New Voices in Iceland
Young Adults with Disabilities in Iceland: The importance of relationships and natural supports

By Dóra S. Bjarnason

Abstract: This paper deals with young adults' perspectives and experiences of growing up with a variety of impairments in Iceland, and how they impact the young disabled adults' approach to the status of adulthood. The paper is based on a qualitative study that explored perspectives and experiences of 36 young disabled adults (16-24 years old), their parents, friends and teachers. The purpose of this paper is to share themes related to the way that choices made by and for disabled children and young persons, place them within different support systems and social network, which subsequent impact the young people's views of themselves and their prospects as young adults. The paper includes different perspectives on adulthood and the extent to which the young disabled people expect to reach that status or remain as "eternal youth" "for a long time", enmeshed in segregated services. Findings show that the type, nature and mix of generic and segregated special services is critical for the young adults' approaching adulthood in mainstream society or expecting to remain (for a long time) in the limbo of "eternal youth" within segregated settings. Earlier choices may, however, be revisited at each subsequent transition point. Further, the disabled young adults who struggled for social inclusion, could obtain full active membership in society, even against social and physical barriers and medically defined disability labels.

Introduction

Drawn from a qualitative study of young adults with disability in Iceland, their parents, friends and teachers, this paper deals with young adults' perspectives and experiences of severe disability, the social relationships they develop in childhood and youth, and how these may impact on their approaches to adulthood. The main purpose of the paper is to share themes related to interconnected patterns of a young adult's view of himself, his situation and experiences, and future prospects. In other papers I will look in much more detail at young adults' life worlds and perspectives, and how their approach to adulthood relates to different parental outlooks and careers (Bjarnason, 2002).
First, I explore experiences and perceptions of schooling, daily life and relationships, and how these may relate to future adult roles and dreams of adulthood. Secondly, I will explore how their dreams and needs may relate to natural and professional support systems. Thirdly, I will discuss how social structure, the Icelandic value base, and personal networks and relationships have an impact on the meaning of adulthood and the communication of disability.

The focus of the larger study is to explore the young adults’ life worlds and perspectives, and how their approach to adulthood relates to different choices made by themselves or their parents, and to relationships the young adults develop within the domains of special service systems and regular community life.

**Concepts: Adulthood and Disability**

Adulthood and disability are both socially constructed phenomena that take their meanings and content from culture and socio-economic conditions in society in time and space. The status of adulthood is endowed with rights and obligations due to a fully participating, responsible member of society. These rights and duties include those of citizenship, legal rights and obligations, responsibility for self and others including setting up a family, making independent decisions, and financial independence via joining the labor force (Arnet 1998). Biological factors such as chronological age and physical maturity signify approaching adulthood, but do not determine when a person is socially recognized as a fully fleshed adult. The transition from childhood and youth into adulthood is a process embedded in culture. Frønes points out that:

The period of young adulthood can extend into the twenties. The upper limit is unclear because adult status may be designated by the establishing a family, or by cultural catchwords that belong to adult life; but young adulthood is also likely to be prolonged by higher education. Because economic and cultural conditions are determining factors, there are many dimensions to the youth-versus-adult dimension. (Frønes 1995: 228)

Adulthood thus involves taking on the status of adulthood which is adorned by relevant symbols in society, and maintaining adult relationships with family friends, colleagues and other community members. In this paper I borrow Bates’ definition of the concept: "The status of adulthood is most often correctly assumed as part of a tacit exchange of complex information through the interactive elements of language and social content and cognitive interpretation of relevant information about age (e.g. appearance, voice, size and so forth.)" (Bates 1975, cited in Ferguson and Ferguson, 1996).
Research shows that disabled young people have problems largely due to social barriers, including parental overprotection, lack of peer group interaction and job opportunities, in gaining the role and status of adulthood as defined along the above-mentioned criteria (Högsbro, Kirkebæk, Blom and Danö 1999, Grue 1998 and 1999, Gustavsson 1999). Further, Ferguson argues that some disabled people, including young people with severe cognitive impairments, have difficulties in accessing culture, making use of its symbols, and letting their wants, needs and opinions become translated into age appropriate roles (Ferguson, P. in press). For such persons reaching adulthood involves adorning them with culturally appropriate symbols and interpretations of their status of adulthood.

