Experiences of Caretakers with their Special Children Living Together in the Community in Japan and the Netherlands

THESIS for AMMA
By Drs Ton Millenaar

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Supervisor: Dr Ria Reis

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*page 1 painting from Yuduke Namahira (1985) Japanese artist with autism from Okinawa*
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First of all I would like to thank all the caretakers who gave me the motivation to start with this thesis. They convinced me strongly about their need for, and the vital importance of, living together with their special children in the community. I am very grateful that they allowed me the opportunity to meet their children and I appreciate that they gave me permission to reproduce some pictures of them and their children in this thesis. They inspired me and taught me the real meaning of interdependence and togetherness.

Further I acknowledge the key caregivers in Japan and the Netherlands who made all the connections and practical arrangements for the interviews with the caretakers; the participant observation with the special children; and the meetings with them in focus and support groups in both countries.

Special thanks must go to the chairperson of Tokajuku, Masako Iwasaki, who was so supportive and made possible the abovementioned arrangements in Japan. Moreover, she gave the professionals from Tokajuku, especially Yoshimi Ishiguro and Nobuko Fujii, the opportunity to interpret all my contacts from Japanese into English.

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All the abovementioned people have reminded me of how importantly we need one another, and I have realized all the more that we can learn so much from each other.
SUMMARY

People with disabilities nowadays live integrated in the community in many countries. However, in countries like the Netherlands and Japan, in which some residential facilities have been maintained, some professionals, providers, and caretakers, are of the opinion that people with profound intellectual disabilities and/or multiple disabilities need to live in protection in places of segregation. From my experiences with a number of caretakers of children with profound intellectual disabilities, I have found that they often choose Community Based Services (CBS) when these kinds of care and support are available. Therefore I am motivated to examine more extensively their experiences of living in the community. In this way I expect to find out more about their special needs for support from people of the community (see section 1.1, background information).

Although professionals and providers claim to be client-centred, I personally experienced and also found in the research literature that they are often oriented in their supply of care and services from their own points of view. I think, and have been encouraged by some articles (see section 1.2, statement of the problem), that especially for this target group it will be relevant to uncover more about the experiences of caretakers and their special children of (non-)acceptance by citizens in the community. In this context the main objective is to examine their needs for support from CBS (see section 1.3, research objectives). At the end of sections 2.1 and 2.2 – the literature review and the CBS – I describe my own search for new perspectives (section 2.3).

In chapter 3, I mention the various aspects of the methodology. I did the fieldwork in cooperation with the caretakers, who are the social agents in their surroundings. In section 3.2 I explain the way in which I made the selection of the caretakers. The research questions and the data collection I work out in section 3.3 and 3.4. In advance, I obtained consent for the interviews from the responsible providers and the caretakers involved (see section 3.5, ethical considerations).

I present the data in the distinguished areas which are connected with the experiences of the caretakers in the sub-questions, namely the experiences with their own family (4.1), the professionals (4.2.), and the community. This has been limited to the direct neighbourhood and the school because of the age of the special children (4.3). I also planned meetings in focus and support groups in which the caretakers support each other (4.4). Finally, I describe the experiences with the laws and regulations (4.5). In section 4.6 I

1 I have worked as director of an organization for care and welfare for people with disabilities in the Netherlands, and as an adviser in the same field in Japan.
analyse the presented data of the overarching themes and the similarities and differences between Japan and the Netherlands in section 4.7.

In chapter 5, discussions, I give my impressions about the problems the caretakers experienced and some recommendations which I found in the (recent) literature research, and some are related with my own frame of reference. In chapter 6, conclusions, I reflect on the findings which are useful for the improvement of the quality of life of the special children and their families in the community. After this I offer some personal concluding remarks which are important for my own career.
CHAPTER 1 – INTRODUCTION

1.1. Background to the problem

Until the 1960s in many Western countries the opinion was widespread that people with profound intellectual and/or multiple disabilities needed protection in separated residential institutions and treatment in specialized facilities (Mans 1998). Such an approach, which is based on the medical model, is only focused on the serious impairment of people with disabilities and causes exclusion from the community and stimulates stigmatization (Goffman 1968).

In the 1960s, campaigns for equal civil rights, especially for black people in the United States, served as a model for people with all kinds of disabilities (Hahn 1985). In the 1980s and 1990s, this development was followed by standard rules on the equalisation of people with disabilities (Herr et al. 2003). Since August 2006 these basic human rights have been described in the UN convention on the rights of persons with disabilities, and have been published on the Internet (UN Convention 2006).

Parallel with these human rights movements, the medical model changed to a model of ‘normalization’, which has been applied in a lot of developed countries. In ‘Normalization, Social Services and Community Services’, Flynn & Nitsch (1980) described the implementation of these principles. The main policy is clearly emphasized by one of the founders, Nirje (1980), that people with disabilities have the same human rights and duties as all other citizens. As a consequence, a process of de-institutionalisation had started.

In most countries, the movement from exclusion to inclusion, and the development of Community Based Services (CBS), has become embedded within social and economic dynamics and cultural patterns. In the Scandinavian countries of Sweden, Denmark and Norway, the governments have made legislation that residential institutions have to be closed down and people with disabilities have to live in the community. In the USA this process was initiated by movements of parents with disabled people. Very large residential institutions – in which several thousand people lived in one facility – were closed down in the 1970s and 1980s. In other developed countries like the Netherlands in Europe, and Japan in Asia, this process of integration developed at the same time in a relatively similar way; step-by-step (Matsuura 2005; Kooiker 2006).

This study aims to concentrate on the experience of children with profound intellectual and/or multiple disabilities living with their most important caretakers – especially their parents – in the community in two countries: Japan and the Netherlands. This study
definitely does not intend to label the children as people with impairments in these countries (see chapter 2.1.2.; Rentlin 2003).

In the next sections I want to mention the specific target groups for the research: the special children; the key people involved – especially the parents – who are responsible: the caretakers; and the people who support them: the caregivers.

1.2. Statement of the problem

In contrast to the example of Scandinavian countries, the process of consistent de-institutionalization in the Netherlands and Japan has neither been radically realised, nor was this process forced by parents’ organisations. One of the reasons is that in these countries the facilities have been built on a much smaller scale. As a consequence, the providers created possibilities for community based facilities and step-by-step services. They followed the policy that could be briefly summarized “as normal as possible and as specific as necessary”. The governments in both countries based the official policy on the principles of ‘normalization’, but in practice regulation is not focused on the closure of institutions. Through this policy, some (residential) facilities have still been maintained and the Community Based Services have not yet been fully developed (Matsuura 2005; Kooiker 2006).

However, in the field of care and welfare, I consider that the caretakers with their special children want to make choices for certain Community Based Services which have been based on their own needs (Millenaar 2004). Theoretical models are not sufficient for these choices which are based on the possibilities of daily practice in the social context. On the one hand, the medical model, in the process of medicalization of society as described by Foucault (1989), hospitalized people with disabilities. On the other hand, the social models of normalization and integration (Flynn et al. 1980) did not emphasize the special needs of people with disabilities. Shakespeare (2006) challenged the assumption that the social models were the only progressive or social-contextual approaches to disability. He proposed that disability always is in interaction between individuals and structural factors in the community.

In a survey article Klotz (2004) emphasized that until now the socio-cultural study of intellectual disability has mostly focused on the experience of people with mild intellectual disabilities. He assumed that these experiences are extrapolated to the nature of intellectual disability in general, while the experiences and life worlds of those whose impairments are profound or multiple, are often ignored.
The first socio-cultural attempt to understand and analyze the experiences of people with disabilities from their own perspectives was undertaken by Edgerton (1963). Edgerton inspired researchers to study intellectual disabilities from a variety of cultural perspectives, emphasizing both the values of qualitative and narrative-based analysis through participant observation.

Through participant observation Goode (1980) tried to enter the everyday world of multiply-disabled children. The key person in one of his earliest studies was a deaf, blind and retarded girl called Chris who lived in a state hospital ward. He realized that it was in fact impossible for him to ever know how she experiences the world. He decided that “only intimate and persistent interactive contact...would enable (him) to enter (her) world” (Goode 1980: 187). He described that Chris did not recognize or utilize linguistic symbols, but he argued that she was still capable of communicating her needs and desires to others.

Goode's interactive encounters with Chris broke new ground in the socio-cultural study of profound intellectual disabilities. Rather than embodying culture and communication in linguistic capabilities, Goode acknowledged that it was possible to accept a shared world through such intimate interactions.

Gleason (1989) utilized such anthropological techniques throughout his work. He provides an in-depth account of people with severe and multiple disabilities. As part of his research, Gleason spent five years of fieldwork observing the social interactions of a group of residents at a state school for physically and intellectually disabled children in North America.

It was through the work of Goode (1980), and Gleason's long-term fieldwork (1989), that serious attempts were made to analyse the lived reality of people with severe and profound disabilities. In their different ways, both sought to portray the social and meaningful nature of severely intellectually disabled people's life worlds. Klotz (2004: 101) argued that:

Goode and Gleason both accepted the inherent humanness of people with severe and profound intellectual disabilities. However neither of them utilized their insights to question the very foundation of our limited notion of what constitutes meaningful behaviour and interaction. Yet it is upon such social and cultural foundations that our perception of "normal" personhood is built. And it is these foundations that need to be challenged if all people with intellectual disabilities are to be accepted and engaged as inherently social and cultural beings.

From this kind of foundation I want to examine the ways in which special children, together with their caretakers, experience the way of living in the community. I also want to find out about their needs from Community Based Services and moreover their experience of (non-) acceptance by people in the community.
1.3. Research objectives

1.3.1. Main research objective

Contribute to the set up of Community Based Services (CBS), in Japan and the Netherlands, which will be based on the needs of the special children and their caretakers for living in the community.

1.3.2. Specific study objectives

- To determine the needs of the special children for living in the community
- To determine the needs of the caretakers who live together with their special children in the community
- To examine the necessity of CBS; based on the needs of the special children living with their caretakers
- To examine the kind of support provided by professional and informal (volunteer) caregivers, based on the needs of the special children and their caretakers
- To aid the facilitation of public health and welfare agencies based on the special needs of people with disabilities living in the community
CHAPTER 2 – THE BROADER PERSPECTIVES

2.1. Literature review

2.1.1. The consequences of segregation and stigmatization for people with disabilities

From the nineteenth century through the Enlightenment and the related individualization, medicalization of the body (Foucault 1989) has grown into a model of hospitalization. From these ideas, people with apparent impairments were excluded from the mainstream of community life into all kind of institutions. Such a unidirectional approach that only focuses on the impairment of people with a disability causes segregation and stimulates stigmatization. In this process, people are divided between 'normal human beings' and those who are not. The consequence of this way of categorizing is that people with a disability need a special approach; like sick people need special treatment. Therefore they were thought to need a separated place in a residential facility. These people do not have the possibility to participate as normal citizens in society.

Erving Goffman (1968) in his widely referenced study Stigma, suggests that the notion of 'normal human beings' may have its origins in a medical approach and it is also very much a normative system of grading people. It is bolstered by an ideological justification for treating those with a perceived stigma as 'not quite human'. Goffman explained that disabled people are often blamed for their condition, or at least for not achieving maximum recovery. As sure proof that they bear stigmatized identities, physical impairment is looked on as something that does not happen to respectable people. For example, the blind are people who make brooms in sheltered workshops or who sit on street corners with tin cups. They certainly do not belong among the mobile people.

2.1.2. The meaning of human rights for people with disabilities

This process of segregation was firmly attacked by the movement in the 1960s for equal Civil Rights, especially for black people, which served as a model for people with disabilities (Hahn 1985), for example through the International Year of Disabled Persons in 1981, followed by the United Nations Decade (1982-1992) for Disabled Persons declared by the UN in 1983. This was followed by Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (UN 1994). Since August 2006 these basic human rights have been described in the UN convention on the rights of persons with a disability. Despite the
paradigm shift from the 'functional limitation model' to the 'human rights model', ethnographic studies of people with disabilities continue to focus on specific characteristics of 'impairments' (Renteln 2003).

In the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, there are twenty-two rules to facilitate full participation and equality for disabled people. Unfortunately, in the ten years after its inception, these Standard Rules were only patchily implemented because they did not get a basis in international human rights law. That has been improved now because the UN adopted a new treaty in September 2006, which will give greater rights and freedoms to people with a disability (UN 2006).

