have on a large and

active social network. However, these positive effects are quite possible not achievable for all people with mental disabilities: the people living in these less restricted settings, are those with less severe disabilities. Part of the people with mental disabilities become revolving door patients in mental hospitals, or worse: end up in the criminal justice system. Because community care becomes the main focus, patients who remain in institutions are worse off.

Living in the community provides this target group with risks they were previously sheltered from, such as undetected (physical) health problems, substance abuse problems, social isolation, victimization of crimes and isolated death. They make more visits to emergency (psychiatric) care. Families of deinstitutionalized patients often resist deinstitutionalisation because their care burden increases significantly, which can lead to mental health problems for caregivers. For the broader community, mental health care has improved: community (mental health) care is more accessible and available for everyone to use. On the downside, other citizens have difficulty coping with mentally disabled neighbours, who cause nuisance. These patients do not integrate well into society and some studies suggest a rise of crime committed by the mentally disabled.

In short, a properly functioning community care system can provide (part of) the mentally disabled with better adaptive behaviour, more community access and thus more opportunities for choice-making, autonomy and new social relations. However, it also opens them up for risks they previously sheltered life protected them against, such as social isolation, crime victimization and poor physical health. The burden for these developments falls on the people with the most severe mental disabilities, for whom community care seems not the best option and whose hospital care has worsened; families, whose care burden has increased and the community at large, who has difficulty living with the mentally disabled in their midst and risks nuisance or even higher crime rates.

This chapter provided an overview of positive and negative effects that have thus far been identified. Due to the broad range of studies included in this chapter, it is difficult to pinpoint the extent of the effects. Different configurations of (community) care in different countries, is quite possibly of great influence on the outcomes of deinstitutionalization. More

broad studies, that aim to identify all possible consequences, would be useful in determining the relationship between the configuration of care and the consequences for patients and for society at large. In addition, more long term studies are necessary, that can show how the situation develops over time and whether effects are permanent or change over time.

## CHAPTER 3: THEORETICAL FRAMEWORK

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### 3.1 INTRODUCTION

This chapter will lay the theoretical foundation for the second, empirical, part of the study – the second arrow in table 1 in chapter 1. In chapter 2, the systematic literature review provided an insight into the consequences of deinstitutionalisation. The objective of this study is to ascertain whether there are differences in terms of quality of care between parent initiatives and residential facilities founded by care organizations, what causes these differences and what the implications of these differences are.

This chapter consists of three parts. Section 3.2 introduces parent initiatives, by looking at who starts them and why. Section 3.3 provides an overview of possible differences between parent initiatives and regular residential facility. Section 3.4 provides a short summary.

### 3.2 PARENT INITIATIVES: WHO AND WHY?

Parent initiatives are a specific type of citizen initiatives. Citizen initiatives are a new type of volunteering organisations, usually focused on a specific area and/or topic. Most citizen initiatives are born out of frustration and/or disappointment with the living conditions in the neighbourhood, the (quality of) public facilities, or the way decisions are made (Van Stokkom and Toenders 2010: 113; WRR 2012). Citizens are involved because they identify themselves with the goal or cause of the organization, often on a local level. Informal contacts are important, in order to be connected to local networks. (SCP 2009; van de Wijdeven et al. 2013: 12). Citizen initiatives are founded to fit a local need and are thus organized to adapt quickly to changes in the local environment or in the lives of the involved citizens (Denters et al. 2013: 213).

Most successful citizen initiatives consist of a small, tight knit group of citizens who are very much alike in character, background and/or views. Thus, they create an initiative that is focused on their own group, where traditional volunteering organisations often provided services for people outside the group of volunteers (Uitermark 2014: 11, 22). This similarity

in character, background and/or views is a useful: since citizen initiatives are usually focussing on a specific goal, a shared vision increases the chances of success (Van de Wijdeven et al. 2013: 25; Fung 2004: 1-2). In addition to having a shared vision, citizens need to be able to organize themselves well, and they need to be able to make investments. Since every member of this group thus becomes invested in the project, they become privileged – the initiative thus becomes exclusive. Citizen initiatives thus benefit from homogeneity and exclusivity (Uitermark 2014: 11-22). For parent initiatives, this means that the chance of success is greater if children are only allowed to live there if their parents invest in the facility, and if parents have a shared vision.

A commonly cited problem with citizen initiatives is then that citizens that do participate are usually older, highly educated men (SCP 2014: 13) – and that thus, initiatives are only set up for their interests. Research in different neighbourhoods in Enschede showed a relative overrepresentation of citizens with medium education levels, instead of highly educated citizens. Active citizens generally have a broad network in the neighbourhood and a strong connection with the neighbourhood, often because they own a home and/or have children (Denters et al. 2013).

However, people with higher social and economic standing are still overrepresented. Mostly because their overrepresentation is more likely caused by them having more capacities and opportunities to participate. These citizens have more resources, not only in terms of money and education level, but also in terms of civic skills. Citizens that not only have those skills, but also a strong sense of self-confidence are more likely to use those skills and become active (Van de Wijdeven et al. 2013: 22-3). Successful active citizens know the relevant institutional frameworks and have access to policy- and professional networks. In addition, they have an entrepreneurial spirit, a large dose of enthusiasm and perseverance and they are able to establish and sustain connections with citizens, volunteers, professional organisations, civil servants and politicians (Jager-Vreugdenhil 2014).

These civic skills not only contribute to the success of the initiative, they can also increase motivation to start one, as explained by the model of Verba, Scholzman and Brady (1995).



This model explains citizen's motivation to participate by the expected efficiency – the expected proceeds weighed against the expected investment – and by three types of gratifications: civil, social and material. These gratifications are benefits citizens expect to receive from participating. Someone with high civic skills is likely to estimate his proceeds higher than someone with low skills. Motivation for starting an initiative is not only wanting a change, but also believing you can achieve it – with a reasonable investment of resources.

In addition to skills and motivation, citizens have different attitudes when it comes to (active) citizenship. Hurenkamp and Tonkens (2008) held focus groups with active citizens, non-active citizens, policy makers and (religious) migrants) to discuss what citizenship means to these groups. As a result, they come up with three groups of citizens, each with their own attitude towards citizenship: the neo-republicans, the emancipation communitarians, and the passive liberals. Neo-republicans are focused on dialogue and finding solutions or compromises that work for everyone. However, when other people do not seem invested as much in the dialogue, and a compromise cannot be found, they feel the people in charge should make a decision, or the minority should adjust to the majority. Emancipation communitarists focus on action instead of discussion or dialogue. Instead of finding one approach that works for everyone, they want the freedom to act according their own values. The last group, the passive liberals, mostly want to be left alone and, in return, they leave others alone. They do not feel the need to act upon frustrations or nuisance, but rather accept it, because they do not believe it will change anything.

For example, if a passive liberal wanted a playground in his neighbourhood, for his children to play on, he would not take any action. He wants the playground, but accepts that it is not there. He does not feel like his actions would make a difference. A neo-republican would go to the local government to persuade them to build a playground. If necessary, he might look for other supporters of his idea in his community and take them with him to the municipality. A emancipation communitarist would start organising the playground himself, look for people who want to help him create the playground and ask the municipality for cooperation when necessary. Where a neo-republican strives to convince the government and other citizens of the necessity of the park, a emancipation communitarist is more likely

to look for likeminded people to realise his idea. He only wants to convince people of the plan if they are necessary for the realisation.

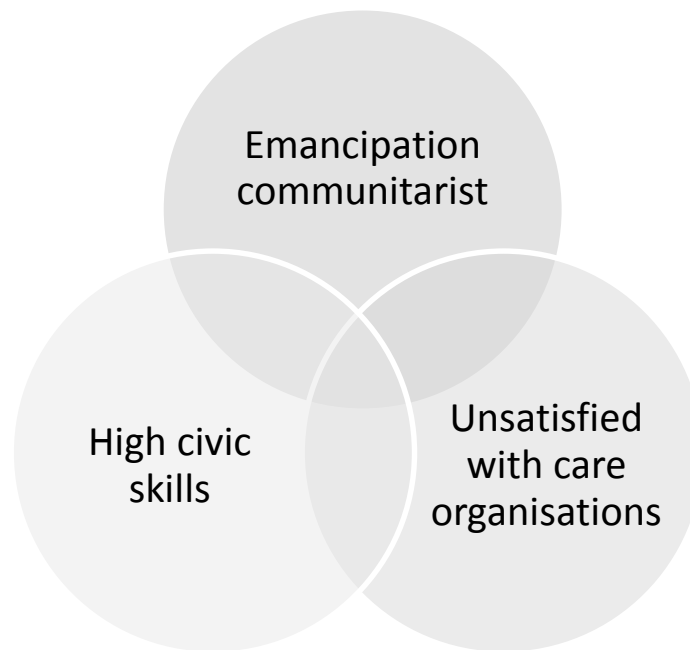
Parents who start parent initiatives for their disabled children are most likely to be emancipation communarians. They are willing to contribute actively to society, if it improves their own environment, circumstances or opportunities. They are foremost focussed on their own neighbourhood. They do not like deliberating in order to settle disputes and find compromise, instead they adopt a liberal mind-set: everyone is entitled to their own choices, as long as they do not cause nuisance.

As active citizens, these parents are thus more likely of higher social and economic standing (Hurenkamp and Tonkens 2008; Van de Wijdeven 2012; Denters et al. 2011; Bakker et al. 2011). With this background, they are more likely to have the necessary skills and self-confidence, as described in section 3.2.1. According to the model of Verba et al. (1995), motivation for participation is best explained by civil, social and material gratifications and by the results, weighed against the time and resources that are invested. Another important reason for active involvement is disappointment or frustration with public facilities and/or public decision-making (Van Stokkom and Toenders 2010; WRR 2012). Applied to parent initiatives, parents who are disappointed in the care their child received, and who think that - together with other parents - they can create a facility that is significantly more suitable for their child seem most likely to start a parent initiative. For this group, the potential benefits outweigh the necessary investments.

Combining the three elements from the foregoing sections, leads to the Venn diagram in figure 2. Parents who fall in the middle area (and thus in all three circles) are most likely to start a home for their child. The mind set of an emancipation communitarist is necessary - one needs to prefer action over deliberation or passivity otherwise no initiative will be taken. However, the motivation to take that initiative needs to be big enough. Which means that the parent needs to be dissatisfied with regular care organizations, so that there is something to gain from starting a parent initiative and he or she needs to have the necessary civic skills and confidence in these skills to ensure that they feel that investing time in a parent initiative

will result in the hoped-for improvements. A side note to this model is that a parent that is unsatisfied and a emancipation communitarist, but lacks in skills and/or confidence is not very likely to start a parent initiative, but might well be joining an existing initiative.

*Figure 2: Active parents with a mentally disabled child*



This overrepresentation of a specific group in parent initiatives does involve risks. Many citizen initiatives - especially when health care is concerned - are exclusive and only provide services to the participating citizens (WRR 2014). In these cases, other and quite possible better types of care become available only for active citizens, while people who lack the necessary skills cannot gain access.

The Dutch Scientific Council for Government Policy (WRR 2014) states that although citizen initiatives in the health care area often find smart ways to create a facility that is efficient, fits the demand from society and combines knowledge, money and man power from multiple areas of expertise, they cannot be seen as replacements of the welfare state or even fulfilment of the participation society the Dutch government is striving for. They are promising, but have not been around for a long time and are very exclusive and thus not attainable for all citizens.

### **3.3 PARENT INITIATIVES AND REGULAR FACILITIES**

Now that the developments leading up to the emergence of parent initiatives are discussed, and it is established what type of people are most likely to start them, it is time to create an inventory of possible differences between parent initiatives and residential facilities set up by care organisations. The following sections identify possible differences based on existing research and are organised around the following themes: organisation and (personnel) management, parent – professional relationship, and the care burden for parents.

#### **3.3.1 Organisation and (personnel) management**

The Dutch Scientific Council for Government Policy found citizen initiatives in the health care area to be smart in creating efficient facilities that fit the demands from society and combine knowledge, money and man power from multiple areas of expertise. Fung (2004) suggests that the small scale of these initiatives causes them to be more efficient: they need less specialisation and bureaucracy, which leads to shorter communication lines, which in turn makes it easier to solve problems and fosters cooperation. Additionally, when citizens and professionals work closely together and professionals have a lot of freedom from their employers, they can come up with innovations that depart from conventional wisdom and are tailored to the local situation by the incorporation of local knowledge.

Potentially, a citizen (or: parent) initiative can provide professionals with more discretionary space. Professionals in a parent initiative are usually employed by a care organisation (Nouws 2011), but the initiative is run by the parents. Professionals are thus at greater length from their employer. On the other hand, the staff has to work closely together with parents. There is the risk of over-correction from parents. Because parents have financial control over the facility, and often have a key and can enter any time they want, professionals work in a glass house (Egberts 2012: 44 – 50). Thus, it is difficult to establish whether professionals in parent initiatives have more discretionary space than professionals in regular care facilities and whether this provides advantages for either type of residential facility.

An important problem for many care facilities is staff turnover. Frequent turnover is seen as a hindering factor for cooperation, communication with families and quality of care and

support in general, because it takes time to establish trust between residents and new staff members, who also need time to learn about the residents and the routines of a facility (Buntinx 2007). However, there can also be too little change in staff, when a professional starts to become family member, when a client indicates that he or she cannot do without the staff member, or when parents do not accept (temporarily) replacement (Egberts 2012: 35). Too much continuity would risk the resident becoming dependent on a specific professional.

Wil Buntinx (2004) researched staff turnover in 188 small scale residential facilities from care organizations for clients with intellectual disabilities. His findings show that teams that work together longer - and thus have little staff turnover - are characterised by higher employee satisfaction, more trust in their own efficacy and experience more autonomy. Employee satisfaction, in turn, correlates positively with the quality of care as experienced by family members of residents.

Dutch consultancy organisation EY (2014) did a cost-benefit analysis for parent initiatives and found that parent initiatives have higher levels of employee satisfaction, less staff absenteeism and turnover. This suggests that parent initiatives are able to retain staff longer, thus providing an important source of stability for clients, families and staff members themselves.

### **3.3.2 Parent – professional relationship**

The parent-professional relationship has been the subject of many studies. Many models have been developed to describe different types of relations that have emerged over the years. A selection of them can be found in table 5.