Disability is another term that, to most people means a medical condition or a learning deficit to be prevented or cured or at least diminished. I adhere to the school of thought (Oliver 1990, Barnes 1998, Barton 1999, Williams 2001) that defines disability as a phenomenon emerging and resulting from the values and practices embedded within culture (Gabel 2001, Devlieger 1999). This approach can be linked back to the long historical tradition of symbolic interactionists such as from Goffman and Becker. See for example Goffman (1963), Becker (1963), but also to the more recent strands of the social model of disability and developments within the disability studies field (for example Gabel 2001, Oliver 1990). Thus I take the concept of disability to be a political one used to enforce and sometimes even legitimate exclusion, or social marginalisation, exploitation and poverty. From this point of view, the construction of disability is both a complex social construction and a personal identity, but neither a medical condition nor a learning problem.

The interpretive approach
The research unwinds through story lines that young disabled adults, their parents, friends and teachers shared with me in interviews. My own story, as active in the disability movement, as a parent, and as an academic working in the area of special education, sociology and disability studies informs my listening and interpretations of the meanings of the stories. The stories themselves, the telling of them, the listening and the interpretation is a complex multi facet interactive act of constructing meanings out of which humans build their perceptions of social realities (Berger and Luckman 1967). One way of describing research methodology within the interpretative paradigm is to say that "it is the systematic collection and analysis of stories people tell about how they interpret reality" (Ferguson and Ferguson 1995:105). Telling stories is not enough, they have to be firmly embedded in thick description (Geertz 1973) and in the more explicit discussion of the interpretivist theoretical assumptions. Interpretivism rests upon a rich
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philosophical tradition. As well as having incorporated elements of American pragmatism with its emphasis on the individual case, especially the strand derived from G. H. Mead (1934) and symbolic interactionism (for example in Howard Becker’s Outsiders (1963), phenomenology (for example Garfinkel 1967, Schutz 1972), and the philosophy of Wittgenstein (1958, Wisdom 1965). A phenomenological approach to a particular issue or topic can be characterized by its focus upon things or issues as experienced by individuals. The interpretivist paradigm and methodology hopefully helps me ask new questions, or old questions in a new way that brings us closer to understanding the experience of disability and the prospects of adulthood within the Icelandic society and culture at the turn of a new millennium. These new voices in Iceland have hardly been heard before, and I hope that these voices will change the balance of political and professional dialogue.

The social model of disability
As disability studies have been taking shape in the last decades of the 20th century, the social model of disability has been at its center. The social model of disability is not a recent idea as mentioned above, and preceeds the development of the disability studies field. Still the construction of the social model remains much debated. Gable (2001) reminds us, that there are in fact several social model stances, that can be located within the broader social model of disability, and that more are added each year. She identifies four such major strands at play; Firstly a Marxist model, primarily concerned with collective economic and social oppression of disabled people (Abberley 1987, Oliver 1990, Barnes 1996, Marks 1999). This is what is often referred to as the British model, which along with the minority group model in the USA, were the earliest versions of the social model to oppose the dominant individual (medical) model. Critics of the Marxist model have argued, that its orientation does not allow for subtleties and ambiguities that are built into post-modern, post structuralist, feminist and other orientations. Secondly, the social model as an identity model. A number of scholars argue that the social model can be used to interpret both individual and collective experiences and meanings (Peters 1996, Priestley, Corker and Watson 1995, Weeber 1999, Epp 2000, Ware 2001, Smith 2000 and others). These scholars point out that while the identity strand of the social model is a political one, its concern for individual experiences alongside collective experiences is often discredited by Marxist scholars who find collective theories more compelling. Third, the approach that disability is a phenomenon emerging and resulting from the values and practices embedded within culture (Miles 1992, 2001, Hirsch 1999, Devlieger 1999). These writers point at the growing evidence for their position in the comparative disability studies. Critics
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have stated that such a position may lead to cultural relativism, and that there is too much disagreement within the disability community within different cultures to make culture the basis for a research position. Forth, some scholars are exploring the potential for a discursive model of disability that can bridge theoretical concerns for individual and group (Corker 1999) or that illuminates the ways in which literary and other forms of discourse create the disabled body and identity (Wendell 1996, Allan 2001). In addition to these four strands of the social model of disability currently in the making, disability study scholars have used many other theoretical approaches, that I here include under the broader definition of the social model. More and more scholars are using feminist theory (see for example Traustadóttir 1992, 1999, Clegg 1999, Corker 1999, Sheldon 1999), some have used race theory (Omansky-Gordon and Rosenblume 2001), critical theory (Marks 1999, Erevelles 2000) radical structuralism (Tomlinson 1995), pragmatism and post modernism (Danforth 1997, 1999), interpretivism (for example Ferguson and Ferguson 1995) and other intellectual tools, to explain, interpret, understand and give meaning to disablement.