In March 2007 many countries came together in New York to sign the UN Convention of 2006, for the rights of persons with a disability. According to the data of the UN, 650 million people around the world have all kinds of disabilities. 500 million of them are living in non-Western countries and 87% of them are still children. Of these children, 90% do not attend any school. People with an intellectual disability are especially likely to become the victims of stigmatization. People involved have to start new policies to fight against this kind of discrimination, segregation, and stigmatization. Further, in the UN Convention it is determined that the policy makers in developed countries are obliged to support their non-Western partners in the improvement of the bad circumstances of people with a disability (Vreeken, in Volkskrant 2007: 2). However, these key people also have to improve the circumstances of people with disabilities in their own countries. They offer many specialized facilities and services for people with disabilities, but at the same time their living conditions are still segregated from the community. This is the first human rights treaty of the 21st Century and the UN hopes it will create a significant improvement in the treatment of disabled people. The former Secretary General of the UN, Kofi Anan, mentioned this international treaty as an historic achievement for the 650 million people with disabilities around the world.

One of the crucial human rights for people with disabilities has been described in article 19 of the Convention. The title is 'Living independently and being included in the community'. States which have ratified the Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others. People with all kinds of disabilities and also the others involved – especially parents – can participate as active social agents in the implementation of all 50 articles of the Convention. This support for human rights will hopefully create a paradigm shift in conceptual thinking about disabled people. In this study I used these articles as a kind of check list for topics which could be relevant for the experiences and the needs of special children and their caretakers in the community.
2.1.3. Normalization and integration in the community for people with disabilities

After the beginning of the Human Rights Movement, and also parallel with these developments, different variations on the principle of normalization for people with disabilities have been implemented in a lot of Western societies since the 1970s. Until 1970, the term normalization was never used in the context of welfare for people with disabilities. Bengt Nirje (1980) in Sweden used ‘normalization’ for the first time in this context and he defined this term as making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances of society. The term became more widely popular when it was used by Wolfensberger (1980) in the United States, who assumed that it would require culturally normative means to offer persons with disabilities life conditions at least as good as that of average citizens, and to enhance or support as much as possible their behaviour, appearance, status, and reputation.

This assumption has been criticised in the sense that people with deviant behaviour have to be normalized in a process of adaptation in the community. For example, Chappell (1997) elaborated that normalization concentrates on the social behaviour of the devalued person with the intention of modifying it, by teaching social skills, in order to facilitate relationships with non-disabled people. Critics have also suggested that whatever normalization achieves for disabled people, it principally facilitates professionals’ adaptation to new policies. Normalization does not challenge the legitimacy of the professional role in the lives of disabled people but guarantees its continued authority (Barnes et al. 1999). That means they just apply the model of normalisation from their own point of view, instead of the perspective of the special children and their caretaker’s needs and perspectives.

Nirje (1980) described that the application of the normalization principle will not “make mentally retarded people normal”, but it will make their life conditions as normal as possible, respecting the degrees and complications of the disability. That means sharing a normal rhythm of the day, with privacy, activities, and mutual responsibilities; a normal rhythm of the week with a normal home for living in, a school or work to go to, and leisure time with social interactions. Normalization also means the opportunity to undergo the normal developmental experiences of the life cycle: infancy, with security and the respective steps of early childhood development and the increase of skills and experience with development towards adult life and options.

However, Shakespeare (2006) challenged the assumption that the social model, like normalization, was the only progressive or social-contextual approach to disability. These criticisms have focussed on the failure of the social model to recognize the role of impairment as well as the inability of the social model to encompass the range of different
impairments/disabilities. The approach that Shakespeare proposes to adopt is that disability always is an *interaction* between individuals and structural factors in the community. Rather than getting fixated on defining disability, either as a deficit or a structural disadvantage, a holistic understanding is required.

The key word in this interaction approach is participation in the community by people with disabilities. Much disability literature speaks of integration as the ideal, when in fact participation might reflect more accurately what disabled people aspire to. Of course it is not necessary that people with disabilities always reach the highest rungs of the ladder of participation (Hart 2002), although a programme should be designed to maximize the opportunity for any disabled person who chooses to participate at the highest level of his/her ability. Such a programme can only be successful when this is based on the needs of the special children.

2.1.4. Acceptance and (non-)acceptance of people with disabilities

Non-acceptance

In a survey article about the stigma of a chronic neurological disorder, Jacoby (2005) found that common to theories of stigma was the emphasis on a social group process. “The labelling, stereotyping, separation from others and consequent status loss are the key elements of stigma”. In a panel discussion, components of stigma are enumerated which also are important in this study (Jacoby 2005: 173):

People differentiate and label socially important human differences
1. Dominant cultural beliefs link labelled people with negative stereotypes (for example, people with a mental disability are a danger to others)
2. People who are labelled are placed in distinct categories (e.g. ‘epileptic’ or ‘disabled’) to separate them from others
3. People who have been labelled experience status loss and discrimination (e.g. unequal socioeconomic outcomes)
4. Social, economic, and political power enables components one to four

One of the clearest displays of stigmatization is the labelling of different disabilities by professionals. Edgerton (1963) criticized the fact that despite the enormous amount of literature in the field of disabilities, nearly all of the research was from the perspective of professionals like social workers, psychiatrists, psychologists, and medical specialists. In such circumstances, people with disabilities are only labelled in terms of their disabilities or abnormalities. As Edgerton (1967: 193) described:

The label of mental retardation not only serves as a humiliating, frustrating and discrediting stigma on the conduct of one’s life in the community, but it also serves to lower one’s self-esteem in such a way that the life of a person so labelled is scarcely worth living. There is no cure, no hope, and no future because the stigma of retardation is total.
Shakespeare (2006) called this phenomenon 'identity spread', meaning that a person's individuality—not only their personality, but also other aspects of their identity such as gender, sexuality, and ethnicity—can be ignored as the impairment label becomes the most prominent and relevant feature of their lives, dominating interaction.

Acceptance
Normalization has to be implemented by creating the necessary conditions for a process of integration. Nirje (1980) distinguished three different kinds of integration:

a) Physical integration, which means that people with a disability can live in a normal house in the community. They can go to regular schools and they can work in regular jobs in the labour market.

b) Functional integration gives people with a disability access to all parts of the environment.

c) Social integration is the most difficult to realize in daily practice. This can only be realized when people with a disability can make their own choices for social relationships and intimate friends in the community. Therefore they need to feel accepted by the citizens of the community.

However, the reality is that disabled people are affected by physical, psychological and external problems. A theory which focuses only on external barriers is an incomplete response to the challenge of disability. Substituting medical treatment for social change is also unacceptable. Both approaches are needed.

Shakespeare (2006) described that through the interactional approach (see section 3.3) problems with disability cannot entirely be eliminated by any imaginable form of physical or social arrangements. The priority for a progressive disability politics is to engage with impairment, not to ignore it. This engagement makes space for an often neglected aspect of disablement: personal attitudes and motivation.

Taylor and Bogdan (1989) introduced a sociology of acceptance. They call for research into what can foster connection, how relationships can be supported, and how both disabled and non-disabled can be enabled to form friendships with each other. Coleridge (1993: 35) emphasized that acceptance of disability is a complex and lifelong process, involving many people and many factors:

...to regard permanent impairment either in a newborn baby or in an adult, as a loss is an understandable reaction; but if it is allowed to persist, such a reaction is not likely to lead to any constructive life process, either for the disabled person or for the non-disabled people around him or her. It is a new circumstance which everybody has to adjust to and come to terms with.
The background of these experiences of special children, their caretakers, and the caregivers with non-acceptance and acceptance by people in their surroundings will serve as a guideline for the methodology of this study.

2.2. Community Based Rehabilitation (CBR) as a good basis for living in the community

One of the earliest initiatives towards CBR was made in the late 1950s. On the initiative of the parents’ advocacy movement, people involved made efforts on behalf of mentally disabled persons, starting in Massachusetts (USA), implementing comprehensive regional services system projects (Hogan 1980). I mention this project as a good example of a CBR ‘avant la lettre’ which became a worldwide movement more than twenty years later.

CBR is a strategy that springs from the approach of normalization and integration in society. This approach is implemented by combined efforts of persons with disabilities, their families and others involved, with support from relevant institutes for health, education, vocational training and social services. This community based approach facilitates the acceptance and participation of people with disabilities in their natural surroundings. CBR can build on existing community traditions, structures and networks such as extended families, local committees, and volunteers.

CBR was promoted by the World Health Organization and other UN agencies in the early 1980s as an alternative option for the rehabilitation of people with disabilities in developing countries who had no access to services (WHO 1981). Since the countries had limited resources to provide high quality institutional services, the emphasis was on developing a method which provided wide coverage, at costs that were affordable to the governments of these countries. Interventions were to be shifted from institutions to the homes and communities of people with disabilities, and carried out by minimally trained people, such as families and other community members, reducing the costs (WHO 1989).

A very good example of such a successful initiative is a project in Mexico, called Projimo. It is a rural CBR programme run by disabled people. This project started in the 1980s as a reaction on the lack of healthcare support for disabled children. Initial support came from David Werner, a disabled American, who had been involved in the independent living movement for a long time. In a kind of instruction book entitled ‘Nothing About Us Without Us’ (1998) he describes the ways in which the whole community is run by disabled and non-disabled people. An important part of their work has been to take up hand-made solutions to the mobility needs of disabled children and adults who arrive in Projimo with nowhere else to go. This is possible in a country where there is very little welfare support or
social provision. These people with disabilities give the strong message that they can be social agents who can make choices and control their own lives.

The disabled people who started Projimo identified the main barriers as the lack of healthcare and the lack of assistance. Then they turned their interpretation of their particular situation into practice by making what they needed and calling for the necessary specialized support. They use the slogan ‘nothing about us without us’, meaning that people have the right to make their own choices in their own surroundings. They are able to live independently or they can make decisions to live in an interdependent community in companionship with others.

I have described this CBR approach more extensively because this could inspire people in developed countries as to how they could mobilize professionals and volunteers in the community to develop companionship for people with disabilities based on acceptance.

2.3. My own search for new perspectives

In my career as a clinical psychologist, and later as managing director of care and services, I worked for many years in the field of disabilities. During this period I experienced a gradual change in the ideology and the way of thinking about the cure and care for this target group. In general, this change was based on a shift from the medical model to the social model. Step-by-step I became convinced that the social model was much more effective. Hence I became involved in the movement from segregation in residential facilities to integration in the community for people with special needs.

On various levels I was busy realising these new targets. This meant we had to convince policymakers who did not want to change the health system. We had to change the behaviour and attitude of the caregivers and other professionals, which was based on the idea of hospitalisation. We had to force the people in the community to accept people with disabilities as their new neighbours. Finally, we had to break the resistance from the family, especially the parents, who did not want to change the safe and secure surroundings in these residential facilities to which they were accustomed.

In the same period I was asked to set up an early detection system in Indonesia, together with professionals in the country. I became impressed by the influence of culture on attitudes towards people with disabilities. We detected children who were often hidden in their villages, in the houses of their families. Mothers with children were called to come to the central place in the village. All of them got a short check with basic test materials,

2 This attitude from parents was different from the parents in movements in other countries (see 2.1).
3 The family members often did not go around with the children because they felt "maloe" (the Indonesian word for ashamed).
presented by a multidisciplinary team. When they found evidence of some retardation they offered the mothers some Community Based Services on how to take care of their children at home. I found that this kind of support was congruent with the principles of the social model of integration.

In the Netherlands, children are checked in a health centre by medical professionals. When they find a deviation in early childhood they are referred to other medical specialists; sometimes this takes many years, during which time the children are not stimulated in their development. After this, they are often sent to a residential facility with 24 hour care. Coincidentally, we got the possibility to obtain a budget for a 'new project' which was based on early intervention by an *interdisciplinary team* and home based services for parents who want to take care of their children in their own environment in the Netherlands. I learned in Indonesia that this kind of service could be very supportive for families with a special child, therefore I decided that we should be involved for several reasons. First of all, we could connect this with other community services which were already based on the social model of integration. Further, it was important that caregivers and other professionals should become more familiar with working in the community. Moreover, it was reinforcement for these workers that they could offer their experience and knowledge in the natural environment of the families.