Table 5: Relationship models (Cf. McNab 2010: 84)

Model	Description
Expert model	Professionals have expert knowledge and are thus most capable to make decisions.
Transplant model	Professionals teach some of their knowledge and techniques to parents, who are allowed to implement them.
Consumer model	Parents are encouraged to use their knowledge of and experience with their child to choose the best facility or caregiver for them.
Negotiating model	Parents and professionals have a working relationship and negotiate to reach a shared perspective.

The first and most classic model is the expert model. As experts, professionals are seen as the ones with all the knowledge and thus they make all the decisions. Parents are only used for input of information, but they do not have a say in the treatment of their child. Later on, the role of parents has become more important, starting with the transplant model, where professionals transplanted some of their knowledge and techniques on parents, who are thus invited to be more involved, but still do not have any decision making power. They get to implement the ideas of the professionals. In the consumer model, parents do have a say: they are to use the knowledge of and experience with their child to choose what type of care is most suitable (Cunningham & Davies 1985; McNab 2010). They now have at least some power in the relationship with the professional who works with their child, in the sense that they can choose to go to another facility if the current one does not satisfy them.

A model where parents do have influence is the negotiating model. In this model, negotiating is key. Parents and professionals have a working relationship where they make joint decisions and strive towards finding a shared perspective. Although they both come

from a different starting point, they work towards bridging the gap and focus on resolving disagreements (Dale 1996; McNab 2010).

The organizational control that parents have in a parent initiative, gives them leverage in the relationship with professionals. From this perspective, it will be interesting to see whether parents and professionals in a parent initiative have a more equal relationship and eventually develop a shared perspective.

### **3.3.3 Parents: care burden**

Setting up a parent initiative is naturally a time consuming work. And after the facility is set up and inhabited, parents continue to run the facility. Parents whose child lives in a regular care facility, have no administrative responsibilities. From this, one could conclude that parents involved in a parent initiative have a larger care burden. At the same time, the parents have more influence over the care their children receive. The parent initiatives in this research all contract a care organization to provide the care. The most common complaint from informal caregivers is that they are not involved in the professional care and that professionals do not listen to them (SCP 2009). This frustration is expected to be resolved in a parent initiative.

## **3.4 SUMMARY**

In short, parent initiatives are facilities that are developed by a specific subset of parents, that can be seen in figure 1: they are unsatisfied with the regular care facilities; they have an emancipation communitarist mind set, which make them prone to take action; and they have high civic skills, probably accompanied by high social and economic standing, that ensures they are able to set up a parent initiative that satisfies their wishes.

Because dissatisfaction with regular facilities is thus an important reason to start a parent initiative, one can expect that these facilities differ in several aspects from regular facilities. Potential differences are identified on the basis of existing literature. A summary can be found in table 6, which describes how parent initiatives can be expected to differ from regular facilities.

Table 6: Expected differences between parent initiatives and regular facilities

Area	Difference
Organisation and (personnel) management	<ul style="list-style-type: none"> <li>• More efficient / less bureaucracy</li> <li>• Shorter communication lines</li> <li>• More innovative</li> <li>• Higher employee satisfaction</li> <li>• Less staff turnover</li> <li>• Risk of over-correction from parents</li> </ul>
Parent – professional relationship	<ul style="list-style-type: none"> <li>• Parents have organizational control over the facility</li> <li>• This source of power could make the relationship more equal</li> <li>• Negotiation model instead of consumer model</li> </ul>
Care burden parents	<ul style="list-style-type: none"> <li>• Larger care burden in terms of time investment and (administrative) responsibilities</li> <li>• More influence over care and thus less frustration, alleviates burden.</li> </ul>

The facility that they set up, is expected to be more efficient, because the small scale makes communication more efficient. The close cooperation of parents and staff also facilitates communication and enables staff to use the local knowledge of the parents. In terms of staff turnover, limited empirical evidence has shown that parent initiatives are able to provide more stability on this matter. From existing literature, it does not become clear whether professionals have more leeway in a parent initiative or in a regular facility and what this means for the quality of care.

A second expected difference is the relationship between parents and professionals. Since parents in a parent initiative have a stronger position, because they have set up the facility,



the relationship could be more equal. This means that it is possible that the negotiation model is an adequate way to describe this relationship, whereas in a regular facility, the consumer model seems more fitting. This is a point of interest for the empirical part of this study.

A third potential source of difference is the care burden for parents. Managing a care facility requires a lot of time and efforts. Parents who do this, also bear a larger responsibility than parents who have a child that lives in a regular care facility. Both the responsibility and the additional tasks increase the burden on parents. At the same time, the amount of control over and involvement in their child's care might relieve frustration they had with previous care arrangements, thus alleviating the burden.

## CHAPTER 4: METHODS

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### 4.1 INTRODUCTION

This chapter will focus on the research design of this study. The design explains how the chosen methods will provide the information that is necessary to answer the research question. First, the goals of the study will be revisited. Then the choices that were made in the design of the study will be explained in the second section, along with the chosen method. The third section will discuss the case selection. In the fourth section data-collection and data-analysis are explained.

#### 4.1.1. Goals of the study

This study aims to explore the functioning of parent initiatives in the care for people with intellectual disability and or autism. Its central focus is a comparison to small scale residential facilities from care providers. Does it make a difference whether a residential facility is managed top down, by a (large) care provider, or bottom up, by a group of parents? Parent initiatives are a new development and fit in a broader trend of citizen initiatives in society, and more specifically in health care. Insights in the differences can thus also point out possible consequences of the increased wish for citizen initiatives in health care and social care.

Determining the consequences alone is inadequate. In order to understand the workings of citizens initiatives in general and parent initiatives specifically, it is important to understand how these differences came about. Since parent initiatives have not yet been researched, it is important to construct a design that allows for a thorough study that identifies not only the differences, but also their underlying causes.

Thirdly, in order to fully compare parent initiatives and regular residential facilities it is important to evaluate the differences and their underlying causes that are found in this study in terms of consequences for all involved: residents, families, professionals and society at large. This way, this study not only contributes to a theoretical debate over citizen initiatives, but also helps shed a light on more practical questions. It could help determine for which

client groups parent initiatives are most suitable, what the consequences are for these clients and their parents and what it means for clients not living in a parent initiative.

## **4.2 RESEARCH DESIGN**

In resuming the foregoing section, it becomes clear that a design is needed that is suitable for identifying differences, the underlying mechanisms that cause these differences and for identifying the consequences of these differences for all groups involved. The main challenge is to balance the need for details on the exact differences, causes and consequences and the need for findings that are generally applicable and can provide data that apply to all parent initiatives. Since this is the first academic research into parent initiatives in the Netherlands, it is foremost important to get a good understanding of the phenomenon.

For this research, a qualitative design is most appropriate: qualitative research is more explorative in nature, studies the phenomenon in more detail. Quantitative research focuses more on why question, testing a set of predetermined hypotheses (Creswell 2007). This is less suitable for studies that aim at exploring complex phenomena: reducing the reality to a limited amount of factors or variables would mean losing important information about the complexity of the reality. Broad research questions, such as the question central to this study, are often the result of a relative absence of knowledge concerning the phenomenon that is to be studied. Otherwise, a more specific question, or a set of hypotheses could be formulated on the basis of this knowledge. A case study is an appropriate design to answer broad research questions, because it provides a thorough understanding of the phenomenon, and allows the researcher to study the phenomenon from different perspectives (Swanborn 2010: 3). A case study enables a detailed, in depth study, resulting in detailed and extensive description of the findings (Van Thiel 2014: 86-7).

Another reason for using a broad research question is to open up the range of possible answers. A case study is suitable for an explanatory research approach, which can be characterised by its flexibility and openness. Collected data influence research decisions and diversions are allowed. The main goal of an explorative approach in a case study is to get

everything out of the available data, to discover what aspects of a case are relevant (Swanborn 2010).

The most commonly cited problem with case studies is that the small number of cases possibly endangers the reliability and validity of the research. The downside of the aforementioned openness and flexibility is that it is difficult to determine whether the findings are reliable, i.e. whether they are there independent of context or researcher. In terms of validity, it is complicated to establish whether the findings are to be contributed to the theoretical framework and/or concepts that are used. This also threatens the external validity, i.e. the possibility for generalization (Swanborn 2010: 36, 66).

There is no perfect solution for this problem. However, in order to limit the extent, I have chosen to do a comparative case study. Of course, the research question already has a comparative element: it involves both parent initiatives and regular care facilities. The use of contrasting cases within these groups, provides an insight between what is specific for that one case and what can be found in multiple, different cases. More details on the case selection can be found in paragraph 4.3.

In other words, the biggest problem with case studies is that it is difficult to establish the relationship between the case(s) and theory. In quantitative, deductive studies, cases are chosen on theoretical reasons. A large number of cases is used to test hypothesis based on theory. In inductive, qualitative studies, this proves more difficult. However, that does not mean this type of study is not valuable. The added value of case studies is the wealth of empirical information that is collected and that can provide the basis for new theories, or the improvement of existing theories. Yin (2008) describes this as analytical or theoretical generalization. Case studies can be generalized to theoretical statements instead of populations. Instead of (dis)proving a theory or argument, case studies can be used for creating and expanding theoretical frameworks that can then be used to analyse similar cases (Swanborn 2010: 66).

### 4.3 CASE SELECTION

As described in the last paragraph, case selection in inductive studies is difficult, but important. Two opposite designs are commonly used in comparative research: the most similar and the most different design. When using a most similar design, the goal is to eliminate variety between cases by ensuring they are similar on certain chosen characteristics. The differences that still occur, are not due to the controlled characteristics of the case and thus need to be explained by (a new) theory. A most different design operates on the opposite logic: if you use cases that are significantly different from each other and still find a similar pattern, it must be a significant finding. Because the variance between the cases is so big there is no other factor that can explain the findings (Peters 1998: 36 – 41). Because this is an inductive study, it is difficult to determine the most important factors – i.e. the ones that should be similar or differ – beforehand. That is why, concerning case selection, I focused on more practical differences such as care provider and target group.

This study uses a most similar design in the sense that regular facilities were selected to match the selected parent initiatives as closely as possible, to ascertain that the found differences are caused by the difference in organisation. Within the two groups, however, there was variance between the cases. From both groups – parent initiatives and regular facilities, two facilities for people with autism and one for people with intellectual disabilities was selected. This way, it ensures that the findings represent parent initiatives and regular facilities in general and not just those for one specific target group.

In this study, the cases are selected to balance similarity and variation. A summary of the selected cases can be found in table 7. Case selection started with the parent initiatives, since it was conducted in partnership with the organization for parent initiatives in south east Brabant, RPSW de Sleutel. The included parent initiatives were thus selected from the member list of the organisation. A first inclusion criterion was that the parent initiative must be inhabited (so not in preparation stage) and for at least two years. This way, possible teething problems are eliminated and facilities have developed to the point where they have had the possibility to establish stable policies, practices and routines and reflect on them.

Table 7: Selected cases

Parent initiatives	Care organization facilities
<u>“Ons Plekje” – Geldrop</u> (light to moderate) intellectual disability 10 residents Men and women, between 27 and 31 Care provider: Lunet Zorg Inhabited since 2009	<u>“Rutselboslaan” – Oosterhout</u> (moderate to severe) intellectual disability, physical handicaps 18 residents in apartments, in a building with other more care intensive groups. 30 total Men and women, all ages up from 25 Care provider: Prisma Inhabited since 1999
<u>“WoonInitiatief Best” (WIB) – Best</u> Autism, normal intellectual ability 10 residents Men and women, between 20 and 35 Care provider: Amarant Inhabited since 2011	<u>“Oosterpoort” – Tilburg</u> Autism, normal intellectual ability 20 residents, mixed with regular tenants (all students and/or young inhabitants) Men and women, approx. 20 – 30 yr. Care provider: Amarant Inhabited since 2012
<u>“Casa Gemert” – Gemert</u> Autism, normal intellectual ability to light intellectual disability 15 residents Men and women, between 20 and 40 Care provider: Amarant Inhabited since 2011	<u>“Doornbos” – Breda</u> Autism, normal intellectual ability 14 residents Men and women, 18+, approx. 20 – 35 yr. Care provider: Amarant Inhabited since 2011

A second important selection criterion was the target group. Parents initiatives that belong to RPSW Sleutel mostly provide residential facilities for people with intellectual disabilities and/or autism. Although some facilities accept people with both disorders, there is usually a focus on one. Cases were selected that represented both of these groups, but no others, so no

physical disabilities. Additionally, facilities were chosen for people with light to moderate disabilities because this way, residents themselves could be included in the research. From the selected cases, two parent initiatives focused mostly on autism: WoonInitiatief Best and Casa Gemert. WoonInitiatief Best focuses on autism alone, Casa Gemert is also open to residents with (mild) intellectual disabilities. The third parent initiative, Ons Plekje Geldrop, was set up for people with intellectual disabilities. All parent initiatives have patient groups that are mixed in gender. Ons Plekje has the least variance in terms of age: all residents are between 27 and 31. The other two parent initiatives have more difference in age, residents are somewhere between 20 and 35/40, although most are between 20 and 30.

A third factor was the care provider. Selected cases have been selected on the premise that the care provider also provided small scale residential facilities, in order to increase comparability: this way, the regular facilities could be selected from the same care providers. Thus, in this study, care is provided by the larger care providers in the area: Amarant (autism) and Lunet or Prisma (intellectual disabilities).

In terms of geographic location, all parent initiatives are located in villages in the area around Eindhoven. From the fifteen inhabited parent initiatives, only three are in the city of Eindhoven and they did not meet the other criteria. Ons Plekje (intellectual disability) is located in Geldrop, six kilometres from Eindhoven, which has approximately 30.000 inhabitants. WoonInitiatief Best is located in Best, which also has approximately 30.000 inhabitants and is located ten kilometres away from Eindhoven. Casa is in Gemert, with approximately 16.000 inhabitants a smaller village and also further away from Eindhoven: 25 kilometres.

The facilities founded by care organizations were chosen to resemble the selected parent initiatives. For the facilities for people with autism, the care provider was contacted and two residential facilities were selected that resemble the two parent initiatives most. The main difference is that the Oosterpoort and the Doornbos are small parts of bigger flats, where clients live between 'normal' inhabitants, while WoonInitiatief Best has its own building and Casa Gemert has its own separate part of a larger complex. Additionally, Amarant separates

intellectual disabilities and autism more strictly. The number of clients was also slightly higher: 14 and 20 versus 10 and 15. A last difference is that Amarant has very few facilities in the area around Eindhoven. The chosen facilities are however located in the same province, albeit in larger cities instead of villages.