The theoretical focus used in this article rests both upon social constructionism and on the social model of disability. By asking young disabled adults and their parents, friends and teachers to tell their stories, I am claiming an entry into the interpretivist paradigm. With that and with the help of recent articulations of the social model of disability, I hope to make the new Icelandic voices heard, and embrace the promise of taking their perspectives further into policy and practice.

Setting the stage: Iceland – A Small Nordic Welfare State

The Icelandic value base is ruggedly individualistic and egalitarian, and there is a tradition of self-help, hard work, and of mutual help in hardship situations. In modern Iceland, as in every other country, some are more equal than others. Differences in wealth and status are growing; marginalization of minority groups is a known phenomenon (Traustadóttir 1999) and disabled people tend to be more marginalized than most according to any measurement one might select (Bjarnason 1996, Margeirsdóttir 1976 and 2001, Report of Guðmundsdóttir 1994).

Currently, almost two thirds of the population lives in and around the capital Reykjavík and Akureyri, a town in the north, while the remaining population lives either in fishing villages or on small farms. People enjoy a high standard of living in a welfare state similar to that of other Nordic countries, but less of the taxpayers' money is used to cover welfare policies
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(Ólafsson 1993). The state provides pensions for the elderly, unemployed, sick and persons with disabilities. The money does not suffice, so in case of hardship, the local communities supplement these pensions.

The state and local communities also provide free education from the age of 6 to 16, and a largely free education at upper-secondary and university levels, free or low priced health services, rehabilitation, medicine and technical aids for elderly, sick and disabled people. A National Assessment Center assesses children and youth thought to have impairments and provides advice to parents free of charge, but people who do not live in or near the capital incur extra expenses for travel and housing in order to make use of these services. The Assessment Center has the role of referring children with impairments and their parents to appropriate services, under the special service system or the regular system as considered appropriate.

The Education Laws of 1974 made, for the first time in the Icelandic education history, provision for all students, including students with impairments, to be educated within the compulsory public school system (Lög um grunnskóla no. 63/1974, see also Lög um grunnskóla no. 49/1991 and from 1995). Special schools for students with cognitive impairments and special classes for students with a variety of labels such as autism, mental illness, ADL and others gradually were opened. (Students who were deaf or labeled blind, however, had had some access to special education since the late 19th century). Students with a variety of disability labels were not generally invited into upper secondary schools until some years after the Education Act of 1994, amended 1996 and 1998 (Lög um framhaldsskóla no. 81/1994 and Statutory Regulation on Upper Secondary Education from 1996 and 1998). At first they were offered one-year courses, in special classes, in less than a handful of high schools. Later the educational program was lengthened to two years and more high schools established such classes. (The Technical and Vocational College in Reykjavík however has admitted a few students for special education since the early 1970s). This was changed to three years in 2000, and finally to four years by 2001 (see Statutory Amendment of 1998). Adult education courses are also available for a limited number of people with cognitive and multiple impairments. The law on compulsory education from 1974 (no. 63/1974) opened up the school system for disabled students. With the law on Support for the Mentally Retarded from 1974, and later On the Affairs of the Handicapped from 1983 (no. 41/1983) normalization and integration became the law of the land (Bjarnason 1996). These two milestones opened up possibilities for disabled persons to become fully included active members of society and to obtain services.
adapted to their needs in regular schools and other institutions in the community. Yet the spirit of a law is one thing and its implementation quite another. Regular society, schools, workplaces and other essential organizations have had problems adapting to the spirit of these laws. Furthermore, sub-clauses in the laws and statutory regulations defined an array of specialized services, from special classes to segregated group homes and sheltered workshops. A battery of segregated services has been developed in the past two decades, as never before in Iceland (Bjarnason 1996). Mostly these services have opened up in urban areas. At the same time, and in particular after mid 1980s, the ideology of inclusive schooling and society has been gaining impact. In the 1980s and 1990s parents, parent associations and some associations of disabled people pushed for inclusive services both in the urban and rural sectors. Two schools of thought have thus marked the lifetime of the young disabled adults of this study; on the one hand the development of a variety of special services (most for people with multiple- or cognitive impairments) and inclusive services on the other hand.