In Japan the development of Community Based Services was rather similar. At an earlier stage I was already involved in cross-cultural research of the Netherlands and Japan. Therefore I also was asked to support caregivers in Japan for the implementation of CBS.

In the meantime, in the Netherlands, we could increase these services because a more generous budget was available and more clients and their families became interested. I became the chairperson for this project and after several years we decided to make a juridical foundation⁴. Nowadays we support more than 500 clients with their families in one region. Last year we had a successful symposium to mark the 20th anniversary, with the Dutch title: "Natuurlijk Thuis", which has two meanings: "at home of course", and "at home in a natural way". People from all over the country attended this symposium, because the foundation became a model in many regions.

This could be the end of a 'success story', but based on these experiences with the social model in various cultures and circumstances I needed new perspectives. In my opinion, the choices we made in our culture are not consequently based on the real needs of the caretakers with their special children. More personally, I thought I was a kind of facilitator for new services for many years. However, I want to find new possibilities for learning more from the caretakers' experiences with their special children in their own environment. Because of

⁴ In Dutch "stichting"
this motivation I made up my mind, and in the context of the study of Anthropology, I could do this fieldwork. With interviews, attendance of support groups, and participant observation, I will try to stand more on the side of the caretakers. In this way I expect that I will understand more about the experiences of the caretakers in the early childhood of their special children. In chapter four, I will present the results of this study.
CHAPTER 3 – METHODOLOGY

3.1. Introduction

This study took place in Japan and the Netherlands after the Research Proposal was accepted at the end of May 2007, and lasted until the beginning of July 2007. I chose to do an exploratory study in this proposal because I wanted to gain insight in two related but little explored fields: how caretakers experience (non-)acceptance of their special children in the community, and how they experience support from Community Based Services (CBS). The study is also descriptive in a certain sense because I describe some case studies more extensively. Finally, this study is comparative because I compare the meaning of the experiences of the caretakers in two different cultures. In section 3.2 I describe the way in which way I selected the informants for this study. Further, I outline the research questions in section 3.3, which I listed in the research proposal. In section 3.4 I describe the sequence in which I performed my fieldwork, and finally I give an account of the way in which I obtained consent from the caretakers for this study in section 3.5.

3.2. The selection of the caretakers and the areas of research

In Japan, with a population of 125 million people, 459.000 (including 90.000 children under twenty years old) have been registered with intellectual disabilities. From this total target group 130.000 (28,3%) are still living in residential facilities (Matsuura 2005). In the Netherlands, with a population of 15 million people, 110.000 people have been identified as having intellectual disabilities. More than 50% are still living in facilities (Jonkers et al. 2005). From this total target group, 40.000 are under twenty years old. In the above mentioned study the researchers6 (Jonkers et al. 2005) found that the number of people asking for Community Based Services (CBS) had increased over the last ten years. Based on these findings they predict that parents will increasingly ask for CBS over the next ten years and that the request for residential care will decrease until zero in 2020.

My first step was to meet parents, as caretakers and informants, who are living together with their children with an intellectual or multiple disability, in the community in Japan and the Netherlands. I wanted to examine the reasons why these parents choose CBS, in spite of the possibilities for 24 hour care for these vulnerable children in residential facilities, which are still available in both countries. Because of their conscious choice for

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6 Researchers of the Sociaal en Cultureel Planbureau (SCP)
community care, I presupposed that these caretakers are involved in a process of acceptance and expression of their children’s special needs in the community.

The study was conducted in the region of Kennemerland in the Netherlands (300,000 inhabitants in and around Haarlem, the capital of North Holland), and the region of Osaka-South in Japan (300,000 inhabitants). I have been involved in the implementation of the policy of CBS in both regions for many years (see section 2.3), therefore I could contact caregivers who knew which caretakers were available, who allowed the fieldwork during the short period, and who could cooperate as informants in this study.

The selection of the interviewees was based on the criteria that caretakers had chosen to live together with their special children and that they could answer the research questions of my study. They were asked to participate by caregivers who were familiar with the families. An extra criterion for Japan was that the caregivers should speak reasonable English so that during the various meetings they would be able to cooperate as my interpreter.

Besides these interviews I attended various focus groups and support groups in both countries. I also made several participant observations in the daily life of the caretakers with their special children (see section 3.4).

3.3. The research questions

The main question:
At first my main question was: how do special children who live together with their caretakers experience living in the community, and in what ways do they express their special needs for support?

However, at a very early stage of my research I switched my main question to: how do caretakers who live together with their special children experience living with them in the community and in what ways do they express their need for support?

The reason for this swift decision is that the period of fieldwork was too short (in both countries I was able to spend four weeks) to build up a relationship with profound and/or multiply disabled children in order to gain a real understanding of their experiences in the different domains of their lives.

Sub-questions:
I chose as my sub-questions those which were based on various domains of the caretakers’ lives, particularly their experiences:
• In what ways do caretakers with their special children experience (non-)acceptance in their own family?
• To what extent do caretakers with their special children experience (non-)acceptance and support/empowerment by caregivers and other professionals for living in the community?
• To what extent do caretakers with their special children experience (non-)acceptance and support from people in the community?
• To what extent do caretakers experience support from other parents/caretakers?
• To what extent do caretakers experience facilitation by public health and welfare agencies to get adequate services for living in the community?

Moreover, I want to examine the special needs of the caretakers of the special children, based on the five domains of the abovementioned sub-questions:
• In what ways do caretakers with special children express their special needs for living in the community to their own family?
• In what ways do caretakers express their needs for support for living together with their special children to caregivers and other professionals?
• To what extent do they express their needs for the continuation of living together with people in the community?
• In which ways do the caretakers express their needs to other caretakers?
• To what extent do the caretakers express their needs to public health and welfare agencies?

3.4. Data collection

3.4.1. The fieldwork in Japan

The interviews
First of all I had two preliminary interviews:
A) With the father and mother of four children, of whom the youngest two are intellectually disabled twin-boys who are fifteen years old.
B) With the father and grandmother of an eleven year old boy who is intellectually disabled.

These were introduction meetings together with one of their caregivers (who also functioned as my interpreter) and we spoke about their life stories, the ways in which they are living together in the community, and their expectations of the future.
Before the fieldwork, the abovementioned caregiver made an appointment for a second interview with these two families, and she told them that we wanted to speak more about their experiences as caretakers of their special children in the community and their needs for support from people in the community. These topics are based on the research questions and related to the objectives of the Research Proposal from May 2007.

The interviews also served as a way to create a relationship with these families so that I was able to gain an obvious entrance for the participant observation (PO) of their daily life at home. Based on my experiences after these interviews I decided that the preliminary meetings were superfluous, and we could arrange a third interview:

C) With the mother of an intellectually disabled daughter of twelve years old.

All three families were living in different suburbs in the Osaka Prefecture.

The participant observation
In family A, I first met the twin-boys separately in a respite unit in the children's section of a residential facility. After this meeting I visited them when they stayed together in their own house with their parents. With family B, I participated in their home life: I stayed overnight and I went with the boy to his school in the neighbourhood. I met the daughter of mother C, in a short stay unit and at her own school.

The focus group
One week after these meetings we decided to arrange a focus group with the three families to exchange experiences in a setting that would allow parents to meet each other. One of my findings is that all the parents spontaneously wanted to speak about their experiences with their special children in early childhood in a retrospective way. I wanted to gain more insight into this first phase therefore I decided to attend a support group.

The support group
This group started one year ago on the request of the health centre in the region, as part of the CBS. Mothers come together with their very young special children, exchange their mutual experiences, and in the meantime they can learn ways in which they can take care of and play with their children.

Caregivers
During this period I also interviewed caregivers - psychologists and teachers - who were involved with the special children of the three caretakers I interviewed.
3.4.2. The fieldwork in the Netherlands

The interviews
In the Netherlands I interviewed five families and did participant observation with three of them. These comprised of:

D) Two parents who take care of three step-children with disabilities.

During the research module, as an exercise/pilot for the fieldwork, I interviewed:

E) The parents of three children. The oldest one is a nine year old boy with multiple disabilities.

In the beginning of the fieldwork I interviewed:

F) Parents with two children, the oldest of whom is a four year old boy with mild intellectual and physical disabilities.

In the later part of the fieldwork I interviewed:

G) The parents of two children, the youngest of whom is a three year old boy with a very serious muscular paralysis.

H) I also met a mother of three children. The oldest one is a boy, almost fourteen years old, with autism and challenging behaviour. The daughter is eleven years old with the syndrome of Gilles de la Tourette, and the youngest son is six years old and he will be examined soon because of behaviour problems.

All the abovementioned families are living in and around the city of Haarlem in the Netherlands.

The participant observation
In various ways I participated in the home lives of the families D, E, and H. I played and stayed with them, together with the older children, and sometimes together with the parents.

The focus group
I also visited a party with a lot of children with Down’s syndrome and their parents. I made an appointment with three of the parents who are very active in the movement for the inclusion of this kind of special child. With these three parents (two mothers and a father), and a panel chairperson, I had a meeting about (non-)acceptance of Down’s syndrome children from early childhood, in the community and at school.

The support group
With eighteen fathers and mothers of autistic children, and a panel chair person, we discussed their experiences of living in the community and the need for (special) services. After the meeting I made an appointment with one of the mothers with a son of eighteen
years. In the past she had to pay attention to him full time. Now she has more time and has started a support group for young parents of autistic children, and also a support group for people who have an autistic partner, to share their experiences. These groups are organized across the whole country and have been facilitated by the interest-movement for autism.

Other key people
During the fieldwork I also spoke with case managers and educationalists/psychologists who were involved with the abovementioned families.

In chapter four, when I describe my meetings with the caretakers in the presentation and analysis of data, I refer to A up to and including H: the caretakers A, B, and C I interviewed in Japan; the caretakers D to H I interviewed in the Netherlands. In the presentation of my fieldwork in chapter four, because of privacy reasons (see 3.4), I have used these letters when I refer to the various families. For the Japanese families I will add “san” which means “Mr” and/or “M(r)s”. I will add “kun” at the end of the first name which means “boy/son”, and “sjan” is also added at the end of the first name and means “girl/daughter”.

3.5. Ethical considerations

In advance of the fieldwork, the directors and members of the board of the organization Tokajuku in Japan, and the Netherlands’ de Stichting Thuiszorg Gehandicapten (STG), Kennemerland – both responsible for CBS in their respective regions – had given their consent for this explorative study based on the Research Proposal. They informed the caretakers whom I wanted to meet. Moreover, in advance of the interviews, the caretakers’ agreement was asked. I told all informants that I would not use their real names in this report. All caretakers agreed that I could make tape recordings of the interviews and focus groups. A popular version of the results will be presented to all the participants in their own language.

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7 Nederlandse vereniging voor Autisme (NVA)
8 In English: foundation home care for people with disabilities
CHAPTER 4 – PRESENTATION AND ANALYSIS OF THE DATA

Introduction

When I designed the Research Proposal I distinguished between the questions relating to the experiences of (non-)acceptance and support in the community on the one hand, and the expression of their special needs in the community on the other (see 3.3). However, during the fieldwork I became convinced that the experiences of (non-)acceptance of the caretakers, which mostly started in the early childhood of their special children, determined the course of family life with their special child in the community. In other words, it seems that the way parents experience (non-)acceptance in this early stage leaves a mark on the way they ask for support or avoid expressing their needs in the next stages of their child's development and education. They do not only ask for and get support from professionals, but also from other caretakers who have common experiences with their special children.

For the presentation and analysis in the next five sections I follow the sub-questions outlined above. This means that the next five sections are based on the presentation of the data of the caretakers' experiences and their needs.

In section 4.1 I describe the experiences of the caretakers with their special children in their own family in Japan and the Netherlands. In section 4.2 the ways in which caretakers experience (non-)acceptance by caregivers and other professionals in both countries are described. In section 4.3 I will focus on the ways the caretakers experience support in the surroundings of the community. In section 4.4 I give an overview of the various ways they experience support from other caretakers with special children. In section 4.5 the experience of the caretakers with laws and regulations are mentioned. Finally, in section 4.6 I analyse the abovementioned collected data based on the experiences and the needs of the caretakers in both countries as overarching themes, and finally I compare the experiences of the caretakers in Japan and the Netherlands.