Finding a match for Ons Plekje proved more difficult, because its care provider, Lunet Zorg, did not want to cooperate with this research. It was important to include two different care providers in the research, to make sure experiences from one care provider are not presented as the whole reality. So another care provider was contacted, Prisma. On management level this care provider agreed to participate in the study, although it proved difficult to find a facility that was willing to and had time to cooperate. The facility that was selected, the Rutselboslaan, is different from the selected parent initiative. The range of disabilities is much broader and includes also physical handicaps. People have more severe intellectual disabilities: from moderate to severe.

The Rutselboslaan is a complex with 30 residents. There are different units with different levels of care. The different units share a large atrium where joint activities are organised. The staff is also organized as one team, although each staff member mainly works one unit. In terms of ages, the range is also much more broad, ranging from 25 to 80+. Because of these differences, the type of care that is provided might differ. This makes a comparison to the selected parent initiatives more difficult. It does however provide the research with a broader scope in terms of different types of care. This way, it provides a point of contrast with all other residential facilities and can further enlighten what are typical characteristics of residential settings for people with less severe disabilities.

#### **4.4 DATA COLLECTION**

In order to study these cases, I held interviews. For every case, the goal was to interview two staff members, two parents (or couples of parents) and two residents. For parent initiatives, the interviews were set up by contacting one of the parents on the board. The parent then would usually set up the interviews. With the facilities organized by care organizations, the



senior staff member was contacted. They would then ask their colleagues, the parents and the clients who would be willing to participate in an interview and those names and contact details were given to the interviewer. One facility just sent out an e-mail, asking those who were willing to participate to contact the researcher. In two of the facilities from care organizations it was not possible to hold all the interviews as planned. At the Doornbos in Breda, only one client was willing to participate. At the Oosterpoort in Tilburg, only 1 client and 1 set of parents were interviewed. The client and his parents were interviewed together in one interview.

As can be deduced from the above, the selection of interviewees was mostly dependent on who was willing to be interviewed and/or available on the agreed date. In cooperation with the coordinating parent, an attempt was made to include a variety of perspectives in terms of different types of parents, e.g. board members and parents that were more in the background, and similar for residents (different characters and disabilities) and staff (different functions and length of employment). This amount of interviews provides a range of different perspectives and an understanding of the important topics and dynamics. The topic lists, based on the theoretical framework presented in chapter 3, can be found in appendix A. Appendix B provides an overview of interviewees.

## **4.5 ETHICS**

The relationship between interviewer and interviewee is always important in qualitative research. When interviewing people with mental disabilities, such as the residents in this study, even more attention should be directed towards this relationship. It is important to protect vulnerable participants, without limiting the research too much. In this research, the main focus is on parents and professionals, because their roles differ most between the two types of residential facilities. Nevertheless, it is important to include the residents themselves, so that their perspective is heard. It would be unethical to only talk about them and not with them (cf. Nind 2008).

All participants were asked for informed consent. I explained the residents even more clearly what kind of questions I would be asking and how I was going to use their answers. I emphasized that it was okay for them to say that they did not want to talk about something. Clients were asked to participate by the staff of the residential facility or volunteered to participate themselves. This way, these professionals act as gatekeeper and I made sure that participants did not feel pressured into participating.

Interviewing people with mental disabilities is challenging. People with these disabilities are sometimes inarticulate, either because their language skills are limited or due to low self-esteem or anxiety. They are sometimes unresponsiveness in open questioning and often have difficulty generalising from experience and thinking in abstract terms. In addition, there can be difficulty concerning time, which makes it difficult for them to tell their story (Nind 2008: 10). In order to deal with these challenges, I asked them direct questions, to limit the need for abstraction. I asked directly about their experiences, what they liked and what they did not like about various topics, and asked them to illustrate their answers with examples. This limited the depth of the interviews, but they still proved valuable because they offered a third perspective on situations described by parents and staff members.

Anonymity was an important concern for all participants. In quotes from interviews, presented in chapter 5, names from people, places and organisations are anonymized in order to protect the anonymity of the interviewee. Details that were irrelevant for the study, but could be used to identify the respondent are also omitted. Since residential facilities are relatively small communities, the overview of interviewees in appendix B does not contain the gender, exact age and occupation of the interviewee. This would limit the anonymity of the respondents too much.

## **4.6 DATA ANALYSIS**

All interviews were transcribed verbatim and made anonymous. Then I coded the interviews, using the computer program Nvivo. I started with open coding, breaking up the interviews in smaller fragments and grouping the fragments into different categories. Some codes were based on the theoretical framework used in chapter 3. Others were added

inductively. Open coding focuses purely on categorising the data itself. In the next phase, axial coding, I started working towards a more abstract framework. I compared all fragments that were assigned to each category to find the essence of that category and label it accordingly. Some of the original codes were merged, or split up between other categories so that each code had a clear description and delineation. This way, I could find patterns that existed in multiple interviews. The last phase of the coding process is selective coding, that focuses on establishing the relationships between the codes that were identified during the phase of axial coding (Boeije 2009: 112-7). I organised the codes hierarchically, into the code tree that is presented in appendix C.

The codes that I developed - mostly inductively - and that were used in the code tree, are also used as guiding concepts in presenting the data in the chapter 5. This way of presenting the data enables me to let the stories of the respondents speak for themselves, by using a lot of quotations, without losing track of the overarching themes.

## **CHAPTER 5: FINDINGS**

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### **5.1 INTRODUCTION**

This chapter presents the findings of the interviews conducted for this study. An overview of the cases can be found in chapter 4, where case selection is discussed. An overview of the respondents can be found in appendix B. This section is organised on the basis of the code tree, presented in appendix C. The coding process is further illustrated in paragraph 4.6.

The first section of this chapter looks into the motives for parents to start or join a parent initiative and how these differ from parents whose children live in a regular residential facility. The next topic is the different dynamic in the relationship between parents and professionals in parent initiatives as opposed to regular settings.

After establishing what type of parents are involved in parent initiatives and how much influence they have in their relationship with the professionals who provide the care, I zoom in on the difference in vision regarding the type of care and the intended goals. I do this by zooming in on two trade-offs where compromises between different values have to be made: autonomy versus protection and group versus individual. In section 5.5, an overall comparison between parent initiatives and regular facilities will be made.

### **5.2 MOTIVES FOR STARTING OR JOINING PARENT INITIATIVES**

The literature study in chapter three resulted in the Venn-diagram shown in figure 3. From this, one would expect parents in parent initiatives to have high civic skills (e.g. highly educated and with high social and economic status), they are emancipation communitarists who prefer taking action over voicing their issues or being passive and third, they are unsatisfied with the care in regular facilities.

Figure 3: Venn-diagram



### 5.2.1 Skills

In terms of skills, most parents seem to be middle class. An overview of the occupations and social standing of the interviewed parents is presented in table 9. In order to set up a parent initiative, a variety of skills is needed. Thus, there is usually one parent who has experience with bookkeeping or financial management, a lawyer or someone with experience in the legal system. A lot of the parents - especially the mothers - work in the education or health sector. Parents with a technical profession also proved useful. Management skills, such as conflict resolution, leadership and lobbying with external partners were also important skills, mostly for board members. Every parent initiative thus has a share of parents that are highly educated and highly skilled. These skills and expert knowledge are necessary for running a care organisation.

However, that does not mean that all parents need to have high (civic) skills or education. The most important part is that everyone contributes, which can be done in several ways. One of the parents describes how it is even necessary to have a balance of skills: “We have a great variety in our group of parents. There are a few experienced businessmen, who can be very decisive. This is very important, for a parent initiative, that we as parents are capable of starting the initiative. Because it is not easy. [...] But mostly, everyone is obliged to

participate. No parent can say: 'here is my son or daughter, good luck'. That is not allowed. Everyone has to do something. But it needs to suit their abilities. We also have parents who are concierges, they are very skilful. [If everyone was an experienced businessman] you would have endless discussions." [R1-4]

*Table 2: Social status of interviewed parents*

	Parent initiatives	Regular facilities
High social status	School director	
Moderate social status	(Remedial) teacher (2x) Social care worker Technician Civil servant	Budget coach
Lower social status	Farmer Housewife (3x)	Construction worker Administrative assistant House wife

### 5.2.2 Mind set

The emancipation communitarist mind set proves more important. A parent initiative requires parents to cooperate, both as a group and with professionals. Parents who are involved in parent initiatives need to be able to prioritize the interest of the group over their own interests or the interest of their child. Even though this tension between what is good for the group of residents (or parents) and the interests of the individual is one of the main themes in parent initiatives (see section 5.4.2) a preference for action instead of deliberation and a willingness to tolerate different opinions is vital. One father describes: "To be honest, with all parents amongst each other, you do not become friends. But it works because you give each other some space. You are not only focused on your child only." His wife adds: "That is where other parent initiatives went wrong in the past, or where they have trouble now." [R1-4] A professional, working in a parent initiative, stated: "Because the children are very different, parents all have their own frame of reference. One child has many capabilities and another has less, that creates differences between parents. [...] It can provide tension. I think most of them deal very well with this tension. They discuss this regularly. I think they try really hard to find common ground." [R3-2] It is important to note that the finding of

common ground only happens within the initiative – not in society. Parents in parent initiatives are focused on establishing a facility that is good for their children. They are not trying to convince care providers or the government to change their policies.

Parents whose children live in regular facilities differ significantly from parents in parent initiatives when it comes to their relations with other parents. Most of them have little to no contact with other parents. If there is contact, it is usually informal. Some parents do not want to cooperate with other parents because they've had bad experiences in the past. Other parents see little benefits in pooling resources when it concerns their children, because they see more differences than similarities between the children. A mother of a son in a regular care facility stated, when asked if she discussed her complaints with other parents: "No [I didn't]. Maybe I would have, if I would see that their children have similar problems. If they would all have such messy houses. Then I would think, maybe we can do something about it together. " [R2-4] Although this mother has made it clear that she wants to do something about her dissatisfaction, teaming up with other parents is not an option. She chooses to voice her concerns towards the professionals.

Among parents involved in a regular facility was a clear example of a neo-republican parent. A mother describes her long battles with a previous care provider, the social insurance agency (UWV) and other institutions. Although this mother was willing to invest a lot of time and energy into ensuring her son was provided good care, her methods were focused on confrontation and claiming rights. "If I mentioned these things, they said I was interfering with things that were not my business. Maybe they were not my business, but I was my business that they were not providing good care. [...] We even went to the clients council. [...] We went everywhere, the health care inspection, the complaints commission of [care provider]. They taught the care provider was doing well and we were nagging. I told them that they did not know what they were doing. [...] I told them that I would counteract them every chance I get. Because I do not think they should be working with these clients. They did not appreciate that. "[R6-3] This woman spends a considerable amount of time trying to change the quality of care and convince others of her opinion. The time she invests could quite well match the investment of parents in parent initiatives, but this attitude would make a parent initiative very unstable.

### 5.2.3. Dissatisfaction

Citizen initiatives are often started because of dissatisfaction with the current level or type of service provision. Concerning parent initiatives, one would expect parents to start such a facility because they are unhappy with the care that is provided for their child. However, most residents living in a parent initiative previously lived at home. Two sets of parents had negative experiences with residential facilities for adults with normal intellectual abilities and autism. Both were mental health care facilities from the same provider. One set of parents finally opted for a parent initiative. The most important reason for this was that they felt their son did not fit in any of the regular facilities: “He was there for two years total when I felt he needed to leave. Two people killed themselves. He knew they were going to do this. He went through all that, it was too much. It was not the right fit. But where to go? There are nursing homes, homes for people with intellectual disabilities and institutions for mental health care. He does not fit there. But where then?” [R4-4] They tried another mental health care institution, where their 35 year old autistic son was placed between people over 65 years of age with acquired brain injuries. They found out that there were parent initiatives who provided care homes for people with normal intellectual abilities and autism. That was the main reason to join a parent initiative.

A group of parents who decided to start a group home for their children with light intellectual disabilities had a similar motivation: “We all felt that an institution was not the right place for our children. They function too well for that” [R3-4]. These parents felt that the disabilities of their child were not as severe as residents of institutions. Parent initiatives are thus a way to create facilities for target groups that now fall between the cracks or that are too undifferentiated – from the perspectives of parents, who are not always able to determine the extent of the disabilities of their child (as will be discussed in section 5.4).

Another important reason for parents to choose a parent initiative is control over the provided care. A professional in a parent initiative, who previously worked in regular care facilities, stated: “I know from my previous job, at a residential facility, that there were parents who eventually chose a parent initiative. I was not surprised, it really suits them. They have their own ideas about how they want things. In a parent initiative, they have more influence of course.” [R4-1] Parents feel they have a stronger position towards



professionals and thus are better able to realize their ideas about what is best for their child. What this means for the relationship they have with professionals will be discussed in section 5.3.

A parent initiative is a lot of work, especially when you are there from the start, and/or a board member. Board members can invest up to 20 hours a week. However, for most parents, the increased control they get over their child's care, makes up for that. So even if the care burden might be heavier in terms of time, emotionally parents might feel less burdened when they are in control.

#### **5.2.4 Familiarity with available options**

When asked how they came to join a parent initiative, many parents mention that they read about in the local newspaper. One father said: "we read about it in the newspaper. We thought we would apply and see how far we would get." His wife adds: We wanted to be involved. This boy is still developing and I wanted to be there to see what is happening. It is not necessary to drop him at an institution and think that our job is done. I hoped this would not be like an institution. Of course, we hired professionals. Multiple care organisations came and explained [how they would provide care]." [R1-3]

This citation also shows that, when thinking about regular care, most parents in parent initiatives think of classic, large scale institutions. They want to make sure that the care their children receive, fits their needs. The regular facilities included in this research, however, were all small scale. The two facilities for people with normal intellectual abilities and autism were started recently, after most parent initiatives were started. So in addition to not being familiar with the options within the regular care provision, these options have changed over the last few years.