The young adults in this study have also gone through a period of radical school change in compulsory education in general (both regular and special) and changes in the service systems. Their schooling has been marked by experiments in teaching disabled children, both in the segregated special education sector and within regular schools, and substantial changes in curricula development, school organization and teaching practice (see for example Jóhannesson 1993). They have jointly been subjected to every variation of the school system's move towards integration and later inclusion in the 1980's and 1990's, but also much of the special education and special school development of that period. The two contrary schools of thought and the two systems of inclusive and segregated services provided the parents and the young disabled adults in this study room for choice.

The Study

The study from which this paper is drawn began in 1998. In it I try to understand the world of young disabled adults in Iceland, the first generation to grow up with the ideology of integration and inclusion as the law of the land. The study focuses on the experience of being a young disabled adult (16–24 years old) in upper-secondary schools, university or equivalent educational settings, in the job market and in society.1 (Up until 1998 young persons became legally adult at the age of 16. This was changed by law but the idea that one is an adult or close to adult status at 16 is still prominent within the society (law no.74/1997). Only one person in my sample was 16, two were 17 and all the others 18 or older).
I am interested in exploring situations and experiences of individuals with disabilities that lead to or counteract social discrimination. I am also interested in what young people with very different disabilities have in common, how they experience their situations differently, and how such differences may be related to different social situations, choices they and their parents made, and the social networks that enmeshed the young adults as they grew up.

Young disabled people in Iceland have not been the focus of scholarly endeavor before, and there is little information available about the social forces that influence their lives.

**Modes of Inquiry**

For this study I used qualitative methods largely influenced by grounded theory and hermeneutics and located the work within the interpretivist paradigm (Glaser and Strauss 1967, Ferguson, Ferguson and Taylor 1991, Ferguson and Ferguson 1995). The Fergusons characterise the methodology associated with the interpretivist paradigm "as the systematic collection and analysis of the stories people tell about how they interpret reality (p. 105)." My own professional and personal experience over the past 20 years as a university teacher and a researcher of sociology and disability studies, and as a single mother of a son with a severe disability, informs and influences my research. (Bjarnason 1996b, Barnes and Mercer 1997)

The primary method for collecting data was interviews. Over the past two years I have interviewed 36 young adults with a variety of disability labels, one or both parents or support persons of 30 young adults (44 individuals), 12 teachers, and 12 friends. I interviewed the parents of the young adults, as well as the young adults myself. The interviews were in-depth, semi-structured and lasted from 45 minutes to over 2 hours. They were tape recorded, transcribed, coded and analysed as the study developed. A young woman of 20 who uses a wheelchair and has experienced both segregated and regular services for persons with disabilities served as my guide in the "habitat of youth and disability" (Bourdieu 1977) in Iceland, and helped me understand both slurred speech, and the colloquialism of youth. She helped with most of the interviews with the young people. A team of 3 students and an anthropologist helped at different times with the interviews of teachers and friends of the young adults and with some of the coding and data analysis.