Presentation of the data

4.1. Living with special children in one's own family

I start the presentation of the data and the answering of my research questions with the first experiences from the early childhood of the special children in their family, because they are of decisive importance. Caretakers realise that there is something uncommon with their child in various ways and at different ages of their child. Sometimes it is quite clear from the
beginning that their children are different from other children; this is the case with children with Down's syndrome. Sometimes parents discover problems in the development of their child step-by-step, and sometimes it takes many years before they get a diagnosis and an indication of the ways in which they can guide their child.

In Japan

Parents A-san have twin boys who are now fifteen years old. Their other two children are six and ten years older. After the birth of the twin-sons they found gradually that they had a serious lack of coping skills and problems with communication. They asked for the help of the professionals in a Child Guidance Centre. They were recommended to place their sons in a residential facility because of the difficulties. However, they strongly told the social worker from this painting by A-kun (centre) the teacher (right) gives instructions in the garden centre that they preferred to live together with all their children. They unsuccessfully tried to get support from their family in caretaking. Father A-san explained:

A-san: I tried to inform my mother about our twin-sons that they are disabled. Then I got a very strong message from her. She said to me and these words are still staying clearly in my mind, “Please do not come with your sons to my house, I cannot accept them”. This strong message was repeated by my brothers and sisters. Since that time we didn't visit my family members anymore. Our sons have been rejected, therefore we cannot go with our children to them. When we cannot get any support from our family we have to take our own responsibility.

Interviewer: How did you feel?
A-san: I am physically disabled, I know the meaning of a hard life...therefore I know how hard my children's life could be! We also were worried about our older son and daughter who are six and nine years older than their disabled brothers. More than ten years ago they had to pass the entrance examination for the high school we thought that the disabled children should be a big barrier and troublesome for their career in the future. Therefore we concluded that it is better that we should kill ourselves together with our twin-sons. In this way we could give more possibilities for our elder son and daughter.

Interviewer: Did you feel lonely in that time?
A-san: Without the support from people we feel very unsure and anxious; in our surroundings there are no other parents with disabled children, so we could not share our problems and we could not discuss how we can solve these problems. Then I made up my mind, together with

9 In the Japanese language “we” (watachi-tachi-wa) or “I” (watachi-wa) are often omitted in the sentence; therefore it is not clear from the sentence what the father exactly means.
10 These and following sentences in the text are translations by the interpreter during the interviews, and transcriptions from the tape-recorder.
11 Father A-san was crippled by polio in his childhood.
12 Passing the entrance examination for high school is a crucial moment in the life/career of a youngster because the particular high school is connected with the later possibilities for attending a good university that is related to finding a good professional career.
the mother of the children\(^{13}\), I decided that it is better that I will give up my job and that I can start to take care of the children\(^{14}\).

During the participant observation in A-san's family house, the father explained to me that he had been a partner in the family business but that he had left the firm after his parents rejected his twin-sons.

In the preliminary interview with father B-san, he mentioned that after the birth his son stayed with his grandmother (the father's mother) and then with him. He did not mention at any time during the interview the reason why the mother refused to take care of her son\(^{15}\). During the second interview father B-san told gradually that they divorced in the early childhood of B-kun, and the father explained that the mother could not accept the disability of her son, she had a nervous breakdown, and went back to her own family. The couple started a process of divorce and as a consequence the father had to sell his house. Since he lost his house and was divorced, he has been living together with his mother and his son to this day. I asked him if he did not try to ask for support from other people, apart from his own mother, but he only made some evasive gestures.

Later in the focus group (see section 3.4.1), when father A, grandmother B, and mother C came together for a meeting, grandmother B mentioned that she had begun worrying about her grandson because the physician at the Health Centre had detected some developmental retardation. After the mother of B-kun had separated from her husband she started living again with her own family for ten months with B-kun. However, mother B and her parents had difficulties in accepting B-kun. They did not want to live with him anymore. Therefore his father, B-san, and his mother, grandmother B, decided to take responsibility for his education. So, from his third year, his grandmother and his father took care of B-kun. When they started living together he had a lack of coping skills; for example he still needed diapers because of a lack of toilet training. His grandmother, who is an experienced caregiver at a nursery school, taught him to use the toilet properly. Within one week she succeeded with this training and B-kun became more independent with his daily activities.

Mother C realized that her daughter had difficulties with contact and communication one and a half years after her birth. In this period the family moved to another city and the mother thought that the problems started after this change. The physician in charge of the medical centre could not find any medical problem and he told her that she did not have to worry so much. In spite of this advice mother C became more unsure because her daughter still did not make any eye-contact with people, including herself. She asked the doctor many times about the possibilities for a more extended examination for her daughter. Finally, when

\(^{13}\) Japanese husbands often do not speak in this context about their "wife" but about "the mother of the children".

\(^{14}\) In the preliminary interview the parents explained that the wife has a full time job as a nurse and the man has some home work besides taking care of the two sons.

\(^{15}\) It seems that it is part of Japanese culture that they do not speak easily about touchy personal matters. In any case, I felt this topic was too touchy to speak about in this first interview.
C-sjan was five years of age(!) he recommended that she go to the Osaka Municipal medical university hospital. An interdisciplinary team diagnosed her as having autism and they prescribed behaviour therapy and speech therapy to improve her communication skills.

Step-by-step C-sjan learned to communicate with gestures. She also could practice some verbal speech with a method of consequent social reinforcement. Mother C told me that she felt a sense of relief after so many years of unfruitful efforts to persuade the professionals to take notice, that finally she found the understanding and confirmation that her daughter needed special support for her way of communication.

In the Netherlands

Both of the parents E are working in the field of health. The mother is working as a nurse in the child section of an academic hospital and the father as a socio-therapist in a psychiatric centre. Because of their backgrounds the parents detected very early on that their baby had difficulties with making (eye-)contact and that his motor skills were not developing in a normal way. They visited the physician with son E and later some other specialists, for example a paediatrician. They diagnosed eyesight problems as the cause of the retardation, however this diagnosis was not related to his lack of communication and lack of motor skills. Finally, when their son

was already five years old, the parents got permission from the paediatrician for an examination in an observation centre with an interdisciplinary team in Amsterdam. Based on complex criteria they diagnosed an autistic syndrome.

The parents studied a lot about the meaning of autism and learned that such people need a very strict structure in their environment. Therefore they made a very strict structure in the daily life of their family. Below I describe such a structure of the daily life with son E as an impression of the impact in family life.

From awaking the parents have to anticipate and prevent everything in the daily household. Son E has behaviour difficulties because he is not aware of the effects of his activities on others. That means that he cannot make the connection between the cause and
effects around him. His parents told me that they and the other children always show
consideration for him, for if they only focused on his maladapted behaviour then it would be
intolerable to continue daily life. Because of these experiences they found that they only can
continue to have a good atmosphere if they follow his needs in a very clear structure in time
and space. When that structure is disturbed he becomes confused and has the tendency to
destruct materials.

Both of the parents said that in the early childhood of son E they got some verbal
support from different members of their families, but from the beginning he could never stay
the night with any other family members. The parents told me that the nuclear families on
both sides were only focussed on their own families. In this sense the parents did not feel
supported to have free time to renew their energy. In the beginning they tried to get some
assistance, but nowadays they just accept the lack of others’ involvement. They did not want
to ask volunteers from outside for guidance because they could only trust experienced
people who knew how to support their son.

The parents F realised after the birth of their son, who is now four years old, that he
was not developing like other children his age. During the regular check-ups in the child
health centre the physician in charge trivialized their worries. However, after two years he
still did not speak and had serious problems with walking. In the academic hospital an
interdisciplinary team diagnosed a serious brain-damage caused by a birth trauma.

Father: We really feel that team got the ball rolling after so many denials.
Mother: Before we got the message we were waiting for the good news that he will recover soon.
Then, suddenly you are confronted with the message that they found a damage that makes him
disabled for his whole life. We still feel difficulties to accept this. This becomes more difficult
because the family around us deny the reality that we have to live with these findings.

The eldest son of the family H is almost fourteen years old now. From his early childhood
he would suddenly become very aggressive; without any visible reason he would attack other
people, including children of his own age. On the other hand, he could also be very kind and
engaging. This made it more difficult for people in his surroundings to accept his behaviour
problems. The mother tried to get help from several professionals from various authorities, for
example the child health centre and youth psychiatric centre.

Mother: Nobody could give us any helpful advice or support. People in our neighbourhood often
suggested that this behaviour has been caused by our bad education. During this period these
kinds of remarks meant that I felt so guilty. People also gave us unasked advice which I tried to
follow but with opposite effects. He became more afraid and aggressive.

Finally, when her son was four years old, the mother met an experienced child psychiatrist who
observed and diagnosed her son. She found he had an inherent special kind of autism which is
called PDD-NOS.\footnote{In Dutch: Consultatiebureau.}

\footnote{PDD-NOS means Pervasive Developmental Disorder - Not Otherwise Specified}
Mother: In one sense I felt relieved because the aggressive outbursts are not because of our education. I also felt as if I got a terrible slap in my face because this makes me so powerless. When I went home with my son, he came sitting very close to me in the car and he looked so amiable. I got the tears in my eyes. On that moment, I still remember vividly, that I decided he will live with our family together on our farm and we will do it in our own way.

4.2. (Non-) acceptance and support from the caregivers

In Japan

Father B-san explained that he found it difficult to actively ask for support, after his experiences with his ex-wife who could not accept their son. He said that if people in his surroundings would have offered him help he would have accepted it, but actually that never happened. He works full time and his mother, grandmother B, takes care of her grandson before and after school time. Before her retirement she was a caregiver in a nursery for young children, therefore she feels confident to educate him. Her only uncertainty is her age of seventy-two years. She already had some experiences five years ago when she broke her hipbone. At this moment father B-san had to ask for urgent support. He had not registered his son as a person with special needs because he had not wanted to ask for external guidance; suddenly he had to make up his mind:

First I asked advice from a director of a facility in our city. He told me that he had no vacant places for overnight short-stay. I could not understand what he meant with "short-stay". I need just a stay for my son. Instead of that, he gave me advice that I had to register my son as a disabled child in the office of the local Government. Until my mother broke her hipbone, I never asked any help from anybody. Therefore my son had never been registered. Now it seems I have to be punished that I did not ask any help in the past. Anyway I had to go to the local government. At the front desk I had to fill a lot of papers and questionnaires. After I finished this, I tried to explain to this local officer that I had an urgent problem with my son. He needed a temporary placement until his grandmother recovers. The officer became very defensive and explained to me that they are not responsible for this kind of urgent problem. In other words he said that they could not do anything for my family. These people are working in the field of human services, but they don't have any feelings about the needs of other human beings. I really felt panic but at the same time I became so angry. I remembered I started shouting because I felt so powerless on that front desk. Several officers came out of their rooms. Then I heard from one of these officers that the child guidance centre probably could do something for me. So I immediately went to this centre and the same procedure started again with a lot of papers. After I filled these forms and I gave them back to the officer he smiled so nicely but at the same time he only explained to me that in their city they could not solve my problem. I already learned that I had to become angry and started shouting again. Finally they recommended me to go to a facility in another centre named Tokajuku, in the neighbouring city named Tondabayashi.

I got good feelings that they understand my problems because they told me that I need a place for my son as "crisis intervention". I could understand this term very well because I felt in a "crisis". So my son stayed for several months in this facility and during daytime he could go to the special elementary school in Tondabayashi [where Tokajuku is located] because his own school is too far to attend every day. After my mother recovered she could take care of my son again and I could build up some trust in the key people who can and will be able to give us support.

It seems that father B-san found the good support coincidentally after a lot of trial and error. While he could have been coached earlier on how to express his needs for support, father B-
san made it very clear that he was able to learn how to mobilize acceptance and support for his son.