Parents who 'chose' regular facilities, on the other hand, often had little knowledge about parent initiatives. Although the number of parent initiatives is increasing, it is still a relatively new phenomenon. Most of the parents interviewed in this study were satisfied with their current care provider. For some, location was also very important: "We are not getting any younger and in ten years we will be retired. What will happen then? I mean, will we be able to take care of him as well as now? That is the reason that we preferred [place of

residence].” [R6-1] They were less critical of the care vision or the way the care is provided – as long as their child is happy.

## **5.3 PARENT – PROFESSIONAL RELATIONSHIP**

### **5.3.1 Source(s) of power**

The most important change between the relationship between professionals and parents in a parent initiative is that parents have a power source of their own. In chapter three, several models were described that depicted different balances in the parent – professional relationship. A summary can be found in table 5 in chapter 3.

The expert model is based on the premise that professionals are experts and thus have the most important power source. Parents have power only if professionals are willing to include them, which gives professionals the upper hand. In the consumer model, parents’ only power source is that they can choose a different facility. However, in a parent initiative, parents are board members of the organisation. As such, they negotiate contracts with the care organisations the professionals work for. One parent explains: “ We are in charge. When we tell [care provider] they are not doing a good job, because they are not providing [my child] enough care, and I have said it three times, but they are not doing anything.. If other parents agree, or support you, then they are not doing a good job. As a matter of speaking, we can tell [care provider] to quit and pick someone else. So we are in charge and that is a very important role in a parent initiative. It means hard work, but you also have a lot to say. There was a lot going on, especially around the time we started. We invited three care providers. All sets of parents listened to them, because they were allowed to give a presentation and present an offer. We asked questions. We had a couple of those meetings. For [care provider], we are the first parent initiative. They were a little scared. Others had four or five, so they knew how to deal with it. For [care provider], we were the first. But that also meant we had a lot of input, because they really wanted this. So it was a real negotiation.” [R3-3].

Another important aspect for parents is being in control of the hiring process for new professionals – often together with residents. A parent from a parent initiative for people with autism and normal intellectual abilities stated: “when staff members leave, or start new,

we as parents have a strong say in the matter. [...] I am in the hiring committee, together with [other parent]. We consciously decided to hire highly educated professionals. That is more expensive, but we have many smartasses here. If you have a very nice, but not so smart girl, they will fool her. These men [the residents] are masters at that and they are vicious. They let you work like a slave, all day. [...] So we decided to have less staff, it will be more expensive, but the quality will be higher. Thus, [care provider] cannot decide which professionals work here. It happened once. So with [care provider]'s new representatives, we will resolve this issue. It will be okay." [R1-4]

This source of power has not gone unnoticed by professionals and it has changed their attitude towards parents. A professional in a parent initiative who has previous work experience in regular facilities stated that it is less easy to make a decision about the care plan when parents do not agree. In regular facilities, he says, "it is more like: 'this is it.' And that does not work here. You are having more conversations. [...] In a regular facility, you also have to have a conversation, but you are less dependent. Here, if next year parents think fuck [care provider], then... I won't lose my job, because I work for [care provider], but [care provider] will lose a facility. And [care provider] needs facilities. In a different parent initiative, where I previously worked, parents decided in the end to quit working with [care provider] on January 1<sup>st</sup> and to contract [different care provider]. It happens. And whether [care provider] or the parents were to blame, I will not comment on that, but it is a fact that it can happen." [R2-3]

These quotations show that the relationship between parents and professionals has a different dynamic in a parent initiative. The dynamic in a regular facility can be described by the consumer model. Professionals can tell parents that 'this is it', and they have to decide whether that is good enough for them. In a parent initiative, dissatisfied parents are more likely to exert pressure as a group, thus threatening the care provider with losing not just one client, but an entire facility. In addition, as board members of the parent initiatives, they control the preconditions surrounding the care, such as the hiring of staff members, but also the amount of hours of care and their distribution over the day and week.

This can influence the decisions of professionals, as the following examples illustrate. Both examples concern parents who fear their son with autism is not able to wake up on time on their own. First the regular facility: “For example when parents told us that their child needs to wake up on time. We said we wanted to do that for a while, but we are not a wake up service. The client has to do that himself. Parents said that their child would sleep in, despite the alarm. We told them there are other options. The parents found none of them appealing. Then we suggested that they would call him, if they thought it was so important. These parents call to wake up the client every day. Both parties are happy this way.” [6-1].

In the parent initiative, the process was more complicated: “When we started, one set of parents had a son who had to leave for work at 6.30u. The parents felt he needed help doing that. He did not. He could do it himself just fine. But, because of this, we had to start our shift at 06.30u, so that this guy could wave at us, to signal that he left for work. And then you sat there until 09.30u. It was a total waste of money. Because there was nothing to do at 06.30u. Everyone was sleeping and those who don’t, are at work or go to work. It is madness. It takes time, the process of letting go, that parents see that it is not necessary. And then it can change. But as [care] organisation, you have less influence than in a regular facility, where you are stronger. Here, it is more like a game, to keep up the parent satisfaction level.” [R2-1].

This last quote shows that parents’ wishes are more likely to be granted in a parent initiative – even if those wishes make no sense in the eyes of professionals. This corresponds with the negotiating model: professionals have to take parents’ opinions into account. They have to make compromises and do things that they feel are unnecessary. However, in the long run, professionals showed that the early shift was unnecessary and parents adapted to that idea. This brings the power source of professionals to light: their expertise. Professionals have noted that parents, although they know their child very well, have less insight in the disabilities of their child. They often overestimate the (social) functioning and the capabilities for domestic tasks, but underestimate their capabilities for making decisions for themselves or being able to deal with failure and mistakes.

That this can be to the detriment of both professionals and parent, shows this quote from a professional in a parent initiative for residents with mild intellectual disabilities: "A boy lives here, [name]. And he is a boy with autism, so he needs strict guidance. And we really push for this and try to apply that. But the parents feel that their son is most happy when he has as much freedom as possible. This results constantly in some kind of... Struggle is a large word, but we have opposite interests. We want to support him in a strict way and parents tell us we should let it go, that it will be okay. Until last month, when he hit a colleague in the face. [...] At that point in time, we were in direct opposition of the parents. Because we feel he needs this and this and that this clearly is a lack of structure and clarity. And the parents think we are too strict and should let him go and give him more space. [...] Parents know their children much longer and much better, but different from how we know them. In this case, we see a boy with a disability, a boy with a specific type of autism. That has certain consequences. And they see their child first, and then the disability. That is completely different. [...] It is a continuous dialogue. Parents are not professionals. They cannot put their child in a different perspective. I do not expect that from them, but this is why you always have a difference in perspective." [R3-1]

It is important to note that parents vary in the extent to which they accept the expertise of the professional: "Some parents are very realistic, and others are not. Every set of parents has their own process. Being able to let your child go, that you dare and are able to let your child make mistakes. Some of them are quite worried and they want us to supervise closely. And others state that they trust us and that we should muddle along. Other parents withdraw completely, and let us fend for ourselves." [R3-1]

Most parents are aware of their bias, or at least they become aware after some time. One mother explains: "We as parents sometimes have an opinion on matters that we do not know that much about, because we do not live there. The distance becomes bigger. We easily have beliefs or opinions that might not be realistic. And in those situations, the view of professionals is obviously very important". [R3-1] The consequences of this difference in knowledge and perspective for the vision of care will be discussed in section 5.4.2. It does show, that even though the parents have more influence, the source of their power is different – it stems from running the organisation. In the end, professionals' opinions still

seem dominant, because they have more (expert) knowledge. The relationship between parents and professionals thus might be more equal, but in some cases, it remains difficult to find a shared perspective.

### **5.3.2 Parents and board members**

Parents have two functions in parent initiatives: they are both parents of their child, and board member of a care organisation. This double function is new for professionals and can result in complicated situations when there are incidents. In the case of the autistic boy, that is cited above, parents and professionals could not agree on a care plan. At the time the boy hit one of the staff members, she did not feel very supported by the board: “Here, the board makes decisions in most cases. A manager of a group [home] is more business-like, but also more impartial, so to say. That is something I am struggling with recently, because of some incidents that have affected me and that bother me. I find it difficult. The first few years it did not bother me, but now that it hits home I find myself struggling. And I should not do that, because I cannot change anything, this is the reality. But I do think it is important to make my voice heard in these matters. [...] A few months ago, I had a confrontation with a client, a physical one. His father is on the board. So it has been discussed with the parents, the board knows – I think - , but not everyone knows. And I feel like privacy is very important in these types of situations, and I understand that, but I think safety of the other clients, myself and my colleagues is more important than privacy. This obviously results in a conflict. My team leader has more direct contact with the board, but has to keep the privacy in mind. [...] Sometimes you feel like they do not hear you, because I really think something should be done. As far as I am concerned, everyone should know what happened. I feel like it is been swept under the carpet to some extent – well, not really, but it is going that way. Or at least it is played down. For me, open communication is very important. I do not like going behind someone’s back. [...] You chose this residential facility, so you have to share, in my opinion. You have to think about us. In a regular facility, it would have been dealt with differently.” [R3-2]

What this incident shows, is that parents – precisely because they are parents – cannot fill in a board member position the way (impartial) manager can. Professionals are not allowed to communicate freely to the board members, because they cannot talk about clients in front of

other parents. This is can be inconvenient for parents as well, because it makes the communication about policies more difficult. In one parent initiative, there was friction between professionals and parents on a specific theme. Professionals decided to organize a meeting to discuss the topic – because of the privacy of clients, that professionals have to respect when talking to other parents. Even though this meeting was specifically about the theme that generated the differences in vision, these differences could not be resolved, or even be acknowledged, because they could not be discussed directly. This is frustrating for professionals: “The disadvantage of that meeting, and I think it is a disadvantage of a parent initiative, is that you are constantly struggling with the privacy of clients. So we could not use actual examples. We made more abstract cases, but that creates a distance. This way, you are not emotionally involved, you do not feel it is about your child, so you might have a different point of view. [But when something really happens], I am sure they will put the interests of their child first.” [R3-1] This makes communication difficult, and the relationship between parents and professionals unbalanced. Professional standards inhibit professionals from communicating with board members of the organisation about things that are happening there.

In addition, the fact that parents as board members are not held to the same standards as (professional) care providers, gives them freedom to make decisions professionals cannot make. When it comes to selection of residents or house rules, parents can set rules that professionals cannot. Parents logically have more decision-making capabilities when it comes to their child than professionals. However, this can be to the detriment of professionals and of the residents themselves.

One care provider allowed parents to write their own protocols, because the ones used by the care provider were too ‘institution-like’. One of these protocols concerned sexuality and more specifically, the code of conduct for incidents. A parent explains their reasoning behind their protocol: “We find it important that action is taken immediately. But some parents said that institutions register these things in some kind of system. They did not want their child in some system of an institution. We feel it should be registered, the team leader should be aware, and maybe a professional from the outside. But the board of [care provider] does not need to know and it does not need to be in a generally used system. [...] Not because

someone else cannot know, but sometimes there are privacy sensitive matters. With such a big organisation, you do not know who has access to the system. Someone who has nothing to do with [residential facility] can open that file. We think that that is unnecessary. Everyone from [residential facility] can access everything, but if you [the interviewer], were to do an internship there, and you would open the file... that kind of thing." [R3-4]

Whether the concern for the privacy of the children is realistic or not, this protocol seems to open up more possibilities for concealing incidents, which has maybe even more serious risks to their children. By all means, this incident shows that parents have a certain leeway in making decisions about their children that care providers or professionals will never have. This can also be illustrated by the following case. One of the professionals interviewed for this study worked at a regular care facility for people with autism and normal intellectual abilities and had recently started working at a parent initiative for the same target group. At the parent initiative, all residents are under guardianship of the parents, allowing parents to make important life decisions for them. In the regular facility, only one resident was under guardianship, all the others do not.

The professional comments: "It is the same target group. It astonishes me too. Parents can do this more easily, make requirements for residents. Here [at the regular facility], we only determine if someone fits in this facility. They need to have an autism diagnosis. When there are really severe psychiatric problems or substance abuse, they need more care. That is the only reason to refuse someone." [R6-2]

A parent in this initiative, when asked about the decision, explained: "We had to go to the court with [son]. Because we have guardianship [*beheer*] over [son]. [...] It is very essential that parents have that. We demand it now. Because if the parent does not have guardianship, and a child does not let the professionals in, there is nothing you can do. [...] If you have guardianship, the resident cannot say: I refuse care. [...] Because then, the consequence is that you leave. That happened once, that someone continuously refused care. *Interviewer: so in principle, as parents, you have an agreement with each other. And not as much with the residents?* Both. The resident knows, he signs it, he is independent, but as parent, you cannot say: "he is



in care know, he can fend for himself". No, then they will come to us and say: "you are guardian, you are responsible." [R1-4]

The guardianship does seem to serve two purposes: to make sure no one can live in the parent initiative and refuse care, and to reinforce parents' responsibility. The first concern is shared in all parent initiatives and all regular care facilities where living arrangements and care are separated: it should be prevented that someone living in one of these apartments does not receive care. Thus, the lease contract usually has a clause that one has to receive care from the care provider in order to live there. Guardianship is – with this target group – usually not necessary. It does however limit the autonomy of the residents severely and it shows a way of thinking from parents: that it is preferable if they are in charge. This might be due to a preference for influence from parents, or because parents want to protect their children or think they are unable to make these agreements and/or stick to them.

Having parents as directors also has positive consequences. Not only is the residential facility small scale, so is the organisation behind it. And parents are not being bound to the same (professional) standards and not operating from the same perspective as professionals, opens up possibilities for more informal communication. The risks, described above, are only one side of the medallion, as a professional describes: "Many parents are really positive about us. They think we are doing a great job. We regularly get the feedback that we are doing well. That is really nice to hear. And I am personal care worker for one client, and when I talk to the father or mother, they tell me I am doing fine and they think the same way. Yes, then you really have their trust. And then I know that with some things, I do not have to call them, because I know how they think and I just do that. So that is also a difference. You do not have this at regular facilities. And if you are waiting for a compliment from your manager, at a regular facility, you might as well retire. You get more in return here." [R3-1].