The study started with a broad focus on the young people's experiences and interpretations of their present and recent past at home, in school and leisure, that of their parents', and some friends and teachers. The "constant comparative method" was followed,
where the data collection and data analysis proceeded together (Taylor and Bogdan (1984). Analysis was ongoing during fieldwork. At the end of each interview I wrote comments in which I summarized what I had learnt and did a preliminary "within case" analysis, with a focus on describing each case on its own premises. Then I moved to "cross case analysis" looking for patterns, connections and relationships. After data collection was completed I conducted a final intense analysis. This work is characterized by a constant process where one goes back and forth from data collection, interpretation and theory development. It consists of a steady formulation of new questions and thus interpretation and reinterpretation of the data. During that stage I wrote three analytic memos. (See for example, Taylor and Bogdan (1984), Bogdan and Bicklen (1992), Wolcott (1995), Kvale (1996), Punch (1998)). Additional information was gained from workers within the local and state welfare services, from statutory laws and regulations, from high school principals, staff from the Ministry of Education and the Ministry of Social Services, and from documents. I apply, what the anthropologist Clifford Geertz refers to as "thick description" in substantiating the data (Geertz 1973).

The method of selecting informants for the study is "strategic sampling", where informants are selected for their ability to provide new insights or expand or add to gained insights. As the inter-

views developed, I looked for young adults with a wide range of backgrounds; from urban and rural settings around Iceland, from different social classes and family structures, and people with a wide range of abilities, interests and impairments. In this way I hoped to include in my sample as broad a diversity of young adults with severe disability as possible. I left out one category of young people who are labeled severely disabled under the Icelandic law on Support for the Handicapped from 1992. These are young people with mental illness. I felt that I did not have enough knowledge to understand their perspectives and predicaments. Still, one person so labeled is included in my sample, but his primary label has to do with physical disability. No immigrants or "new Icelanders", and no families of openly gay or lesbian people were included in the sample. This is because I could not locate any such families with adult children with severe disabilities. Everyone involved in this study was promised anonymity. "Hiding" people, many of whom are conspicuous or known, in a society on the scale of Iceland is difficult. I have changed names, places and facts that do not alter the content of the data.

Findings

The data suggest that the type and intensity of relationships and the mix of natural and professional supports that engulf the young disabled adults
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throughout childhood and adolescence coincide with the extent to which these young people became part of regular society or the more segregated world of disabilities. The choices parents and children made during the young adults' childhood and adolescence did not only involve the use of regular or special services; they involved much more. For example, they involved lessons about self and others, the social network the young adults encountered in school and community, their opportunities for establishing friendships with regular and disabled peers, their selection of leisure activities, and their opportunities to find work, romance and sexual partners (Shakespeare et al. 1996, see also Grue 1998, 1999, Högsbro, Kirkebak, Blom and Danö 1999, Ferguson and Ferguson 1993, 1996, and Ferguson in press).

My thesis is that decisions about the use of the professional service system (type and mix of segregated special services and regular services) and of other support systems, throughout the disabled adults' childhood and youth, will coincide with the social networks they develop and subsequently influence their claims to adulthood. The more they select from the segregated "special service plate" over time, the harder it becomes for the young disabled adults to embrace adulthood in a normative way. This thesis is substantiated by the findings.

The roads to adulthood

The young disabled people approached adulthood differently. I use the metaphor of travelers on two roads and nomads in a wasteland in between. The data show that it is as if the young adults were traveling along two parallel roads (A) and (C) or on the wasteland (B) between them:

1. Fourteen young disabled adults, a group of travelers which I call group A, seemed to be on the same road as the rest of us, the road of the mainstream society. One or two traveled at high speed at the middle of that road, succeeding in school and leaving most of their non-disabled peers behind, and one was already an adult, married with children. Most of the travelers on this road traveled at a much slower speed nearer to the edge. Still, all had in common that their parent(s) had been more inclined to take action, rather than to feel hopeless, or passively accept the rules of the game (See Bjarnason, 2002). The young disabled adults had been in inclusive schools for many of their school years and mostly in inclusive classes. They had learnt to become effective self-advocates. They had at least one real friend, but many spent much time alone and felt lonely, or trying to fit in with "hi friends" (people who stop and say "Hi, Johnny"), but not much more (see Högsbro, Kirkebak et al. 1999). Few of the young adults in this group had partners or steady boyfriends or girlfriends; however, two disabled
women lived with a partner and a husband. One woman had been sterilized on her mother's advice, as a precaution against pregnancy, and accepted that because she did not want children. These young people all had in common the firm belief that they would eventually become fully adult, slowly but surely. In one case a young man knew that he was likely to die soon and not become more adult than he was already.