In section 4.1 I described all the efforts that mother C-san made to find a right diagnosis and the adequate guidance for her daughter C-sjan. C-sjan has a lot of difficulties making new contacts and accepting unknown circumstances, and she starts crying when she is separated from her mother. Therefore her mother stayed together with her for a certain time in the day care centre. During that period she found that the caregivers did not have a good sense of support for the children; they had the tendency to force certain behaviour and they used punishing approaches to “succeed”. As the Interviewer I asked her if she remembered a typical example of this attitude. The mother answered:

When the children have difficulties to eat the food, they pinch the nostrils of the children together between thumb and finger [mother also made the gesture]. This also happened with my daughter. I saw that a caregiver closed her nose until she almost choked and she has to open the mouth. They did not feel embarrassed when I watched this happening. Even when I tried to emphasize and explain to the staff members so many times that this attitude is not in the interest of our children. This is just one example that the workers did not have the good feelings for the interests of our children. My experience is that it was impossible to convince them that they have to choose the children’s side. Finally, I decided that it is better for C-sjan to find another place for her. Later I spoke with other parents who had the same experiences, and also took the children to other places.

In the Netherlands

The parents E spent the first five years of their son’s life finding the right professionals who could make right diagnosis for him. Based on a lot of criteria they found that their son has an autistic syndrome, and with this diagnosis he got an indication for a special school for children with disabilities. He got permission to start at a school for physically disabled children (Mytyl School) because, the parents thought, this was an environment with more stimulation than a special school for intellectually or multiply disabled children.

At this school he also gets a fixed daily rhythm and programme. When a new teacher is not accustomed to following this programme, the behaviour difficulties start. During holidays son E attends a day care programme for children with disabilities. The parents also go for their holidays to a holiday centre with special services and facilities for children with disabilities.

After Family F passed a lot of medical barriers (see section 4.1) they experienced the process of indication for their four year old son as a kind of paradox. The mother is a teacher at the first grade of an elementary school and she is accustomed to finding the learning possibilities of each child.

18 Despite a new law in the Netherlands that children with disabilities have the right to follow the mainstream in a regular school, the reality is that twelve various types of special schools are still available for children with different kinds of disabilities.
We always want to see the positive possibilities in the development of our child. Once we emphasized this too much in the forms we could not get enough support at home. Therefore we learnt by ups and downs\textsuperscript{19} that we have to focus more on his shortcomings. It is very difficult to write in such indication forms all kind of arrangements we have to make to take care of our son from the early morning until late in the evening. We also have to awake several times during the night. It is like taking care of a newborn child, which never finished for us.

They spoke with a rehabilitation medical specialist in the centre where their son got physical therapy. He recommended an educationalist\textsuperscript{20}, who started early intervention in their house as a kind of family coach.

Father F: Such a person really makes the difference. She coached us how to bring structure in our family. She arranged the occupational therapy from the rehabilitation centre when she found some adaptations are necessary in our house. She taught us how we could get a 'personal bound budget' [PGB] and how we can organize the support for the care. She advised how we can get the acceptance from family and our friends. After all ‘that tinkering’\textsuperscript{21} on our own we could find the good direction again.

4.3. (Non-) acceptance and support in the community

In the former sections I describe my findings that the caretakers have a lot of difficulties to get the right diagnosis and support once they have decided to live with their child at home. Then they have to spend a lot of time to “mobilize” basic acceptance and good services.

In Japan

Father and grandmother B-san could create the good conditions for B-kun at home. After they put in a lot of effort to find a better life for him, he could meet the basic acceptance in the neighbourhood. However, the grandmother did not feel sure about his safety. She gave a good example during the interview.

Recently B-kun has been playing much longer outside, once he comes back from school and during holidays. In the past he just played on the street for one hour but now sometimes he stays out for more than three hours. On one hand, this is a good change because he is being accepted more by the other children in the neighbourhood, but on the other hand the grandmother feels unsure because he plays with his kick-board in the busy traffic which is rather dangerous. The father is not so worried about this because he is together with other children and he can carry a detecting device to locate him regularly. With the modern way of telecommunication they can find possibilities with which they can locate him.

\begin{footnotes}
\item[19] The mother used the Dutch expression "met vallen en opstaan" which literally translates to “with falling and stand up”
\item[20] In Dutch: ‘Pedagoog’, an academic study, in the domains of social science
\item[21] In Dutch: ‘Dokteren’
\end{footnotes}
During the participant observation I took the opportunity to experience this. In the beginning B-kun was rather careful when he went up and down the street and he kept a low speed. However, he wrapped this up step-by-step as he forgot our watching. He could move with such a high speed that I could understand better that the grandmother worried about his safety. It became clear that direct participant observation gave me a good opportunity to be able to base my opinion on the daily reality of the situation. During the second interview I just followed the father’s opinion because I felt sympathy with him; he wanted to reinforce the possibilities of his son instead of focussing too much on his disabilities. The moment that I watched the dangers of the child’s high speed on the street I could understand the grandmother better.

When we returned to the house and I exchanged my experience with the grandmother, she felt understood and together with the father we made this a subject for discussion. During the second interview the proposals of the father had just remained a one-way communication; now they found the real solution. With the modern detecting device they can locate him easily. The grandmother agreed with this because at the same time the father promised to find a way to make the surroundings safer for him.

After our discussions the father prepared a bath; B-kun took a bath first, the grandmother followed him, and after her the caregiver. Then I was offered to take a bath. Finally the father followed me. In Japan such a way of bathing in the evening is common. They are always focused on cleaning the body and they are doing this in a very hygienic way.

B-kun went to bed soon after and the grandmother showed me the place where she prepared the tatami mat for me on the floor. It seems to me that this kind of daily routine and rhythm is very useful for people with disabilities who need structure in time and activities.

The next morning when I was still lying on my tatami mat, B-kun came into my room and without saying anything he was sitting in the corner and was watching me. He presented me with some toys and later a book with Japanese characters. I am unable to read this so B-kun and I looked at the pictures and I had the feeling we shared something without words.

After these communications early in the morning I took a cold shower because I could not arrange the warm water. Later I heard from my informants that most Japanese people do not use a bath or shower in the morning. They evidently felt clean enough after their extended bath before sleeping, and after all I felt the same.

The father had already gone to his work. We took an extended Japanese breakfast which is quite different from the more simple western style, and the grandmother prepared the Japanese lunchbox for her grandson. The grandmother told us that she accompanied B-

\[22\text{ In traditional houses people took the tatami mat every day from a cupboard and it is prepared on the floor. As a blanket they use a 'lay out bedding' (in Japanese: futon o shiku).}\]
kun to school until the third grade. Since then he has been able to go to school independently. Because of our interest she will go together with B-kun and us one time more.

Soon after we left the house more children came from different houses and streets. All the children were wearing the same school uniform, so it was very easy to realise the direction of their walks. The children greeted B-kun and us, and especially me, with “hello, good morning”. B-kun ran forward and backwards the whole time and some of the children followed him and enjoyed this pattern. From this experience I could realise all the more the real impact for special children when they can go to the regular elementary school in their own surroundings instead of attending a special school far away from the children in their neighbourhood.

That is just a very concrete meaning and a good example of “mainstream”. It took around fifteen minutes walking to reach the huge school with hundreds of children on the schoolyard. The children were very noisy but after the bell rang all the children entered the school, took off their shoes, and went to their own classrooms. It happened in a structured and calm way.

We could watch the group from the corridor. B-kun was sitting in the front of a group with thirty-six students of the sixth grade. He was rather unquiet but he did not leave his place. He followed naturally the programme and he did not ask for special attention. We also met C-sjan with her mother. She guided her daughter everyday to the school. C-sjan participated in another group of the sixth grade. After half an hour, when the language lesson started, B-kun left the group and we followed him to another place where he took his own reading course with a remedial teacher in a special class. He reads his short sentences very quickly and after a mistake the female teacher corrected him with a nice smile. Her attitude to B-kun was very kind and warm. Grandmother B confirmed later that she had the good feeling that the teacher really accepted him. Later we met C-sjan again as she took her own lesson with a musical instrument. It seemed that these children developed in a harmonious way with the attendance of regular classes at a normal elementary school, in combination with a special group with individual guidance for certain lessons.

Until recently, the mother of C-sjan was busy trying to find capable and trustworthy people for her daughter. However she still has a lot of difficulties in new circumstances and with unknown people. She needs to be prepared in advance very slowly, then she can learn to adjust to a new situation. Mother C learned that these problems are related with her syndrome of autism, and in her opinion the teachers of the regular school have difficulties

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23 In Japan it is quite usual that people take off their shoes inside buildings. In public buildings, like temples and schools, slippers are offered after entering the building.
24 The sixth grade is the last grade at the elementary school. The school B-kun attended had three groups of this grade.
25 This combination of regular and special education is only realised in the elementary schools in Osaka. At other places people with disabilities attend either the regular school or a special school for people with disabilities.
understanding this phenomenon. This causes a lot of miscommunication, therefore the mother feels that she has to intervene many times to persuade the teachers that she needs a process of adaptation. The mother gave a good example of this kind of problem:

I need frequent meetings with the teachers because I have to instruct them how they have to guide C-sjan. In one such meeting the teacher told me that she made difficulties to enter the swimming pool with the regular class. In the dressing room she already started screaming and crying. I felt strange because she likes swimming. So I decided to go together with her the next time. It was very crowded in the dressing room with a lot of noise. I saw that these circumstances made her unsure and afraid. After the children changed their clothes they took a shower; C-sjan was hesitating to take this shower. Then the teacher pushed her physically under the shower with the words "go...go...". At that moment she started screaming. I asked the teacher please stop this kind of pushing, she needs time. I realised that the automatic shower was too cold and too pressured for her, so I asked the teacher to change the temperature and the pressure. I went with her together and I taught her to enter the shower room. In this way she could literally learn step-by-step in which way she can adjust to this new situation. After a certain time she was accustomed and she enjoyed swimming together with the other children.

We agreed during our interview meeting that this is as a good example of the experiences of special children together with their caretakers and caregivers in the community. Sometimes you have to make the environment more barrier-free and/or you have to teach the children how they have to adapt to new, unknown situations, literally step-by-step. Sometimes you have to teach the teachers. This is the way to build up acceptance for the special children in the community.

In the Netherlands

The parents of son E told me during the interview that he cannot go alone in the neighbourhood, because he always needs one-to-one guidance:

Father: The people in the neighbourhood know John. When we are sitting on a bench the children greet us. They say, "Hello John". Sometimes he will answer the greetings. When we are going to the supermarket I took him in the cart. Of course people can see that he is a child with an intellectual disability. He is also charming therefore he got sympathy from the people.
Mother: Sometimes he makes noise; in this sense he irritates the people.
Father: We are walking with him in the shopping centre; from the way of walking you can see that he is disabled. The good thing is he has a certain aura that makes people mild. As parents we can use this to make him accepted by people. His point is that he does not have the feeling about things from others. For example, we went to the vegetable shop and there he just picked up an apple just on a moment I could not control him when I have to pay. However it is easy to correct him.

Interviewer: Do you think in this way his life is better than in a setting with only disabled children?
Father: We take him to all the places in the surroundings that stimulate his possibilities in contact.
Mother: I am sure in a separated place he will become very introverted. Without stimulation he will be more retarded. I know that because it happened when he is playing on his own, he is not exploring the surroundings. Then it is difficult to reach him. So I am sure when the situation will not be stimulating, he will be isolated more.

Interviewer: I suppose stimulation will be more natural in natural surroundings?!
Mother: In his own surroundings he seldom gets negative reactions. Sometimes it happened when he disturbed the children, not purposefully. His eyesight is not good therefore he sometimes collapsed other children. It is difficult to explain the he did not do that purposefully. Some people gave it back to me as if I am not a good educator.
We discussed that their son always has always been focussed on impressions of his own interest, which are not common for other people. Mother gave a good example about this in the following quote:

> When we go to the zoo he had his own interest not the exotic animals but, e.g., the noise that he can make with his feet on a bridge. The essence is that we have to adapt to John but he never make attempts to do something for others.

During this meeting I realized more that participant observation is necessary to experience his way of existence. I asked them if this was possible and I got permission from them. Later, when I met Son E during a participant observation, I could understand that because of his unpredictable behaviour he needs this support outside the protected house and garden.

Sometimes the behaviour of the children is impossible to understand by other people in their surroundings. That happened with the son of parents H. He is not intellectually disabled but has difficulties integrating the information in adapted behaviour.

Mother H: Once some mothers of teenage daughters came to me very angry and upset. My son had extinguished a burning cigarette on the skin of a girl. They wanted to go to the police because of this aggressive behaviour. I told them that I understand that they are angry but I also explained that my son has a special type of autism [PDD-NOS] so I offered that we should ask him why he showed such a cruel behaviour.