Professionals also feel more involved in this specific residential facility. Because parents take on such a strong organisational role, some staff members feel more distance towards their employer, the care provider. This does differ between parent initiatives: because parents negotiate contracts with care providers, their influence can vary. Plus, professionals with more management tasks, are more involved with the care organization because they have

more contact. This commitment to the facility instead of the employer could well explain the lower rate of staff turnover that is found in the social business case from EY (2014). A professional explains: “[care provider] pays my salary, but [care provider] is located mostly in the neighbourhood of [city; distance 50km] and we are a remote corner. I think we all made the decision to work here consciously. Because you do not change easily. If you are working for a large organisation, where many facilities are close together and where you know each other, then people maybe change locations much easier and you do it easier yourself, because you think that you like it there, or you know someone.. It is attractive. While here, we chose this. And I think we all also just like it. I think everyone here works with pleasure and does not want to leave. For now, at least. “ [R4-1].

#### **5.3.4 Regular care facilities**

In the previous sections, I outlined the distinguishable characteristics of parent initiatives. However, most of the citations of parents showed that they compared their facility to large scale institutions. As the previous chapters have shown, deinstitutionalisation has brought on changes in this sector. In other words, regular facilities have changed a lot over the years and the facilities included in this studies do not meet parents’ ideas of institutions. One assumption that is often been made about parent initiatives is that parent are significantly more involved in their child’s care. This is not necessarily true. Within both parent initiatives and regular facilities there is a great variety in involvement of parents: from micro-managing or overprotective to quite detached. The only groups of parents in regular facilities that are structurally not involved are parents that are intellectually disabled themselves, parents who no longer have parental authority and parents who brought their child to an institution a long time ago – and were told not to interfere.

One important difference in terms of parental involvement is that where it is expected in a parent initiative, it is a choice in a regular facility, as a professional explains: “We discuss with the client if they feel it is okay to include the parents. The client decides. We explain why we think it is important and discuss possible pros and cons, so that the client can make an informed decision. We stimulate it, because it is useful to strengthen the network of the client. It is not an automatism, and I think in [parent initiative], it may be more of an

autonomism because parents have created the initiative, so they have they involvement and want it." [R6-1].

The involvement itself does not differ, but the dynamic does, as another professional explains: "In a regular facility, you work towards involving the parent more. At first, the focus is more on the client and you have to start working towards involving the parents more consciously. In a parent initiative, we notice we really have to focus ourselves on the resident that lives here. In the preparation stage, parents are very busy. Residents are not contributing, or do not want to contribute. When the resident moves in, the balance needs to be shifted back: parents need to be in the background so the focus is on the resident. Different dynamic, but when you meet in the middle, the process is similar." [R1-2].

The parent – professional relationship in regular facilities can be characterised by the consumer model described in chapter 3. Parents can decide what is good care for the child in the sense that they can choose a facility – and if the current one does not suffice, they can choose another one. The models described in chapter 3 are based on parents with small children. The one 'problem' with adults, especially those with normal intellectual disabilities, is that they have a say in the matter. One mother explained she felt her son looked shabby and his house was a mess. The professionals told her that since her son did not care and did not want to change, they were not going to do anything about it. She said: "It is difficult for me. I looked it up on the internet, there is a guideline for what you can expect or what the minimum is they should do with the care assessment he has. [...] He should get between 9,5 and 12 hours care. They get paid for that. So in my opinion, they can do a lot of cleaning and ironing. [...] They do not want to do it themselves, they are only talking.[...] I have talked about it. So I do think that they will do something about it. They do something about it, if you tell them. For example, when they have their next appointment, they clean the countertop or something like that. [...] It is not really structural and well, it is just always a mess at his place." [R2-4] Although this mother is unhappy with the approach of the professionals, she does feel like they listen to her. When asked if she considers to look for a different facility, she said that that would likely cause a fight with her son.

## 5.4 CARE VISION

In the previous section, I discussed the parent – professional relationship in terms of sources of power and influence and dynamics. In this section, I will look at the content of the discussion: where do parents and professionals differ in their vision when it comes to good care and how do these differences translate into differences between the facilities? From the collected data, it became clear that for managing care facilities, a careful balance needs to be made between different values. Two trade-offs turned out to be most salient: autonomy versus protection and group versus individual.

### 5.4.1 Autonomy vs. protection

This trade-off has been mentioned before, in the sense that parents are prone to decide things for their children and favour protection over autonomy, mostly from loneliness and neglect of (personal) hygiene – with the accompanying social consequences. However, in doing so, they can limit possibilities for self-determination. The mother of the autistic son, cited in the last section, wanted the professionals to do more about her son's lack of cleaning. She explains the problem: "I think [son] looks shabby. I feel his bed linen should be changed at least fortnightly. His laundry should be done better: not let it in the washer for three days and then put it, as a pile, on a laundry rack. Everything gets wrinkled, and then he puts it on. [...] They are adults, but still. I think they [the professionals] should look through the eyes of society and decide what is acceptable and what is not – and where they should intervene, even when the client does not feel like it. [...] I think [son] looks shabby, he barely has any pants left so he will have to buy new ones. He likes to wear shirts, but they are never ironed. In my opinion, that means you do not represent yourself well. When he goes to a pub or something and he stands there in a pair of pants that are well-worn and a shirt that looks bad, than that is not good for your social network." [R2-4].

Although most people would probably agree with the mothers concern, the professionals, when asked about the situation, took a different perspective: "It is difficult, because [parents say] he has that care assessment, so we should do it. [...] But clients do not want you to be around six hours each week. Or every day. So it leaves you in the middle. [...] [We take] the clients perspective, mostly. But you do take the parents seriously. I understand it, you see you son or daughter go downhill. So you try to keep the dialogue going. But, when you talk

about discussion points, housekeeping is definitely one. Parents expect more and also they expected us to take action more often and faster. [...] But we feel that we would make them dependent and we strive towards making them as independent as possible. And that they do not depend on us for cleaning, but that there is some kind of system. And you don't set that up within one or two months, it takes time. [...] The discussion can be there. But you notice that the client feels that it does not bother them, or it does not yield him anything [to clean]. When you have cleaned your house, you might feel good about yourself. But many clients do not have that. So what motivates you to do something? When it does not bother you and it does not yield anything.. [...] So you look for the motivation. That could be something like, how do you feel when people come to visit? You look for what motivates them, what drives them to do something. We have a client here who can look very shabby. But when he has an appointment, or when he goes to a pub, he does iron his shirt. That is important to him: when I am going out, or when I go to work, I make sure I shave. At other times, he can look really bad. He does not care. And so you talk to him, about how people see him, how they treat you. Because you are treated differently when you look like that. He responded that that says more about those people than about him. And he has a point. So it does not bother him. [...] Then what is the problem, and whose problem is it? But I can imagine parents see it differently. We do not have the means to say: "you are going to do this". We cannot even do that. We are standing empty-handed what this is concerned. It is not that we do not want to see it." [R2-2].

These professionals really focus on the autonomy of the client. For clients with more severe disabilities, however, that becomes less important. One professional compares the facility included in this setting to a 24-hours care facility: "Recently I have started working at a different facility, [name] of [care provider], that is a facility that is a step back from here. This is the last place you go before living on your own. [...] At the other facility, that is a more protective environment. You have 21 apartments, all 21 have autism or acquired brain injuries. There is someone there 24 hours. So there are three shifts: morning, evening and night. There is a lot more care. Here, we try to get a client to ask for care or help themselves. And when he does not, that is his responsibility. That is a real difference with the other location where I also work. [...] We provide more intensive care. Not that we spend hours in

an apartment, cooking and cleaning, but there is a lot more oversight and a little more care and contact moments. It is a lot less here. [...] At the [other facility] they try to take someone by the hand. Telling them to tidy up. A little patronizing. Because we think it is important and we want it to be done. And here, at [name facility], we let someone have their own values. We teach them to take responsibility and let them take it. And if does not work, for example because they do not clean the apartment, and it causes nuisance, as a last resort – but only as a last resort – we would call a cleaning company to clean and the client will have to pay for it. Because apparently, this is just how it works in the real world. “ [R2-1]

That the severity of the disability influences the importance of autonomy, is true for all regular facilities in this research. A staff member of a regular care facility for people with moderate to severe intellectual disabilities explains, when asked if autonomy is something they work towards: “No, we do not think about that. Because if people come here, the idea is that they can stay here forever. We are not working towards independence or something like that. [...] The people who were independent have left. I do not expect that there will be [new clients like that]. [...] As long as government policies are like this.” [R5-1]. However, that does not mean that professionals take over all responsibility: “For most people, we have clear agreements with the family and the client about how it needs to be done. Nine times of out of ten, we try to keep it up, with clear rules and a good approach. But, we do not spend 24 hours with a client, so if someone creates a mess, we try to stimulate and to activate, and sometimes we take over a little, but you try not to do too much. [...] They have their own apartment. In principle, especially with people who have their own apartment, we feel they should do it themselves. We help, if needed, but we mostly stimulate. It is their house. [R5-1].

In parent initiatives, the difference between people with people with severe and less severe disabilities is less clear. Professionals in regular facilities for people with normal intellectual disabilities and autism would help their clients to learn how to clean their apartment, they would activate and stimulate clients, but they would not make a weekly appointment to clean the apartment together. If that would be necessary, an alternative solution would be needed, such as a family member or a cleaner. In parent initiatives, a weekly appointment is more standard. A client in a parent initiative describes: “At this moment, I have help with

cleaning. It is not that I cannot do it. I have all the skills. I just do not keep going. When I have to clean my house – it is not that big – at this moment, I have help two hours each Saturday. Then, we do everything. Everything is cleaned, vacuumed and mopped. [...] If I have to do it on my own, I will still not be done at the end of the weekend. [...] I get distracted. [...] We had hope – my father, mother and me – that when I moved out, I would do many things on my own. With some things, it is true. I cook without help and that goes well. Laundry too. [...] Dusting the bookshelves, if no one tells me to do that, I would not do it for two months. I do not think that is necessary. But I vacuum now and then out of my own initiative. [...] For me it is like ‘is it necessary’? Next week, the windows need to be cleaned. And then I wonder, why is that necessary? I can still look through them. But if a dove would fly into them tomorrow and it would cause big stains, or if I open the curtains and I cannot look outside because of the bird droppings, then it has to be done and I will do it.” [R4-5]. In a regular facility, this apartment would probably be cleaned less often – as often as the client would want to do it. The supervised cleaning schedule clearly does not harm the client, but one can question the necessity of it.

It also points to a system where choices are made for clients that they can make for themselves, thus undermining their autonomy. Because in parent initiatives, parents set up the facilities and (mostly) determine the preconditions for care, they are in a position to take over choices that can be made by their children. Being in such a position, it is more difficult for parents to see the facility as the home of their children instead of a lengthening of their own home. This can be seen in the next quote from an interview with a resident in a parent initiative who talks about the involvement of parents: “The interference in the beginning was really annoying. Especially since you are a little insecure when you move in, so I did not know what is normal and what is not. So in the beginning, you kind of go with what the parents expect from you. But after some time, you feel like you can have your own life, it does not have to revolve around the initiative. Because that is the life of the parents, so to say, this is really their project, they invest a lot of time. [...] In the end, you are supposed to live your own life and do your own things. That also involves letting go and a little distancing from your parents, to set your own priorities, what you do and do not think is important. [...] There were also two parents who [...] came to record the meter reading, or to

repair something and they just used their master key to come into the house. From the beginning, I was very angry about that. I told them that they absolutely cannot do that. They did it twice, that they came in my house without telling me. [...] They felt that they were the parents, so... But I told them it is legally not allowed, that I could call the police for this. So at some point, they stopped. I was really angry, I really thought it was an infraction on my [privacy].” [R1-6].

This theme that is most relevant in facilities for people with higher levels of functioning - in this research, the facilities for people with autism and normal intellectual disabilities or light intellectual disabilities. This is mostly because autonomy is more important to the professionals, who see opportunities for these clients to go live on their own, outside the facility and want to prepare them for that. At the same time, as the last quote makes clear, this group of residents has more capabilities to voice their opinion and to stand up for themselves. Parents, on the other hand, seem more focused on the ‘responsibilities’ that their children have and whether professionals help them carry out these responsibilities.

One professional in a care organization suggested a solution to this tendency for parents to organize too much: “I think it is advisable for parents who start a house that they involve the residents in an early stage when it concerns ideas for living and care – whether it is useful or not. For me, it is important that at a certain point, parents have created a residential facility that they are satisfied with, but where the cohesion is not felt emotionally. My advice would be that it should be important for the resident as well. If he would not want to go to a meeting for the facility, because it does not mean anything to him, he should be convinced that it does mean something to him: he is going to live there, so he is an important part. He can listen, or give suggestions afterwards. That they are involved, I would advise that. This differs greatly in different [parent] initiatives.” [R1-2]

All facilities included in this research had a residents council of some sorts, where residents can discuss problems within the facility – both with each other and with policies or rules. In parent initiatives, this sometimes leads to clashes with the parents, when residents do not agree with policies that are decided upon by parents – or vice versa. For example, in one parent initiative, there was a discussion over the communal spaces: who was allowed to



enter them? Obviously, these spaces are meant for the residents as a group. The problem was: are parents also allowed to come there? Some parents felt that since they had started this project, it is important to have some connection with all the residents, not only with their own child. Thus, they wanted access to the communal spaces. Other parents, however, felt that these spaces were for residents and that they should stay out of them. One of the staff members explained: "Someone with autism needs a lot of predictability. If this person walks into the communal space and suddenly sees someone else's parent that he did not expect to be there, he could be in distress. I will not comment on whether it is this black and white, but this is how parents see it and that causes a conflict. So then, there was an agreement that residents should have a say. Who do they want in the communal space, who has access. It is only for parents, or also for romantic partners of residents. How many days a week, at what times. There have been a lot of discussions. In the end, the residents council made an agreement, with a majority of votes, that the space would be open for parents in the weekend. However, what you do see is that the vision from the parents influences their own children. They [the residents] already were divided, but they made a decision with a majority of votes. That decision was presented to the group of parents. The parents who did not agree, got really upset. So the board of the foundation eliminated the decision.[...] In the last meeting of the residents council, I had the honour to tell them that the parents had decided the agreement was off. It escalated completely. For several months, there was no residents council. Everything was put on hold. At the beginning of this year, we started again. Now we have an independent president from a different facility, I am only the secretary, so I am completely objective. I do not interfere with the discussions substantively. There is an agreement: the majority of votes decide. Parents do not interfere." [R4-2]

There were similar stories in other facilities. Although they are eventually resolved, as the example above shows, this can take up a lot of time and cause a lot of friction, especially among parents and residents. In all facilities were parents who are protective. For these parents, giving their child more autonomy to determine their own life, is more difficult than for other parents. In parent initiatives, there seem to be more overprotective parents, who also have more opportunities to 'protect' their children. In regular facilities, parents have less options, which might make the process of letting go of control easier. In both cases,

parents need to work on a new type of relationship with their (disabled) child, one in which the child has become an adult who lives his or her own life.