2. The second group of travelers (group C), fifteen in all, was on a slower road where they enjoyed more segregated service than group A and where fewer demands were put on them. With two exceptions, these young people felt themselves to be much younger than their chronological age indicated. They had in common parents who were more likely to react, or adapt to formalized rules and regulations prescribing the services they and their children were entitled to. The choices they made for their disabled children reflected this (See Bjarnason, 2002). More of the young adults in group C than in group A were cognitively impaired, but the group also included people with physical and sensory impairments. They had all been to special schools or special classes; all but one young man had learnt to accept their disability in a fatalistic manner, and to fit into the system. Many of these young people were very content with their lives and led a rich social life inside their particular special gemeinschaft (Gustavsson 1999), contrary to the young adults in group A. Most had only disabled friends and primarily associated with them in segregated settings. Some of these young people had been together since the special pre-school. Some had "paid friends" (paid support people near their own age) who took them to the cinema or to other regular leisure activities and a few had only "paid friends" and "hi friends". Some had a "special" girlfriend or boyfriend, but no one lived with a partner. Eight people in group C had been sterilized to prevent reproduction, some against their will, and one person without her knowledge.

3. Thirdly, between these two groups are seven young people nomading in what one might call the wasteland. I call them group B. Two of these young people are labeled autistic. The others carry a variety of labels including deaf, cognitive disability, physical disability, physical illness, maimed from disease, or accident. These young people have experienced a variety of school situations from being outstanding students in regular school (before their disease or accident) to being average students in special schools and special classes. The parents of these young adults resembled parents of the young people in both groups A and C. What characterized these young people is how they seem to jump from one road to the other without belonging on either. They had no real friends, but some had "paid friends" or only "hi-friends". Two had been sterilized. They
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sometimes advocated for themselves, but more often took the fatalistic attitude. Many found it difficult to accept that adulthood could apply to them. Not all wanted to become adults. For some of these young people, the road to adulthood may pass through a period of "wandering about in the wasteland", that is, as a part of their growing up, similar to that when non-disabled youth "drop out" for a while, to return to regular society again in due course. These young disabled people seemed in search of meaning in their lives or to have lost any kind of meaning. Even though each storyline is unique to the individual, the examples below are chosen to illustrate the perspectives and experiences shared by the young adults in each group.

On the highway (group A. tot. 14)

María: From a china doll to a regular high school student

María's story illustrates well the experiences and perspectives of the young people who traveled mostly on the highway of mainstream society. She is 20 years old, has quadriplegia and has used a wheelchair all her life. She was in a special class for physically disabled learners in compulsory school, but was regularly integrated in classes and social life with non-labeled peers throughout compulsory school. She graduated and became fully included in high school. She describes her experiences in the special class as such:

We were very much protected in the school. When I arrived in the morning, they took my coat, the wheelchair was pushed into the classroom, and they took my pens and stuff from my school bag and put it on the desk. So in some ways I was not allowed to do things by myself.

She received help from classmates and teachers when she went into the regular classrooms, where she participated on an even foot academically and made friends, but she belonged in the special class. That was where responsibility for her learning and her personal care was firmly placed. According to María, there were certain positive aspects of being a member of the special class, but they did not outweigh the negative aspects of belonging there. She said:

The special class gave me a shelter, a private place where I could go to the WC and where I got extra teaching hours. But I still think we were too much focused on being part of all that, and I don't find that good. Of course they did many good things there, but more bad things than good because this did not support us, did not prepare us for what lay ahead.

María's complaints were not the least directed at how she felt the special class prevented her from making mistakes and learning from them. She said:
You were not really allowed to try out new things and get burnt. I was not allowed to make mistakes and had no opportunity to get scorched. I was treated like a china doll, and learnt to treat myself a little as if I was brittle.