Her son explained that the teacher at school strongly warned the students that it is not allowed to smoke cigarettes under the age of sixteen years. He met some smoking girls and he warned them, like the teacher. They did not take him seriously and started laughing. This made him so furiously angry that he extinguished the cigarette on one of the girls. His mother asked him if he regretted this; however the son explained to the mothers that they had to be happy because he had prevented them from having to go to the police because of the underage smoking. After this explanation the mothers were still upset but they also felt embarrassed. They promised that they would not go to the police.

### 4.4. Support from other caretakers

During the interviews caretakers often referred to their experiences of support from other caretakers. They share a kind of companionship because they experience the same matters about (non-)acceptance and support in the community. This companionship made them motivated to support each other in the so-called support groups.
In Japan

The focus group of the caretakers A, B, and C

The caretakers whom I met during the interviews meet each other and other parents during various activities. They also organize meetings together to exchange experiences. Therefore we proposed to the caretakers A, B, and C to come together and exchange their experiences with their special children in the community. In this sense I call this meeting a support group. It was also a very valuable opportunity for me because I could get more information on the way they exchange their experiences. In this sense it was also a focus group.

It was remarkable again that the parents started their discussion with their experiences in the early childhood of their special children. It seems this exchange is a good basis in which they could realise that they have these experiences in common. After that they spoke about the way they participate in the cooperation with caregivers and teachers. The participants agreed that their experiences as key caretakers for their special children in their early childhood could be very useful for other caregivers, to guide them in the next period. However, they all experienced that some caregivers and teachers have difficulties accepting the caretakers as informants and participants in their own educational surroundings.

During the meeting the parents discussed their experiences of caregivers who did not want to accept when they asked for attention for the special needs of their children. Mother C said that the caregivers sometimes used the model of normalisation as a reason to ignore these special needs. Because of mother C’s experience, the participants had discussions about the real meaning of normalisation. They found that normalisation does not mean that the special children always have to be able to adapt to the norms of the people in the community. Instead of that, they thought that the real meaning of normalisation has to be based on the adaptation to people with disabilities by citizens in society. Their children have the right to live in the community and they have to be accepted by the people in the community. This also has to be clear for teachers; when they only follow their own educational norms they do not develop an open mind for the special needs of the children. As a consequence, it appeared that they could not unconditionally accept the children. Moreover, the participants exchanged examples that they often felt difficulties bringing up their own ideas based on their own experiences, on the basis of equality with the caregivers.

Because of all his different experiences with the caretakers, father A-san thought it was better to become a member of a parents’ association to make his position stronger at the school. On behalf of this association he wrote a paper to the school stating that they should take his information into account in their activities with his sons. The other participants

26 A parents’ association which stands for the interests of parents with special children.
agreed with this kind of action and they considered the ways in which they could increase their participation. In any case, the parents also wanted to take their own responsibility in various circumstances. For example, every month they made a programme to organize leisure activities for their special children, together with other children and their parents. They get support from the staff members of Tokajuku when they organize these various activities.

**Early intervention support group**

During the various interviews with parents I was impressed that they vividly remembered their experiences with their special children from early childhood. Mostly they intuitively realized that there was something unusual in the development of their child. On the one hand they have to find ways to accept the possible disabilities. On the other hand a lot of parents searched for several years to find the right people for early detection and the right diagnosis. At the same time they had to make their way, with difficulties, in search of (family) support for their special child.

Recently the caretakers of Tokajuku, at the request of the Child Health Centre, started an early intervention programme for parents (mostly mothers) to come together with their young children. It offers one possibility for overcoming the difficulties which parents are confronted with in the early years of childhood. Therefore I decided to attend such a meeting two times. It is not only a support group for early intervention but also a kind of training group for the mothers on how to take care of and educate their special children.

**Participation in this early intervention support group**

Once a week the mothers come together with their young children. They get a reference from the Child Health Centre to attend this group. The children are between nought and four years old and still very vulnerable because of several medical problems and multiple disabilities. On the first meeting two children with their mothers attended the meeting. One girl was one and a half years old with Down’s Syndrome and several other medical problems (including swallowing difficulties and heart issues), and there was a three year old boy with a rare syndrome that causes problems with physical balance. Two other children could not come because one had to stay in the hospital for an examination and one stayed at home with an illness.

When the mothers entered the meeting room they were very much focussed on the physical difficulties of their young children. The professionals took the children and started to play with them with various materials which were available in their playground. In this way

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27 Tokajuku is one of the oldest residential facilities in Japan (90 years old) with a section for children and a section for adults. Since 2002 they also are allowed to provide day care and Community Based Services because of the new Act of Support for Independent Life. However, the budget for this kind of service, until now, is still limited compared with residential care.
the mothers got the possibility to exchange some experiences. They live in the same region, and from my interpreter I understood that together they knew much more than each individual parent. They also got support from a professional and they could start discussion about the needs of their child and the whole family as well. After a certain time the mothers joined the staff members who were still intensively playing with their children. They could show them how to play with the children by modelling. It is a natural way to learn how to accept the children.

At the second meeting the three year old boy from the first meeting came again with his mother. Moreover, two mothers with their children attended the meeting for the first time. One child was a one year old girl with Down’s Syndrome who was still functioning like a baby. The other one was a three year old boy, and he needs intensive care because of a catheter he has for drip-feed. The mother cares for him very gently and quietly. In the meantime she could have contact with the other mothers. With the professional they discussed the ways in which they might be more confident to organize support for their family and acceptance in their surroundings.

In the Netherlands

A support group for parents with Down’s syndrome children
The parents are members of a nationwide parents’ organisation for Down’s syndrome children. In the region of Kennemerland, where I did the fieldwork, 160 parents are registered as members. They regularly organise parties for the parents and the children. Other people involved in their overall care can also attend these events. They also organize meetings to exchange their experiences with their special children in the community. I attended a picnic party where the children played together and the parents exchanged information and pieces of news. In the meantime a company for adapted bicycles gave demonstrations and the parents with their special children could have trial rides.

During the party I was able to make an appointment with three parents who were available for a support group meeting; one father and two mothers attended the meeting. This meeting also started with parents exchanging experiences from early childhood. It seems that the parents still have to come to terms with these early experiences. One of the mothers mentioned that once she realised that she had a child with Down’s syndrome, this was a big shock for her. The other parents agreed and referred to their own experiences. Two of the children had serious medical problems just after birth which were connected with the Down’s syndrome, for example heart problems. Therefore they were highly occupied in the medical field.
The three caretakers had wanted their special children to attend a regular elementary school. They exchanged stories about the process, and how much effort they had put in to find acceptance by the teachers. They could not get any support to keep their children on in the regular schools. In fact, the parents experienced the opposite, as the teachers wanted the children to go to special schools:

Father: My son attended the regular school until the third grade. He meets the other school children in the street. He makes a lot of friends and they like him because my son is very social and humoristic. After the third grade he got some difficulties with intellectual courses, therefore they thought it is better for him that he attend a special school for people with serious disabilities. I had a lot of discussions with the teachers because I thought it is not only a good stimulation for my son's development to stay together with 'normal children', but it is also good for them to meet my son. Finally, we gave up because it is not good for our son when the teachers are not motivated to integrate and accept him. Now he attends a special school in another city. He still meets the school children in the street. They are saying to the other children that they know him because he attended the same group... That hurt me.

One mother had the same experiences with this kind of non-acceptance:

I persuaded a lot to keep my daughter at a regular school. The most degrading remark came from the director. He told me your daughter runs the average of the school down. But I told him you run my daughter down. I thought my daughter has the right to attend a regular school. Finally, the teachers changed their minds. She found a good way of stimulation, a programme for her and she developed in a good way.

The second mother stated that her daughter attended a day care centre for people with disabilities:

I want that she should attend a regular school but I could not convince the teachers. In fact I had no choice. My daughter is hardly able to speak and he is not toilet trained.

They did find a kind of compromise: instead of the day care, the daughter started at a special school for children with very serious learning difficulties.

During the exchanges of these common experiences parents could make it very clear that they still are not ready to reconcile with this situation of non-acceptance. They discussed the recent possibilities to claim a kind of person-bound budget, like in the field of welfare, which was introduced several years ago. The parents discussed when they might collect various so-called "rugzakjes" (which means children get an extra budget for special teaching), and the children can get regular education, for example with a remedial teacher in small groups. This means that teachers have to become more creative and flexible, to cooperate with the parents and to accept their participation, in order to realise this kind of solution. In

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28 Despite a new law in the Netherlands that children with disabilities have the right to follow education in a mainstream, regular school, the reality is that twelve various types of special school are still available for children with different kinds of disabilities.

29 In Dutch: "de school voor zeer moeilijk lerende kinderen" (ZMLK). This is one of the twelve various types of special school.

30 See note 17, PGB. In the field of education this has been called in Dutch: "rugzakjes" (literally 'small rucksack'), which means a personal budget to receive some special education in the mainstream of a regular school.
politics there is a strong movement now to implement the new law definitely by 2010; then the regular schools will be obliged to accept special children.

A support group for parents with autistic children
The parents meet each other periodically in this support group, which has been set up by the association of the parents with autistic children (NVA, see footnote 2). This time eighteen parents attended the meeting (fourteen mothers and four fathers). They discussed in a way of free association. This means that someone starts with a recent experience and the others associate this with their own experiences. This time they talked about the difficulties of informing other people about the meaning of living together with an autistic child.

The people in their surroundings could hardly understand that children with autism cannot react adequately. When they do not make contact or do not communicate adequately this causes a lot of misunderstanding and non-acceptance. The parents discussed that they have to pay full attention to their children on many different levels. First of all, autistic children always need special attention because their parents have to create a clear structure in time and in place. Once events happened in an unexpected way the children tend to panic or exhibit other behavioural problems. At the same time the parents have to explain to the people in their surroundings the cause of the excessive behaviour, and they have to find ways to make other people accept their children, even when their behaviour is not understandable. One of the major reasons is that most of the children look normal; they just look pretty.

The parents also have to convince the teachers that their children need their special attention in regular education, instead of in a special school. Moreover, they have to inform the caregivers about the importance of structure in daily life. Last but not least, they have to go through a lot of bureaucratic procedures to get the right indication for the right services. Parents who are already busy on various fronts need to do a lot of administrative work. Some parents mentioned that when they submit all the application forms and they have to account for all their expenditure, this makes much more work than the tax papers every year. Recently, the parents' association organised special courses on how parents can deal with these kinds of accumulative problems. Some of the parents in the support group followed such a course and they could motivate other parents because of the positive effects they experienced.

The movement of support groups is growing because parents who are having to deal with a young special child are able to learn from parents who have already had more experiences with their growing children. At the parents' association's request, these experienced parents have started to build up new support groups. During the meeting I made an appointment which a mother who started as a so-called 'parent contact person'.

41
The parent contact person
The mother told me when I visited her at home that her autistic son is now eighteen years old and he attends training in computers. Her daughter is older and she already lives independently. The mother told me she encountered a lot of difficulties with her son because though he is not intellectually disabled, he could hardly cope with changes in his surroundings. When he did not get special attention he often said as a child, “I want to die”. His mother was busy full time with him, and she could not get support from her husband because he also was diagnosed with a certain type of autism31.

Mother: For certain time I lived rather isolated. I ran around in a circle and the circle became smaller more and more. I lost my best friend and most of my family members did not visit our family anymore. I felt lonely and isolated. Then I became member of a support group and I recognized people with the same difficulties. This experience gave me courage again to come out of the small circle. Once I met more people I could find new possibilities for my family.

She shared these positive developments with others and after a certain time she decided to start a training course for panel chairpersons, which has also been organized by the NVA. She announced in the newsletter for people with autism that she would start a support group. In the beginning, three parents participated and the group has increased now to twelve members. She also started a support group for people with an autistic partner, and recently she started a new group with immigrant mothers32. She contacted these mothers in cooperation with key people in the Moslem community. Mothers from this group are already living in rather isolated situations, but mothers with special children much more so. In the support group they could, with an interpreter, share their experiences in their own language.

Mother: It was really useful that I could share my own experiences of separation with these mothers. They could be informed about a lot of matters about the Dutch welfare system and I could encourage them to find more connection with companions. It also made my own life meaningful.