#### **5.4.2 Group vs. individual**

A distinguishing feature of parent initiatives is that they are set up for a specific set of residents. For parents, an important advantage of a parent initiative is that their child can have their own apartment, but they also live together in a group. The residents can get to know each other before moving in, thus increasing the chance of a good social atmosphere. In addition, selecting the residents themselves makes that parents can set additional criteria. One of these criteria usually is drug use: in parent initiatives this is absolutely not allowed. Residents who use drugs can be evicted. In regular facilities, (moderate) drug use is tolerated – although it is discouraged. It also provides the opportunity to make sure the future residents like each other, which in turn would benefit group cohesion. This in contrast with regular facilities, where admission is based on whether someone fits the setting in terms of diagnosis and whether the provided care fits the needs.

One of the parent initiatives was founded by a group of six sets of parents, whose kids knew each other from school. They needed a total of ten residents to make the initiative financially viable. In the search for the additional four residents, the original six had a large say: they got to say whether they liked the new residents. Parents really thought it was important that the residents liked each other. In the other two parent initiatives, residents got to know each other beforehand, but as long as there were no big problems, whether they liked each other was not really a necessity. However, parents often find the social component of a parent initiative very important, as one parent explained: “In the initial phase, we felt that the group is very important. Every parent worries about loneliness for our kids, so the group process is most important. Actually, we feel that the youth are supposed to be a part of that. They have to participate, within their abilities.” [R3-3]

However, this ideal can prove difficult in practice. One residents explains: “We had a few group activities before it started. So we could get to know each other a little. [...] So you know which name belongs to which face. Whether you like them or not. This way, you form your little group that you hang out with. [...] There are differences in terms of level [of

disability]. You socialize with people that fit your level, more than with people who have a lower level. I can talk with them, but it is different. Sometimes it is nice to talk to someone who is at the same level as you, or maybe a bit more intelligent, and who understands better what you mean. [...] It is like in school, you have groups you hang out with and people you see, but you do not really connect with.”[R4-6].

This is not necessarily a problem. In regular facilities, one can see a similar pattern of social interaction: some people really enjoy the organized group activities and make friends within the facility. In the regular facilities for autism, residents also have the opportunity to live there ‘incognito’: these facilities are part of apartment buildings. One cannot see from the outside which apartments belong to the care provider. Although most residents know each other, this is not obligatory. In all facilities, various social activities are organized and usually visited by a subgroup of residents. Some residents have a larger social life of their own, with romantic partners, friends and (sport) club(s). Others have less needs in terms of social activities.

Type and severity of disability is important in this matter. Where the question of autonomy from the last paragraph was most difficult for parents with children with less severe disabilities, this question was most relevant in facilities for people with intellectual disabilities. A professional provides the reason why: “I have worked with a similar target group, with moderate intellectual disabilities. You can offer things more collectively, because their experience level is more similar. People are screened for this and put in the same facility. [...] Here, you have one label – normal intellectual abilities and autism – but that does not say much. Characters are very diverse. The type of autism also makes a difference. [...] But even if you place people with similar experience levels together, you still need to be careful: they are still all individuals with their own characters. It is easier to prepare a range of activities. But still, I feel you have to be careful. You cannot see it [the disability] apart from the person.” [R1-2].

In parent initiatives, it is sometimes difficult to see for parents that what is good for their child, might not be good for other residents. Or sometimes they even have trouble identifying the needs and capabilities of their own child, as this professional from a parent

initiative experienced: "For example dinner. Some parents feel that their child should eat with the group every day, and all children should eat there at least five times a week. For some residents, that is too difficult, and it has no added value. Some are just not capable of doing that, because we also have to deal with people with autism. So we have to look at what is suitable for the client and what is best. Yes, sometimes that is difficult for parents to see." [...] It is useful to have a vision with a group. A general vision. But you have to be able to deviate when it concerns individual clients. And you see that in the course of time, more and more side roads emerge. Because all ten are different. In terms of level of disability, in terms of capabilities, everything actually. But, you have to have gone in the same direction as a group." [R3-2]

It is difficult to balance the needs of the individuals against the needs of the group. Both parent initiatives and regular facilities deal with this dilemma. In times of deinstitutionalisation, great value is placed upon individual development and being as self-reliant as possible. Most professionals thus emphasize the position of the individual. Parents in a parent initiative want their child to belong to a larger group, to not be on their own. They will stress the need to strengthen the cohesion of the group, even if that sometimes limits the individual. However, as times change, visions on care can also change. The regular facility for people with moderate intellectual disabilities in this study is developing towards a less individual approach, probably mostly as a reaction to cutbacks in health care, but also because residents requested this. One of the parents sees the benefits of this approach: "They want the staff to start cooking with the residents, every day. That there is reciprocity. We think it is very positive, because I do not like the ready-made meals, even when they taste good. [...] In former times, it was like that, everything communal. Then it became: 'They have to do it all themselves again, they have to be able to do it themselves'. [...] I think the social part is very important. The individual is also important, but not on the long term. They already are socially handicapped because they can do less things. So I think they should be allowed to have that. And then they can choose whether to participate in the activity or not. But the possibility has to be there." [R5-3].

## **5.5 PARENT INITIATIVES AND REGULAR FACILITIES: A COMPARISON**

The findings presented in the foregoing sections point to differences in dynamics between parents and professionals. These different dynamics, and more specifically the larger influence of parents on the care vision of their facilities, lead to different approaches of care and organisation. Parent initiatives are collectives. As such, they are closed systems: set up for a specific group of residents and run by a specific, corresponding group of parents and preferably: a specific set of professionals. This is in accordance with the literature on citizen initiatives discussed in chapter 3: homogenous groups, who agree on vision and goals, tend to create exclusive initiatives.

As one professional describes it: “ Parents in a parent initiative found each other. They have had conversations. It is a small scaled group of people, that wants to create something for their sons or daughters who need care. Along the way, people have joined, because they have the same vision and want to put in the effort to achieve that vision. It has a certain sense of collectiveness that regular facilities miss from the start. There, it is the [care] organisation that starts the facility, usually in combination with a housing cooperation who takes care of the physical part. Then you fill the facility with people who are on a waiting list. Parents meet as freestanding people and sometimes that leads to sense of collectiveness over the years, but not in the beginning. For, me, that is the difference: the sense of collectiveness, knowing each other, building a vision together, having conversations about what the care should look like, what we expect.” [R1-2]

Parent initiatives either buy the building themselves, or, more commonly, have contracts with a housing corporation. Especially in the case of new buildings, parents (and residents) can have a lot to say about the design of the facility. This leads to a more personalized living situation. Residents can have a say in the colour of the kitchen or bathroom. Apartments are spacious and communal spaces are luxurious. Parent initiatives often attract a lot of sponsoring, often including a favourable deal with the housing corporation concerning the rent of the communal spaces. Facilities run by parents thus seem to have higher likeability than regular facility, probably because of their small scale and informal organisation (cf. Van Alphen et al. 2010).

Parents start these facilities to make sure their children have a good place to live, where the care is organised the way they want it and where their children can live together, in a safe and stable environment. Parent initiatives are designed as long term facilities, that can be sustained when parents are no longer able to run them themselves. Thus, stability and continuity are very important.

In terms of residents/parents and staff, parent initiatives have lower turnover rates than regular facility. Although when staff is concerned, recent cutbacks in the health care sector have made this more difficult. Care providers prefer employees with temporary contracts, which makes turnover inevitable – since they are only allowed to have a limited amount of temporary contracts in a row. Staff members have stated that they work longer in a parent initiative because they are committed to the initiative themselves and not to the care organisation, and thus are less likely to switch to another facility. Thus, it seems that a parent initiative really can become a collective project. However, where the involvement of parents has been described as ‘a life’s work’, for professionals the commitment is professional and as such limited in time and space. Parents can be very disappointed when a staff member leaves, almost taking it personally. For professionals, this can be overwhelming: “I feel parents are not always realistic in how they think we see the job. For example, I was working last Christmas. I was serving the Christmas dinner when one of the mothers came in and said: ‘How nice that you get to work now!’ And I thought: ‘seriously, I would have preferred to be home.’ I do not think that is realistic.”

The collective approach on care, with a focus on the group and on long-term arrangements can however limit the residents in terms of self-reliance and independence. This is particularly true for the residents with less severe disabilities, in this study mostly the people with autism and normal (to high) intellectual abilities. If they would live in a regular facility, they would have more options to determine their own life and they would usually move to their own apartment outside the facility after some time. In parent initiatives, they live in a much more protective environment: parents tend to be way more protective than professionals, and the influence of parents is much larger in a parent initiatives. Residents sometimes move out of parent initiatives, for instance to get married and start a family. But most residents are happy where they are, also stating that they could never get a larger or

better (located) apartment on their own. This way, a parent initiative has the risk of becoming a golden cage, keeping residents in who could learn to live on their own.

A regular facility is a much more open system. They are started for a target group, but not for specific residents. Residents come and go. There are social activities organized, but being part of the group of residents is not as obliged or stimulated as in parent initiatives. Parents have a lot less influence – they ‘lose’ some of it to professionals, but also some to their children. The vision of care for people with autism and normal abilities focuses on independence, and on using as little care as possible. Staff turnover is higher, but also less seen as a problem. Professionals try to avoid residents becoming dependent on them, so they use a system-approach, as this professional explains: “We try to avoid that, that we make them [the clients] dependent on us. I am personal care worker of a client, but that does not mean that I am the only one that helps this client. The whole team can do a visit. We make the plan and the whole team can do the visit. [...] I try to ensure that the goals that they have, do not depend on one person, but on a system. It should not matter who comes to help you.” [R2-2]

Where in this (regular) facility, dependency on a professional is to be avoided, in a parent initiative it is not necessarily seen as a bad thing – within certain limits. A mother explains: “She [her daughter] recently got a new personal care worker, the one she had, had too little hours for the amount of clients she had. She asked [name] if she would mind it. I thought it was a bad sign [that she did not mind]. It was a decent care worker, I had good contact with her. But her handicap was that she was not very punctual. That really bothered [daughter]. But she was a good personal care worker, so I thought it was a shame. We had to get used to a new one, who indeed is more punctual.” [R4-3]

In parent initiatives, parents spend a great deal of time and energy to make sure that the vision of care is formulated and implemented the way they want it. They try to make sure that their children live in a safe, protective environment, with people they know, like and trust. They create a new home for their children. In regular facilities, there is less focus on creating a group of residents that live together. Clients are first and foremost a part of their own social network. Recently, with health care cutbacks and the popularity of the idea of a

'participation society', professionals have become focused on involving the social network of the client. Professionals should only do these things that parents or other family members cannot do. Parents are thus less involved in the vision of the facility, but they do more practical things for their children.



## CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

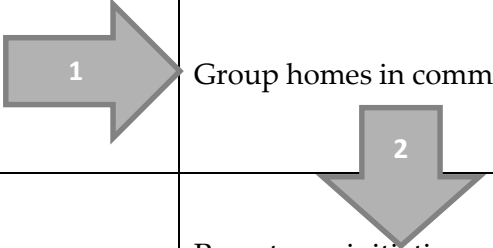
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### 6.1 CONCLUSION

This thesis focused on the question whether it makes a difference in the quality of care whether a small scale residential facility for people with intellectual disabilities and/or autism is set up by parents or by a care organization. Since the focus on small scale facilities that came with deinstitutionalisation is relatively new, it was necessary to study this development first. Thus the first part of this study was a systematic literature review to determine the consequences of deinstitutionalisation for people with mental disabilities, their families and the community at large. The second part of this thesis is an empirical study in the second development: the emergence of parent initiatives alongside small scale facilities set up by care providers. An overview of the two developments can be found in table 9.

*Table 9: Developments in the care for people with mental disabilities*

Type of organization	Scale	Large	Small
Top-down		Asylums	Group homes in community
Bottom-up		---	Parent initiatives in community



Regarding the first arrow, the review showed that locating people with mental disabilities in the community can have large implications for everyone involved. Mentally disabled people who live in the community more often have paid jobs and contact with neighbours. Their social functioning improves. A subgroup even makes new friends in the community. The more their living arrangements approximate independent living, the more chance they have on a large and active social network. However, these positive effects are quite possible not achievable for all people with mental disabilities: the people living in these less restricted settings, are those with less severe disabilities. Part of the people with mental disabilities

become revolving door patients in mental hospitals, or worse: end up in the criminal justice system. Because community care becomes the main focus, patients who remain in institutions are worse off.

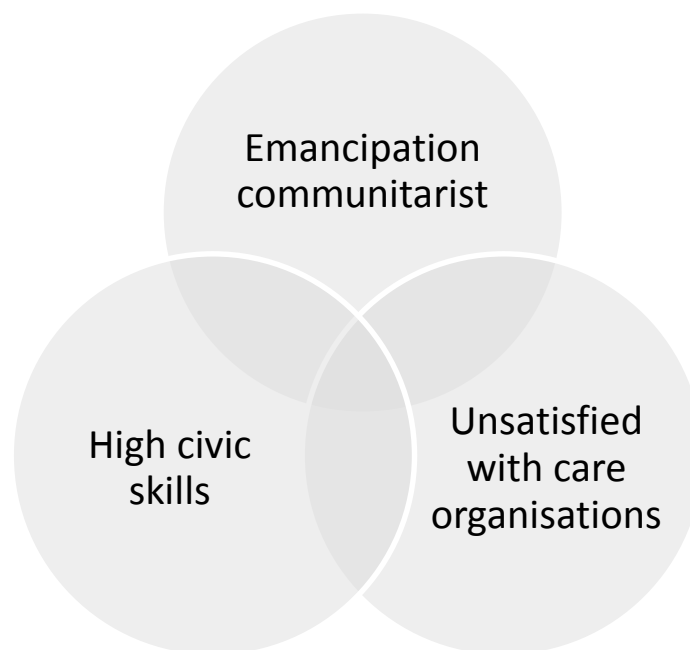
Living in the community also provides this target group with risks they were previously sheltered from, such as undetected (physical) health problems, substance abuse problems, social isolation, victimization of crimes and isolated death. They make more visits to emergency (psychiatric) care. Families of deinstitutionalized patients often resist deinstitutionalization because their care burden increases significantly, which can lead to mental health problems for caregivers. For the broader community, mental health care has improved: community (mental health) care is more accessible and available for everyone to use. On the downside, other citizens have difficulty coping with mentally disabled neighbours, who cause nuisance. These patients do not integrate well into society and some studies suggest a rise of crime committed by the mentally disabled.