She experienced a traumatic change when she moved from the special class into a high school. She said:

I needed to learn to do everything on my own, from reading the timetable and finding my way around a school I knew nothing about. I did not know a soul, and had to learn to rely on myself. This was terribly difficult because I simply did not know how to rely so much on myself. Then...I had very little belief in myself because I felt I did not belong with all these kids...[a little later]...If you are always alone in a corner it is no fun to learn,... you dread going to school every morning...

María realized that she had to get accepted "at a table" with regular peers, if she was to continue in the school. There were several tables in the hall, where the same groups of friends sat during each break. She began to wonder if the other kids were not just as shy of her as she was of them or if they were scared of her difference, and she decided to act. Before being accepted, she experienced several rejections but kept on trying. She said:

I just went and broke the ice. It was tremendously difficult. I well...I just explored all the tables [laughter]. Deep inside I kept hoping that someone would approach me, someone would ask me to come and sit with them, but that was not about to happen. I just asked if I could sit at this table, and I have been at this table now for three years, so I don't regret doing this, not at all. The kids have accepted me as one of the group and so on, so I have done that too...

Three years later the school guidance counselor asked María to talk to new students about her experiences as a first year student with disabilities. María shared her experience and encouraged them to approach people with disabilities. She was pleased with her advocacy and said:

The new students come more often to me and I see them go to other disabled students and ask if they can help. I am thrilled by this, because this has maybe opened them up a little... People can talk to us just like ordinary human beings. ...We all come to school with the same ambition, to graduate...the only difference between me and them is that the wheel chair separates us...When I have finished talking to them it is as if it has set the ball rolling...
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Personal supports were inadequate at the high school. María needs support to go to the WC, but that was at first hard to find.

The first year was one of [hesitantly] the most difficult I had so far experienced. At first I had problems going to the bathroom, because I could not really ask anyone to help me. I went to the school guidance counselor, but, of course, she could not help me on the WC... The next year some of the teachers helped me. They came during the lunch break, and in the mid-morning and mid-afternoon breaks and helped. That, too, involved lots of stress, because it was as if I had to pee on demand...

She solved this problem like so many others by getting trusted friends to help her.

Educational supports were also a problem. During the first year María was insecure about the quality of her work, because she did not get all the praise she was used to in the special class, and the teachers did not monitor her work closely. When she asked them to check her work, some refused and said "this is your problem not mine. I will see how you are doing at the next exam". Some of the teachers were, according to María, inhibited by her wheelchair. She said:

The teachers... for some, it is as if they do not want to have anything to do with us, as if it is difficult to have a student with special needs in class. They do not say anything to you directly, but you just feel this when you are taking exams and such... Well, I remember an exam when I got the school guidance counselor to write for me, and I did really well ... But when the teacher gave me my paper back, he asked; "Are you sure you did this all by yourself... Some [teachers] are OK; others may not really want us...

María also experienced that the teachers did not put the same educational demands on her as they did on their non-disabled students. She gave this example:

Sometimes a teacher avoids asking me questions, skips over me when students are asked to read something, ... my felling is that they simply dare not do it because they do not know how to behave...Some teachers are trying to be too kind...others not...In a recent lesson the teacher of French said to me; "I will not let you read now because you are so tired". But I told him; "I am not tired, I want to read like everyone else. I want to be allowed to exercise my reading, ...They don't really understand that one does not want to be spared ...They should make exactly the same demands on all ...they have to change the means to their demands, but the demands have to be the same...
For María, the good teacher is the teacher who pays attention to her needs and does not hesitate to change something if that is necessary. María was about to give up and quit school in her first year. She said:

I came home almost every day in that first year thinking that I would quit. I thought about quitting after every single school day, but then I thought; well, I cannot just give up. I looked at this as a challenge, and gave it time. I gave myself time to get to know people and the new surroundings, and then it was not so terrible...