At the end of the meeting with the mother I met her son, who entered the room. He introduced himself and he asked, “Are you coming for me?” I explained that I was visiting his mother. This seemed to set his mind at ease and he started to speak about his hobby, and the computer course. I told him that he is a happy man because he can make a job from his hobby. He smiled with an expression of understanding on his face.

31 Syndrome of Asperger.
32 In the Netherlands most immigrants are from Morocco and Turkey who are called in Dutch ‘allochtonen’.
4.5. The experience with laws and regulations

In Japan

Up to 2003 All services were directly paid from a tax system from the central government, through the Prefectural Government, to the Providers. This system was based on the Child Welfare Law that was passed in 1947 and the Law for the Welfare of Mentally Retarded Persons that was passed in 1960.

From 2003 until 2006 These acts were revised in the Law for Independence for the Benefit of People with a Disability. Clients/users could make their own choices about what kind of service and/or facility they need, based on their needs for support. After they had made a choice, and in agreement with a provider, the budget would be sent directly to the provider by the Municipality, such as cities, towns, and villages. This new regulation is more demand-, and therefore client-, oriented.

From 2006 A new Act of Support for Independent Life for the Disabled was enacted in October 2005, and the implementation process started in April 2006. From that time, the client needs an indication that is based on six levels of classification. From that level the clients will decide what kind of service they need. From this year the care will be directed step-by-step by a compulsory collective insurance system, like in the Netherlands’ (AWBZ). The implementation of this process has to be client-, instead of provider-, oriented.

With the establishment of the new Act of Support for Independent Life, the parents have to pay almost double the price for their own contribution for the service. Compare, for example, that for one day, short-stay, they used to pay ¥2.200, and now this costs the parents ¥3.600 – currency 1 Euro : 150 Yen – including payment for the daily food during the stay. It is almost impossible for parents A-san, with only one regular income and two disabled children, to pay this higher amount, not to mention that they already pay a lot of extra costs for their other children, such as transport, clothes, and other equipment.

Besides that, in Japan parents have to contribute a lot of money for children who go to university. This means that the parents A-san have to pay for their other son’s college education. Naturally, it is not surprising that the parents are very critical about this new Act. This criticism has been supported by the wife of one of the former Prime Ministers, named Hosokawa, who is the President of the Sport Federation for the disabled. She emphasized in a conference, which they attended, that the state of welfare in Japan is the lowest among developed countries.
In the Netherlands

The financing system for people with special needs has been based on compulsory collective insurance: Algemene Wet Bijzondere Ziekte Kosten (AWBZ). This system has been based on solidarity and started in 1968. Still, more then 90% of the nationwide budget will be paid to the providers. They offer care services and facilities for all people with an indication for chronic diseases. Clients who want to arrange their own care could receive a so-called “person-bound budget”. This is called a client-centred system. Both of them are financed by the AWBZ.

Family E receives such a budget for several hours of community care every week, as personal care for their son at home. Such a regulation gives the caretakers the possibility to create a social network with caregivers and volunteers who are capable of taking care of their son, and this makes it easier for the parents to live with him in their own family in the community.

Interviewer (I): This was the first time you got such a PGB?
Mother (M): We did not ask it earlier because the social worker did not inform us about this possibility.
Father (F): Afterwards we heard that we could ask it much earlier but we were not informed in a good way. They told us we have to pay all the costs for the cure and care; so for example also the cost for physical therapy. Later we heard the difference that cure is from the health insurance and for care you can use the PGB budget.
M: After that it became clear for us finally we could start the request for indication.
F: We found somebody who was experienced with this procedure at the central indication team. That lady made a report for us about the level of his disability and how much care he needs and finally, based on that, we could get the PGB. That happened three years ago. From that amount we could "buy" the care he needed. We could find various caregivers...
M: We also could pay the day care during the school holidays.
I: How did you find capable people?
M: We heard it from other parents, they recommended us good people and good care. We are very happy with the day care during the holidays because we also have to work and the caregivers are students from the college for education; really nice people. We are eager that we could find people who get a good “click” with John. We are also looking for the people who understand children with autism and who feel sympathy for them.
I: How do you know from the very start that such a person is a good match with John?
M: After some people are recommended by parents we had a good contact then we started. Sometimes they could not get the click then we stopped the relation.
I: In this way you created a natural relationship
F: Yeah...we created a kind of network in this way we find our useful connections. So we spent the money in our opinion in a good way; that is important because after a certain moment we have to account this for the PGB office. We became very capable [laughing] to organize this in a creative way. We did it in a satisfying way for three years.
M: In these years it became more difficult to leave him alone. He always needs “one-to-one” guidance.
I: That is not easy for you?!
M: We also have to pay attention to the two other kids; they also need our attention. Therefore I always need to organize all things. I went for shopping and cooking before John is coming home from school. When he is at home he always needs attention, from me or one of the caregivers.

33 Each citizen has to pay 12.8% of their income for this AWBZ, which guarantees care and services for all kind of chronic diseases and disabilities which are not covered by the health insurance.
34 In Dutch: "een persoonsgebonden budget" (PGB). The caretakers get a budget. It is their choice how they spend this based on certain criteria. This also has been covered by the AWBZ.
35 They are members of a support group for parents who have an autistic child. I attended this support group (see section 4.3).
I: You always have to organize everything.
F: That is true; we never can do something spontaneously or improvise something. John always needs clarity. On Friday we make a clear plan for the whole weekend. Every step we have to clarify for John.
I: You told me earlier that the PGB has been finished but when I hear your experience with PGB this seems successful?!
F: After a certain time you need a so-called re-indication. In our case that was after three years before 2007. Now it took a long time and we did not get any message. Therefore I gave a call several weeks ago then I heard that they lost the application report. So I brought them a copy. Coincidentally I heard this afternoon that the indication team consider now to refuse PGB because the community care became too costly.

The responsible person from the indication committee told them it is better that their son live in a residential facility 24 hours a day because of his profound and multiple disability.

I: What are you going to do now?
F & M [Almost together]: We cannot accept that he is not living with us together. We will start an appeal.

Several weeks later when I visited the family for the participant observation I heard that the authorities had finally decided to allocate the PGB to them.

Family G has two children. The youngest one is a three year old boy with a clear diagnosis from the specialists of the Academic Hospital in Amsterdam. They found a serious muscular paralysis. He cannot use his muscles and the prognosis is that he will need a wheelchair his whole life, and artificial respiration during night time. Despite this unambiguous diagnosis, the parents have to submit an application form for each type of care and for every adapted material, every time.

Father: It is not only all these forms but the officers also expected that I came with my son together to their office of the local government. On my question if they received the medical reports from the medical specialists they told me they don't have the medical professionals in their office therefore they want to see the consequences of his handicap with their own eyes. Even for a parking card for free parking, I physically have to show that my son has a profound disability. I feel every time they forced me to my knees.

Moreover they do not trust each other because for the next application to the next officer they do not use the

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36 The official policy for people with disabilities is that they have the right to get community based services. Moreover, residential care is more expensive than several hours of home care per day!

37 In Dutch: "Het voelde alsof ik elke keer voor hen op de knieën moest."
reports from their colleagues. They start the whole procedure again with the same forms! It seems if they have to pay this out of their own pocket.

Mother: All this administration is almost a full time job beside all the care and special attention which he needs during day and night. We do not find any time to become adjusted to this other way of life.

Analysis of the data

4.6. The overarching themes

It is striking that I had problems distinguishing the domains in the various sections. One of the reasons is that the professional contribution (4.2) has a rather big impact on the life of the family (4.1), especially the caretakers. Further, the community (4.3) for the special children is limited to the nearby neighbourhood and the school environment. In this sense, the community is still a kind of extension of the daily life of the family.

The way the caretakers support each other (4.4) is a kind of reinforcement for how they have to deal with people in the community. Moreover, they informed each other on how to receive the right conditions from the authorities to create a better life for their special children in the community (5.1).

In finding the answer to the first question, asking about the ways in which caretakers with their special children experience (non-)acceptance in their own family, I wrote about the impact of the experiences of the caretakers during the early childhood of their special children on the life of the family, especially when they could not find experienced professionals to make a clear indication based on a good diagnosis. Despite these difficulties, the parents in my study had decided to take care of their special children in their own families. This strong decision is remarkable because in both countries it is still possible to send the children to a 24 hour residential facility. It is also striking that all the caretakers in both countries vividly remembered their experiences from the early childhood of their children, even when their children were in their teens. While coping with issues around the realisation that something is wrong with their children, and in accepting it, they also have to pass through many stages in a long search to find the right support.

Following a complicated indication procedure, they needed psychologists and physicians to obtain the right diagnosis about the level of disability and the syndromes. They surely need such an insight into the best way to educate their children. This whole procedure often takes many years in the most crucial stage of the early childhood of their children. This constant uncertainty has a deep impact on the life of the family. They have to learn the

38 In Dutch: "Alsof zij het uit hun eigen zak moeten betalen".
language" of the professionals to understand the meaning of the behaviour of their children. At the same time they have to claim the right to participate in this whole process. Finally, they have to find a good balance to create safety in their own family for their special child and their other children. For all the parents with whom I spoke this was an unforgettable experience, that they could not get effective support in this process. In my meetings with the professionals I found that they are mostly focussed on the child with the disability, without an understanding and/or knowledge of the impact of this whole process on the family.

However, recently professionals in the Netherlands have found that early intervention is crucial for a family taking care of a special child at home. Family F in the Netherlands explained about a family coach who could support the family in all aspects of daily life with the special child as a family member. Such a professional also coaches the family on how they can get acceptance from people in the community, including their family and friends.

When I analysed the answers related to the lives of the caretakers with their special children, the answer to the second question, examining the extent to which caretakers with their special children experience (non-)acceptance and support/empowerment by caregivers and other professionals for living in the community, came at the same time, because it became obvious that the caregivers and other professionals were very dominant in the family with a special child. On the one hand, caregivers could be very disturbing when they are only focused on the procedures and regulations. In fact, they do not accept the needs of the caretakers. On the other hand, they could be very supporting when they are mainly focussed on the needs of the whole family with a special child.

Analysing the data to get the answers to the third question, asking to what extent caretakers with their special children experience (non-)acceptance and support from people in the community, I found that the area around their home and the school are the most important places of their experiences in the community. In all kind of circumstances the caretakers have to explain the special behaviour of their children. This means that they often have to defend them in front of others. In this way they try to gain acceptance from other people for the idea that their special child also has the right to participate in the community. It would be very fruitful if they could get empowerment in this process through acceptance from professionals.

From the participant observation at the home of B-san in Japan, it became very clear that contacts in the neighbourhood with children whom the special child attends the same regular elementary school were crucial for special children living in the community. The different experiences of the Dutch caretakers with their children in regular elementary schools, and the loss of contact with their neighbouring children when they have to attend a special school far from home, is revealing for the importance of inclusion in "mainstream" education.
When I attended the focus and support groups I found in both countries that caretakers could also get a lot of reinforcement from other caretakers, which addresses the fourth question. During the interviews, the caretakers often referred to this support. Sometimes it would be concrete information from other caretakers, in other cases they were reinforced because they heard that other parents shared the same experiences. Once the support for caretakers starts in the early childhood of their special child, they learn how to cooperate in the support, together with the caregivers. They can also stimulate each other to command participation in this support, and can find the arguments to force mainstream education and services for their special child. Parents with a lot of experience and knowledge can coach young parents on how to get their rights.

The experiences of the caretakers related to the last question, asking the extent to which caretakers experience facilitation by public health and welfare agencies in getting adequate services for living in the community, are very clear. They expected to be facilitated by the people who manage the financial sources. Instead of this, however, the caretakers experience barriers which they have to overcome in order to obtain the budget for the Community Based Services to which they are entitled. They often heard from the responsible people that it would be easier for them and the caretakers if they would choose the supply-centred residential facility. Parents from both countries told me that they were confronted with these kinds of alternative "solutions". Every time they have to resist against the oppression of the decision makers, to insist that they really choose to live with their special children in the community.