In short, a properly functioning community care system can provide (part of) the mentally disabled with better adaptive behaviour, more community access and thus more opportunities for choice-making, autonomy and new social relations. However, it also opens them up for risks their previously sheltered life protected them against, such as social isolation, crime victimization and poor physical health. The burden for these developments falls on the people with the most severe mental disabilities, for whom community care seems not the best option and whose hospital care has worsened; families, whose care burden has increased and the community at large, who has difficulty living with the mentally disabled in their midst and risk suffering nuisance or even higher crime rates.

The second part of this thesis focused on the second arrow from table 10 and consists of an empirical study into the differences between parent initiatives and regular facilities. Professionals, parents and residents of six small scale facilities for people with intellectual disabilities and/or autism were interviewed. First, I looked at who starts a parent initiative – and why. On the basis of existing literature, I identified three characteristics that would make parents likely to start a parent initiative: high civic skills, the right (emancipation

communitarist) mind set and dissatisfaction with the current provision of care – together, they create the Venn diagram in figure 4. Out of these three factors, the mind set seemed the most important: these parents all focus on providing the best care for their child and on their own initiative. They do need to be willing to make compromises with the other parents. In terms of skills, every parent initiative had a group of highly skilled parents. Usually people with skills in terms of management, finances, and some health care or education professionals. But there are also parents with lower social economic standing. As long as one wants to contribute to the group, different people can join a parent initiative. It still requires a lot of time and one has to have a connection with the other parents. A parent initiative is probably not for everyone, making it a somewhat privileged form of care.

*Figure 4: Parents who start or join a parent initiative*



Another reason for parents to start or join a parent initiative was the increased control it provides them over the care their child receives. This control made up for the heightened care burden. Rather than being unsatisfied, these parents are looking for something they do not think regular care can offer them. For some parents, it was also more a matter of availability. They read about the parent initiative in the paper and felt like it could be something for them. A substantial number of parents in parent initiatives never really

considered a regular facility. The same is true for parents in regular facilities: they often had little knowledge about parent initiatives.

The second part of chapter 5 zoomed in on the differences between the facilities. Table 10, on page 82, provides a summary of the findings, compared to the differences as expected from the literature study in chapter 3.

The relationship between parents and professionals is different in a parent initiative. In a regular facility, the consumer model seems most fitting. Parents' most important source of power is that they can take their child to another facility. But in the meantime, professionals dominate the relationship. In a parent initiative, parents have a stronger position, because they run the organization that has a contract with the care provider / employer of the professional. However, professionals are still the only ones with expert knowledge. They have more insight in the disabilities of the residents. The relationship is more equal in parent initiatives, but in the end, the professionals still have the advantage. Because parents and professionals have different visions on care, it is sometimes difficult to find a shared perspective.

Because parents are not bound to the same standards as professionals, the organizational side of a parent initiative is more informal. The lines of communication are short and there is less bureaucracy. The relationship with parents can be more tense, because they have a greater influence, but it can also be very rewarding. Professionals feel more committed to the initiatives, which explains the lower staff turnover rates. However, the fact that parents can do things professional care organizations would not be allowed to do, can also bring on some risks. Parents could implement policies that limit the autonomy of the residents. For parents, it is unattainable to react as impartial board members to incidents when their children are involved, which can make the position of professionals very difficult. Summarizing, parent initiatives provide more leeway, mostly to parents. This has positive effects, but also results in significant risks.

In terms of differences in care vision, two themes proved most important: autonomy versus protection, and group versus individual. Parent initiatives provide a more collective approach to care. Facilities are set up for a specific group of children. Parents focus on long term continuity. The problem is that quite a few parents in parent initiatives are overprotective and tend to think for their child. This limits the autonomy of residents, whereas in regular facilities, autonomy is a very important theme – which can be very frustrating for parents. This is most important for people with autism and normal intellectual abilities. If they live in regular facilities, it is usually not permanent: after a few years they are ready to move to their own apartments. This happens in parent initiatives too, but less often. Since parent initiatives provide luxurious, spacious apartments, residents often do not feel the need to move to their own apartment: they could not find a better one.

The more collective approach on care in parent initiatives also means that the group process is more important. Residents are sometimes obliged, or strongly encouraged, to take part in group activities, even when they do not want to, or when it simply has no value for them. Professionals sometimes feel they need to convince parents that it is worthwhile to provide a good social environment, but that they should factor in the needs of individuals more. On the other hand people with more severe disabilities tend to enjoy a lot of group activities. Regular facilities start providing more collective care moments, both because it is cheaper and because (most) residents prefer this.

Table 10: Differences between parent initiatives and regular facilities

Area	Expected difference – theory	Actual difference – findings
Organisation and (personnel) management	<ul style="list-style-type: none"> <li>• More efficient / less bureaucracy</li> <li>• Shorter communication lines</li> <li>• More innovative</li> <li>• Higher employee satisfaction</li> <li>• Less staff turnover</li> <li>• Risk of over-correction from parents</li> </ul>	<ul style="list-style-type: none"> <li>• More efficiency, due to limited bureaucracy.</li> <li>• Informal communication, shorter communication lines.</li> <li>• Employees feel more connected to the facility instead of their employer.</li> <li>• Less staff turnover.</li> <li>• Over-correction and overprotectiveness from parents limits efficiency.</li> <li>• Parents as board member is difficult: impartiality is difficult, and privacy rules prevent professionals from communicating clearly.</li> </ul>
Parent – professional relationship	<ul style="list-style-type: none"> <li>• Parents have organizational control over the facility</li> <li>• This source of power could make the relationship more equal</li> <li>• Negotiation model instead of consumer model</li> </ul>	<ul style="list-style-type: none"> <li>• More equal relationship; parents have a source of power through their organisational control.</li> <li>• Professionals still dominate in terms of (expert) knowledge.</li> <li>• Parents have insufficient insight in the disabilities of their children.</li> <li>• More negotiation than in regular facilities, but finding a shared perspective is difficult, especially in the beginning.</li> </ul>
Care burden parents	<ul style="list-style-type: none"> <li>• Larger care burden in terms of time investment and (administrative) responsibilities</li> <li>• More influence over care and thus less frustration, alleviates burden.</li> </ul>	<ul style="list-style-type: none"> <li>• Higher care burden in terms of (administrative) tasks and responsibilities.</li> <li>• Involvement in care child similar with parents in regular facilities.</li> <li>• Parents feel they have more control over the organisation, which compensates for the higher care burden.</li> </ul>
Protection vs. autonomy	-	<ul style="list-style-type: none"> <li>• Parents in both types of facilities can be overprotective, favouring protection over autonomy.</li> <li>• Because parents in a parent initiative have more power and are not bound to professional standards, they have more opportunities to be (over)protective and thus risk limiting their child's autonomy.</li> </ul>
Group vs. individual	-	<ul style="list-style-type: none"> <li>• Parent initiatives are set up for a specific set of residents.</li> <li>• They have a collective approach to care.</li> </ul>

		<ul style="list-style-type: none"> <li>• The group processes is deemed very important, to prevent social isolation.</li> <li>• However, parents have difficulty seeing that some residents do not have a need for group activities.</li> </ul>
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In short, both parent initiatives and regular facilities have their up- and downsides. Where regular facilities are good at stimulating autonomy, giving residents the possibility to determine their own life (choices), independent from even their parents, they provide less stability and less social activities than parent initiatives. For people with more severe disabilities, who are most likely going to be in a residential facility for the rest of their life and prefer living in a social setting, parent initiatives provide stability and options for personalization of the living environment, policies and even group formation. For people with less severe disabilities, who might, after some time, be able to live on their own and who have less needs for a social living environment – whether that is because they already have enough social contacts or because they have less needs in this area – a parent initiative can be limiting their potential for autonomy.

This is an intriguing finding, since one of the main advantages and goals of deinstitutionalisation is increased opportunities for autonomy. Deinstitutionalisation is supposed to give people with mental disabilities more control over their lives and living environment. Parent initiatives can contribute to this goal, because the apartments can be customized for the resident, and policies can be adapted to fit the need of this group of parents and residents. However, the parents have gained more power – not necessarily the residents. Thus, parent initiatives can be seen as furthering the goals of deinstitutionalisation – but only in so far as the new opportunities for choice making and autonomy are also available for residents, not just the - sometimes overprotective - parents.

## **6.2 RECOMMENDATIONS**

The foregoing conclusion makes clear that parent initiatives provide new opportunities in the care for people with mental disabilities. However, there are also new risks and challenges. Some of the themes discussed in this study deserve further attention from politicians, professionals and parents.

An important area of concern is the difference in (professional) norms: parents are not held to the same standards as professionals. Citizen initiatives are welcomed for their new way of operating. This research shows that parent initiatives have an easier, more informal communication style. They are also less bureaucratic. However, that parents do not have the



same status as professionals can also hinder the communication between these two groups, because professionals cannot discuss clients with other parents than their own - due to privacy regulation. It is very unpractical at the least that the board of a residential facility and the professionals who work there cannot communicate openly.

The imbalance in rights and duties between professionals and parents can also result in parents becoming too dominant. This can have repercussions for professionals, who are limited in the ways they do their job, but also for residents, who have less individual freedom. Parent initiatives are a special type of citizen initiatives: active citizens are not active for themselves directly, but for their children and their provision – care – is indispensable.

Citizen initiatives and active citizenship are applauded because they provide citizens with opportunities to shape their life and their surroundings - for which they then in turn can take more responsibility. One of the goals of deinstitutionalisation was to increase the autonomy and decision-making opportunities for vulnerable people. Lack of (professional) norms and standards for parents could endanger this goal. New policy on this terrain should make sure that the increased autonomy for active citizens does not go to the detriment of the autonomy vulnerable citizens, who cannot take the responsibility for organizing their lives and surroundings themselves and will need others – whether parents or professionals – to do it for them.

These concerns show that is necessary for a government that advocates for more involvement of family members, neighbours and other non-professionals in the care of vulnerable people to develop a clear vision on their responsibilities and competences. This is necessary both for the functioning of organizations that are managed by non-professionals and for the residents of these facilities, so that their autonomy is respected properly.

For parents, a parent initiatives provides many challenges, of which one is to soften their understandable need to protect their children - because protection can rapidly merge into limiting the autonomy and decision-making capabilities of their children. The composition of the board is also a point of interest. Parent initiatives could consider adding one or more

independent board-members to their board. If members with a background in the care of people with mental disabilities are chosen, they could provide the parents with the knowledge about disabilities that they now sometimes lack. This would make their position more equivalent to professionals and could provide very useful in composing the care vision and new policies. In addition, these members could provide a bridge between parents and professionals when tensions arise. In the current situation, professionals can feel isolated when they have a disagreement with a parent, since the same parents make up the board of the organisation. They could contact the care organisation they work for, but the management of that organisation might not be able to mediate conflict because they are contracted by the board.

The ideal composition of the board of an organisation that is run by people who are directly involved with the clients, but also work with professionals who provide the daily care, would be a good topic for further research. A new study could determine how both parties can work together, without one dominating the other. This would be a very relevant line of inquiry in a participation society, where the involvement of non-professionals in public services is likely to increase.

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## APPENDIX A: TOPIC LIST INTERVIEWS

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### Bewoners

#### Verhuizing

Herkomst

Verwachtingen

Medebewoners

Dagbesteding

Regie

Begeleiding

#### Welbevinden

Fysiek

Maaltijden

Zelfzorg

Genoeg rust

Mentaal

Thuisvoelen in huis

Contact met medebewoners

#### Relaties

Vrienden

Met of zonder beperking?

Waar leren kennen?

Ondersteund door begeleiding?

Familie

Frequentie

Wat voor hulp?

#### Deelname aan samenleving

Werk / Dagbesteding

Vrije tijd

In omgeving of verder weg?

Veranderd sinds verhuizing?

#### Eigen regie

Inbreng over dagbesteding, vrije tijd, relaties etc.

Verhouding tov. Begeleider

Verhouding tov. ouders

Betrokken bij zorgplan

Betrokken bij beleid woonvorm

### Ouders ouderinitiatieven

#### achtergrond

Opleidingsniveau

Beroep

Inkomen

#### Achtergrond kind

Diagnose

Zorgtraject

Toekomstbeeld

#### Keuze ouderinitiatief

Aanleiding

Redenen

Verwachtingen

Kinderen

Eigen inzet

Toekomst

#### Opstartproces

Taken

Gezamenlijke visie

Starters/kerngroep

Aanhakers: wanneer / type

Locatiekeuze

Samenstelling groep

Verhoudingen / communicatie binnen groep ouders

Hulp van derden?

Zorgaanbieder

Woningcoöperatie

MEE / Woonlink

#### Relatie met zorgaanbieder

Keuze

Beleidswisselingen

Afspraken

#### Begeleiding

Frequentie contact – met of zonder kind?

Onderwerpen

Gelijkwaardigheid / gezamenlijk belang

Andere zorgverleners?

Verdeling 'taken'

Tevredenheid

### Relatie met kind

Hoe vaak contact

Regie

Zorgtaken

Verantwoordelijkheden

### Welbevinden kind

Fysiek: zelfzorg, genoeg rust

Mentaal: zelfbeeld, thuis voelen, gewaardeerd voelen

Interpersoonlijk: goede relaties, goede communicatie, omgaan met affectie en intimiteit

Deelname aan samenleving: dagbesteding, hobby's, eigen omgeving

Goed zorgplan

Veiligheid

### Beleid

Bestuur

Samenstelling

Taken

Invloed bewoners

Invloed zorgverleners

Financiën

### Family burden

Hoeveel zorg (vaak/tijd)

Invloed op:

Werk

Sociale relaties

Gezondheid

Vrije tijd

Verdeling van zorg in familie

kosten



### Ouders zorginstellingen

Achtergrond

Opleidingsniveau

Beroep

Inkomen

Achtergrond kind

Diagnose

Zorgtraject

Toekomstbeeld

### Keuze woonvorm zorgaanbieder

Redenen

Alternatieven

Ouderinitiatief overwogen?

Samenstelling bewonersgroep

Verwachtingen

Kinderen

Eigen inzet

Toekomst

### Relatie met zorgaanbieder

Beleidswisselingen

Afspraken

Vrijwilligers

### Begeleiding

Frequentie contact

Onderwerpen

Gelijkwaardigheid / gezamenlijk belang

Andere zorgverleners?

Verdeling verantwoordelijkheden

### Relatie met kind

Hoe vaak contact

Regie

Zorgtaken

Verantwoordelijkheden

### Welbevinden kind

Fysiek: zelfzorg, genoeg rust

Mentaal: zelfbeeld, thuis voelen, gewaardeerd voelen

Interpersoonlijk: goede relaties, goede communicatie, omgaan met affectie en intimiteit

Deelname aan samenleving: dagbesteding, hobby's, eigen omgeving

Goed zorgplan

Veiligheid

### Beleid

Invloed bewoners

Invloed ouders

Belangrijkste thema's

### Family burden

Hoeveel zorg (vaak/tijd)

Invloed op:

Werk

Sociale relaties

Gezondheid

Vrije tijd

Verdeling van zorg in familie

Kosten

Frequentie contact

## **Begeleiders**

### Achtergrond

Opleiding / functie

Werkervaring

Komst naar deze woonvorm

    Typering groep/ bewoners

Tevredenheid

### Organisatie

Relatie met management / bestuur

Hoeveelheid begeleiders per woning / turnover

Competent personeel

Beleid(swijzigingen)

Invloed ouders

Invloed bewoners

### Zorg

Zorgplannen

    Andere zorgverleners?

Veiligheid

    Fysiek

    Sociaal/emotioneel

        Sociale klik groep

    Protocollen

### Welbevinden cliënten

Fysiek

Mentaal

Sociale contacten

    Familie

    Vrienden

    Huisgenoten

    Participatie in samenleving

        Werk/dagbesteding

        Lokale community

    Eigen regie

### Contact met ouders

Frequentie

Onderwerpen

Professionele ruimte / afstand-nabijheid

Samenwerking? Verantwoordelijkheden?

Algemene taken

Bewoner-specifiek -> type beperking?

## **APPENDIX B: INTERVIEWEES**

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Group 1: Parent initiative for people with autism and normal intellectual abilities

R1-1: Professional 1, 20 – 30 y/o

R1-2: Professional 2, 40 – 50 y/o

R1-3: Parents 1&2, 60 + y/o

R1-4: Parents 3&4, 60 + y/o

R1-5: Resident 1, 25 – 35 y/o

R1-6: Resident 2, 25 – 35, y/o

Group 2: Regular facility for people with autism and normal intellectual abilities

R2-1: Professional 1, 20 – 30 y/o

R2-2: Professional 2, 45 – 55 y/o

R2-3: Parents 1&2, 40 – 50 y/o

R2-4: Parent 3: 45 – 55 y/o

R2-5: Resident 1: 20 – 30 y/o

Group 3: Parent initiative for people with light intellectual disabilities

R3-1: Professional 1, 25 – 35 y/o

R3-2: Professional 2, 25 – 35 y/o

R3-3: Parent 1, 45 – 55 y/o

R3-4: Parent 2, 45 – 55 y/o

R3-5: Resident 1: 20 – 30 y/o

R3-6: Resident 3: 20 – 30 y/o

Group 4: Parent initiative for people with autism and normal intellectual abilities

R4-1: Professional 1, 25 – 35 y/o

R4-2: Professional 2, 40 – 50 y/o

R4-3: Parents 1&2, 60 – 70 y/o

R4-4: Parents 3&4, 65 – 75 y/o

R4-5: Resident 1, 30 – 40 y/o

R4-6: Resident 2, 20 – 30 y/o

Group 5: Regular facility for people with moderate to severe intellectual disabilities

R5-1: Professional 1, 25 – 35 y/o,

R5-2: Professional 2, 45 – 55 y/o,

R5-3: Parents 1&2, 55 – 65 y/o,

R5-4: Parent 3, 70 – 80 y/o

R5-5: Resident 1, 65 – 75 y/o

R5-6: Resident 2, 40 – 50 y/o

Group 6: Regular facility for people with autism and normal intellectual abilities

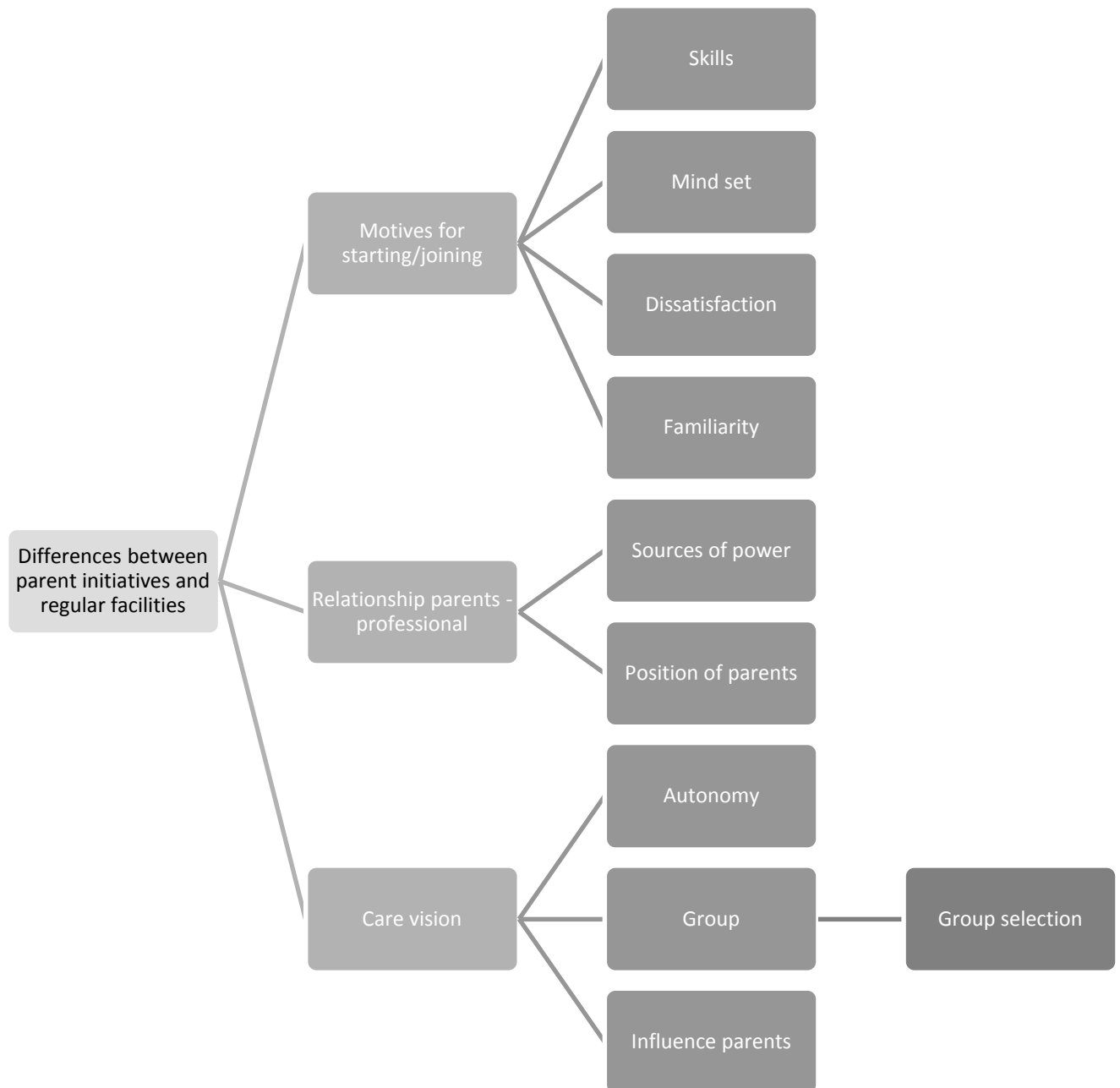
R6-1: Professional, 40 – 50 y/o

R6-2: Professional, 20 – 30 y/o

R6-3: Parents 1&2, 50 – 60 y/o and resident 1, 20 – 30 y/o

## APPENDIX C: CODE TREE

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## APPENDIX D: SUMMARY TABLE

		Number of studies (S)/ participants (N)	Outcome
<b>POSITIVE EFFECTS</b>			
<b>Quality of life</b>			
Physical domain	Young and Ashman 2004a	S4	+
	Bigby and Fyffe 2006	S4	+
	Young and Ashman 2004b	N104	+
Social relationships	Young and Ashman 2004a	S3	+
	Young and Ashman 2004b	N104	+
Psychological well-being	Sealy 2012	Compare days of care in (mental) hospital	+ (for whole community)
	Young and Ashman 2004b	N104	+
Community access:	Young and Ashman 2004a	S5	+
	Young and Ashman 2004b	N104	
<b>Social inclusion</b>			
Social network	Young and Ashman 2004a	S3	+
	Kozma et al. 2009	S9	+
	Emerson et al. 2000	S4	+
	Duggan and Linehan 2013	S7 (amongst which Bigby 2008)	0 (small; mostly family, care givers and other patients)
	McConkey and Collins 2010	N245 staff members	+ (in individualized housing options)
	McConkey 2007	N620 residents	+ (higher increase in more individualized housing)
	Forrester-Jones et al. 2012	N85 patients	+ (mostly family, caregivers and other patients)
	Forrester-Jones et al. 2006	N213 people with ID	+ (mostly family, caregivers and other patients)
	Amado et al. 2013	S3	+ (mostly family, caregivers and other patients)
	Bigby 2008	24 residents	0 (mostly family, caregivers and other patients) - (decrease after time)
Community participation:	Dusseljee et al. 2011	N653 people with ID	+ (possibly dependent on level of disability)
Social distance:	Ouelette-Kuntz et al. 2010	N625 community members	+ (influence of age and education level)



<b>Adaptive behaviour</b>	Hamelin et al. 2011	S23 (meta-analysis)	+
	Kozma et al. 2009	S10 (amongst which Young and Ashman 2004ab)	+ (depending on environment and residential facility)
	Young and Ashman 2004a	S3	
	Young and Ashman 2004b	N104 residents	+
	Chow and Priebe 2013	S14	+ (curvilinear affect: plateau at 24 months)
	Kunitoh 2013	S11	+ (not for all patients; paternalistic staff + (after rehabilitation training)
<b>Better quality of care</b>	Singh & Castle 2007	S6	+ (but lack of early intervention systems)
	Parker 2014	S0	+
	Killaspy et al. 2012	N213 patients	+ (mostly through increase in autonomy)
	Young and Ashman 2004b	N104 residents	+
<b>Economic benefits</b>	Knapp et al. 2011	N11	+ (when related to outcomes)
<b>NEGATIVE EFFECTS</b>			
<b>Health and well-being</b>			
Physical health	Salonkangas et al. 2007	S2	- (poor physical health can prevent rehabilitation)
	Schmetzer 2007	S1	-
	Bertoli et al. 2011	N884 residents	-
	Yohanna 2013	S2	-
Substance abuse	Slayter 2010	N226.974 burgers	- (people with ID are less likely to seek treatment)
	Schmetzer 2007	S2	-
Emergency care / revolving door	Kalucy et al. 2005	N10 year ER records	-
	Bruffaerts et al. 2008	S8	- (lack of adequate community care)
	Saz-Parkinson et al. 2011	N24 year admission rates	-
	Machado et al. 2012	S16	-
	Livingston et al. 2011	N335	+ (after realignment care settings)
Suicide	Yoon and Bruckner 2009	N16 year suicide rates	- (increase in community health may help)
	Heila et al. 2005	N58.761 patients	-
	Matheson et al. 2005	N5 year police calls suicide	-
Social isolation	Nilsson and Lögdberg 2008	N53 years autopsies	- (increase of isolated death)
	Martinsson et al. 2012	N7 elderly patients	- (powerlessness, vulnerability and disrespect)

<b>Redistribution within target groups</b>	Hall and Hewson 2006	N123 residents	- (little community links)
	Novella 2010	S3	-
	Davis et al. 2012	S3	-
	Arvidsson et al. 2005	N10 years case register	- (attention for schizophrenia means less for other diagnoses)
	Csipke et al. 2013	N16 inpatients + activity records	- (severity of illness of patients means less time for activities)
<b>Criminal behavior and victimization</b>			
Criminal behavior	Gostin 2008	S12	- (inadequate community care)
	Abramowitz et al. 2008	N data on admissions	-
	Kramp and Gabrielsen 2009	N 17 years case register data	- (long term effect)
	S5		- (many offences related to substance abuse)
	Schmetzer 2007	N2861 patients	- (compared to community comparison subjects)
	Wallace et al. 2004	N 50 years census data	- (from 1980s onwards; mostly men)
	Raphael et al. 2013	S2	-
	Toib 2006	N156 police officers	- (extra police training necessary)
Victimization	Psarra et al. 2008		
	Short et al. 2013	N 30 years case register data	- (for (sexually) violent victimization)
	Teplin et al. 2005	N 1782 patients	-
<b>Burden of care: family members</b>	Schmetzer 2007	S1	-
	Isolation from community		
	Wiesel et al. 2013	N field observations	-
	Wiesel and Bigby 2014	N survey + interviews	-
	Rossow Kimball and Goodwin 2014	N 12 visitors + staff senior centre	-
	Van Alphen et al 2010	N 30 neighbours	-
	Hall and Hewson 2006	N123 residents	-(no change over time)
	Van Asselt-Goverts et al 2013	N 33 people with ID	-

Family burden	Tossebro et al. 2006	N family and staff of 221 patients	-(but reinstitutionalisation is also not an option)
	Basta et al. 2013	N residence status of 400 patients	-
	Wang (2012)	S 7	-(especially when patients live at home)
	Chan (2011)	S15	-
	Gray et al. (2014)	N 536 young adults with ID	-
<b>Disappointing financial consequences</b>	Knapp et al. 2011	N 3 countries	- (if outcomes are taken into account)
	Sealy et al. 2004	N 30 years care expenditures	-
	Power et al. 2013	S 3	- (deinstitutionalization often accompanied by cutbacks, which hurt quality of care)