The law, on which the solidarity for people with a disability has been based, guarantees the right for people with a disability to get the budget for supported living in the community. Instead of that it still seems that the support is based on charity. The word charity has several meanings. According to the Oxford English Dictionary, the positive meaning is "love of fellow men; kindness and affection". The second is "institution for helping those in need". The frustration and anger of the disability rights movement seems to be directed towards charities as institutions (Shakespeare 2006). Disabled people are entitled to full civil rights for living in the community without being dependent on institutions which separate them from other people in the community.

4.7. Similarities and differences in Japan and the Netherlands

The Japanese word for handicap is shogai, which also means obstacle, difficulty, or barrier. "Shogai sha" is a person with a handicap. Since this phrase has connotations with the medical model, the "people first movement" promoted the change of the phrase to "Shogai
no aru hito”, which means “person with a disability”. The same change happened in English, from “handicap” to “disability”. The Dutch language is very much influenced by the Anglophone language, and the phrase switched from “gehandicapte” to “een persoon met een handicap”. There is no word for disability, therefore people often use “mensen met een beperking” (where beperking means ‘restriction’).

Caretakers in both countries had similar difficulties in finding the right diagnosis in the early childhood of their special children, which serves as a basis for adequate intervention. This is very crucial because the children consequently could not get enough support for a good development in their education.

The parents from Japan had more difficulties in asking for support in their surroundings. They did not want to disturb other people with the problems they had with their special children. They tried to find their own solutions, which made them more isolated from society. The Dutch caretakers were more opinionated about their right to support from professionals and volunteers. They learnt in a support group (4.4) the ways in which they could communicate in “the language of the professionals”. In this way they were able to have a kind of confirmation about the ways they need guidance and support. In Japan, such an opportunity for learning in support groups has not yet been developed. After my interviews with the three caretakers, I asked the key caregiver to organize a focus group with them. It was interesting that in just one meeting they learnt from each others’ experiences ways in which they could find possibilities for their special children. In fact, they started a kind of support group. This also happened with the mothers of very young special children; they were taught how they could receive early intervention, and how they could ask for support in the community.

The big difference in both countries is the school system. In Japan, from the 1970s, special children have been granted the possibility to attend a regular school. I described the way in which B-kun participated in school, and I experienced the positive side of the so-called “mainstream”. In a support group with Dutch parents, they exchanged their experiences about the problems of keeping their children in a regular elementary school; in the end, they were often forced to send their children to special schools.

The financial possibilities are basically available in the Netherlands, because with the personal budget they can choose from a variety of care and services, including community services at home. However, the problem is that the regulation is very complicated. It is also difficult to convince the decision makers that it is necessary to receive such a budget. In Japan these financial possibilities are still limited. With a new law they were promised to receive more of a budget for community support; however, many clients tried to receive this support, which went far beyond the expectation of the government. Therefore the government decided to limit the possibilities again. This means that they decreased the
budget for community services and increased the contribution which parents have to pay for this support.

In both countries I found a lack of real acceptance of the special children by the people in their surroundings; the professionals and the authorities did not create good conditions for the special children to live integrated in society. They could not get the human rights as they have been described in the UN Convention on the Rights of Persons with a Disability (see section 2.1.3). The governments in all countries in the EU, including the Netherlands, signed this Convention; however, the Japanese government has not yet signed it. In all these countries the convention has not yet been ratified by the parliaments.

Based on this comparison I conclude that in many senses the similarities between Japan and the Netherlands are much more than the differences, in the field of welfare and services for people with disabilities.
CHAPTER 5 – DISCUSSION

This research started with the main objective (section 1.3) to investigate the set-up of CBS in Japan and the Netherlands, based on the needs of the special children and their caretakers for living in the community. Therefore I selected caretakers who chose to live together with their special children in a normal household. With this important decision they realised the necessary first condition for a process of integration, which has been mentioned by Nirje (1980), as physical integration. This should be supported and accepted by the people involved and the professionals, who have to create the conditions for the next steps of integration which I described in section 2.1.4.

It is remarkable that in Japan and the Netherlands, until the present day, the main budget for welfare has still been directed towards full time residential facilities. In other words, the support for Community Based Services is still limited (Matsuura 2005; Kooiker 2006). This is in sharp contrast with the report from researchers of “Het Sociaal Cultureel Plannbureau” (SCP), (see note 6), who predicted that parents will need only CBS by 2020 (Jonker et al. 2005). This is consistent with my own experiences that parents, once they have the possibility for integration, choose for CBS (Millenaar 2004).

Because of this inconsistent policy the decision makers did not make real choices, therefore the caretakers experienced a lot of difficulties in getting support in the realization of the functional and social integration of their special children. This happened in all the domains of life which I described in the various sections in the presentation of my fieldwork. The caretakers need engagement from the people in the community in the process of acceptance of their special children. Shakespeare (2006) emphasized this engagement as a priority for an interaction approach (section 3.3). This is the basis for the acceptance of the disability, rather than ignoring it. In this discussion chapter I will mention three reasons for the difficulties experienced by the parents whom I met during the fieldwork.

First of all, caretakers often experience ignorance from health providers from the early childhood of their special child. In fact, this is a kind of non-acceptance which makes the process for the caretakers a long search to find the best possibilities for their special children. This has been manifested very clearly with children who have only been properly diagnosed with autism after five years of age. Parents whom I interviewed in Japan and the Netherlands have been confronted with this uncertainty for a long period.

The second problem is that in both countries the parents of the nuclear family experienced a lack of understanding from the members of the extended family. The parents A-san in Japan, and the parents F in the Netherlands, were quite explicit about their disappointments. The other parents also made some remarks that they experienced a lack of
support. Sanderson (1995) developed a model of how to overcome the position of isolation experienced by the immediate family. She called this a “circle of support”, which is a group of family members and other people involved in their lives, who get together to help a special child with intellectual or multiple disabilities. Meetings are held when the caretakers need them. A “circle of support” is a practical expression of the acceptance which caretakers need, which can help them to overcome their difficulties.

In the meetings with professionals – psychologists and educationalists – I met a third problem in both countries. I realized that they are used to treating or guiding the individual with a problem. For the most part, they are not focused on the cumulative effect of all the kinds of non-acceptance that parents experience in their daily lives. However, I also met other professionals who are involved in the family relationships, for example between mother and child; this was demonstrated in the focus group for mothers with very young children with Down’s syndrome. I also heard of a very good approach from parents F: an educationalist coached the parents in all stages of their daily life at home in a very comprehensive way, which is radically different from traditional care.

This approach seems rather similar with the approach of “independent living”; Shakespeare (2006) wrote about how the attention of professionals changed from the individual and their abnormalities and limitations, to the service environment and how it could empower and facilitate people. This can be arranged by what Shakespeare called “a personal assistance”. He focussed this approach on disabled people and the other people involved in their lives and care. I think this function can also be adapted as a kind of family coach for the caretakers and their special children. After a certain time this personal assistance can be switched to the independent living of the special child.

As I described, the most important domains of the special children are the direct neighbourhood and the school. In Japan, mother C-san experienced that the teachers must be instructed on how to respect the dignity of her daughter. Despite the new law in the Netherlands stating that children have the right to attend a regular school, the number of children in special schools is still increasing (Kooyker 2006).

The UN convention on human rights is very clear in article 24, on education, (see section 2.1.2; UN 2006):

2a: Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education or from secondary education, on the basis of disability.
2b: Persons with disabilities can access an inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live.

These articles make it acceptable that special children have the ultimate right to attend a regular school. Inclusion of disabled children in schools establishes familiarity between
children with and without a disability. In a later stage of their lives these experiences ensure that they are accustomed to meet each other in other domains of community life.

During the meetings with the parents I was quite impressed that they frequently mentioned the importance of experienced support from other caretakers. Especially in the Netherlands they were motivated to attend support groups and parties in which they exchanged a lot of information about – and experiences with – professionals and services, and the common stigma they experience. Goffman (1968) described such sympathetic others who are ready to adapt their standpoint in the world, and to share the stigma which parents experience living with a child with disabilities in the family. Although the support group which I participated in during my fieldwork in Japan was the first experience of its kind for the Japanese caretakers, they already began exchanging relevant information.

Recently, after I finished my fieldwork, I heard the news that a group of researchers from Nijmegen University in the Netherlands (Buitelaar et al. 2006) had developed an Early Screening of Autistic Trait Questionnaire (ESAT). With fourteen questions, professionals, for example physicians from the Consultatie Bureaus (child health centres, see note 18), are able to detect autism from an age of between eighteen and twenty-four months. The questionnaire has already been tested for its usefulness in some provinces in the eastern part of the Netherlands. With a certain result, based on the scores produced by the test, the children are referred to a multi-disciplinary team for further assessment. The researchers have made a plan for the implementation of this questionnaire across the whole country for next year. After the interviews and participation in the support groups with caretakers, I realised much more the importance of such early screening.

Policy makers always have the tendency to make plans based on ideology and models. Research based on direct communication with the key people makes it possible to go beyond models. I found that for the caretakers, it is considered obvious to live together with their special children. I also found that it is not obvious for providers and caregivers to appreciate the consequences of their policymaking based on inclusion. In my fieldwork it became very clear for me that this inconsistent policy makes it very disturbing for the people involved. They were continuously confronted with this “double bind”, which starts from the early childhood of their special children. Earlier in this chapter I offered some recommendations on how to support and guide the caretakers during early childhood while they are living with their special children in the community.
CHAPTER 6 – CONCLUSION

The problem is not how to wipe out all differences
but how to unite with all differences intact.

Rabindranath Tagore (1861-1941), born in India.
Nobel Prize winner for Literature, 1913.

When starting this research my purpose was to contribute to the setting up of Community Based Services in Japan and the Netherlands. In my research questions I focussed on the experiences of caretakers living together with their special children. During the fieldwork I found that these experiences were my main resource about what is relevant for the lives and inclusion of their special children.

In this part I want to emphasize the main findings and conclusions. First of all, it is really necessary that an early detection system be implemented, which would indicate for professionals how they can best coach and guide caretakers. Further, these professionals need training in how they can coach the family as a system. It is very crucial that parents get support from their children’s early childhood, especially in the ways in which they can learn to accept their own special children. On this basis, the caretakers can be coached by professionals on ways they can mobilize acceptance in their surroundings. Then they can support them with the creation of a “circle of support” in their neighbourhood. I also became more impressed about the importance of support from other caretakers. This could be continued even after the special children have grown up. It is necessary that these support groups be financially facilitated by collective insurance. Researchers have to make it clear that the support of these kinds of professionals is a good investment for the improvement of the quality of life of special children, and moreover they can prevent expensive and intensive care later on in 24 hour facilities.

A basic condition is that the providers and the policymakers have the courage to decide to cut back on services, particularly schools and facilities which are not integrated in the community. This is the optimal way to promote the participation of special people in the community.

All countries will eventually have to ratify the UN Convention on the Rights of Persons with a Disability. From that moment, people with a disability can claim the rights of inclusion in all aspects of their lifespan. For example, Article 19, on living independently and being included in the community, states:

State Parties to this Convention recognize the equal right of all persons with disabilities to live in the community with choices equal to others, and shall take effective and appropriate measures to
facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community and to prevent isolation or segregation from the community.

In this context it is necessary to recognize that all human beings are interdependent with one another:

In striving to realize their objectives, human beings are forever dependent and almost everyone is needed by some others. That is what conveys to people their significance for their fellow human beings and that is where they find the fulfillment of their existence (De Swaan 1990: 21).

My personal concluding words

It is my personal belief that this kind of interdependence helps to overcome the difficulties of the difference between people who are disabled or non-disabled. Everybody needs support in different ways. In this sense, I also believe that we have to overcome the problems of the differences between developed and developing countries. In the next stage of my life I want to do my bit to make this more of a reality. The experience in the AMMA course was very fruitful for me to find the right position from which I am able to support vulnerable people in daring to participate in the community. The above mentioned Convention of the UN can be a guideline again for this mission.

Article 32: International Cooperation

State Parties recognize the importance of international cooperation and its promotion in support of national efforts for the realization of the purpose and objectives of the present Convention and will undertake appropriate and effective measures in this regard between and among States in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities.

As a member of the Board of the Dutch Coalition on Disability and Development (DCDD) I am already involved in this process. We have chosen five countries to develop a partnership with and over the next three years we have been subsidized to develop this relationship for promoting the human rights of people with disabilities. My real dream is, as quoted above, not to wipe out all differences but to discover how to unite with all differences intact.
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