María succeeded in breaking through the barriers; by her last year at the high school she had many friends. Most were regular high school students, but two of her good friends were also impaired. However, she went out less than her peers, and avoided social situations where she could expect drinking or sexual advances. She said she was shy of her body, and that "she felt really backwards" in matters of sexuality. She was scared that although a boy might be interested in her, he might think: "Yes, but I am not ready to live with her and help her all my life". Still, she was hopeful of meeting someone later "who will come flying into my arms without seeing the wheelchair".

A fellow traveler
Other young adults traveled closer to the margins of the highway. Ólafia aged 22 has cognitive impairments. She has been in a regular class throughout her compulsory schooling. She made friends at school and became included in the school community while simultaneously using some special services. When she tried to enter high school with her classmates, the special teacher at the school denied her that option. She said: "They (students with cognitive impairment), learn more in the special class and feel happier with their own kind". Ólafia did not agree. She said:

I like school. I always have...but I want to be with friends. I have not changed, so why does the teacher not let me be with them now?

Special class placement had the effect of separating Ólafia from her former classmates and her small group of non-disabled friends. This meant that she participated less in age appropriate activities and that there were fewer people to support her and tell her story. Consequently she was moved closer to the margins of the highway of regular community life.

Victim of mobbing
School inclusion demands both professional teaching and administrative skills, and a caring environment (Ferguson, D. L. 1995, 1996). The data did not include enough evidence of either in many cases. Disabled children were too
often "dumped" into regular compulsory classes without adequate supports, and expected to fend for themselves. Mobbing was a serious problem in such cases. Seven young people in the sample moved from regular classes to special classes, while at compulsory school, because of mobbing by schoolmates. There is also some evidence of mobbing amongst a few respondents who remained in regular classes. These victims were, in particular, young disabled people whose impairments were not easily recognized. It is almost as if these students attracted such behavior because they looked much like all other students, but could not always behave like them, and the school deprived them of adequate supports and protection. Jóhanna, aged 24, who has cognitive impairment, is a sad example of this.

At the time of the interview Jóhanna was a married woman, a mother of three small children and expecting her fourth. She lived with her family in her parent's house. They had always supported her, and her mother, who has a learning disability herself, has taught her to hold her own with the social service system. Jóhanna glowed with pride and happiness at her sparkling clean home and well-dressed children, but when asked about her schooling, she started to sob. She said:

I started school in my hometown when I was six. I soon felt that it was difficult for me to learn. The greater my need for help, the less help I got. I only got help when I started in the special class in Hightown [in her last year at compulsory school]...In my school...they jumped on my back, they would sometimes surround the house so I could not go to school. The boys did this...This went on every day from the time I was six years old until the year before my confirmation. They pulled mine and my sisters' pants down and everything. Now [when] I take my six-year-old son to school, I remember all this every time...[Dóra: Did anyone help you?] Once a man came and saved me. There was a boy who had jumped on my legs, on my hands and on my head. Then a man came and saved me and went to talk to the headmaster, but the headmaster said all was OK because they were trying to get rid of me...

Some of her teachers had, in fact, tried to stop such "games" from time to time, and her parents went to see the headmaster, but things did not change and eventually she moved at the age of thirteen to a school in a different community. There she found a friend in the special class and liked her teachers and found herself included in some of the regular classes. She dropped out of school a year and a half later to get married because she had become pregnant and because her husband to be did not want her to continue her studies.
Just friends
The compulsory- and high school years are crucial years for forming friendships, experimenting with romance and sexual relationships, finding partners, expanding one's interests and deciding on a course of further studies or work. Good non-labeled friends can be the most important key to full active participation in the life on "the highway". Friends provide practical supports, share and exchange resources, spend time together for enjoyment, and tell each other stories, adding meaning and perspectives (Lutfiyya 1991). Þór illustrates well the importance of such a friendship in his young life. Þór aged 24 has quadriplegia. He is born and bred in the country and went to regular schools throughout his compulsory and high school education, partly as a boarder. His father said that he "changed every school he [Þór] entered". Building ramps were necessary and they eventually managed to get each school supplied with other needed technical devices. For a time, Þór's parents drove him back and forth to compulsory school in their community, often over snow-blocked roads, but through advocacy, they managed to convince the local community services to take on that job. Þór's father got involved in advocacy for disabled children in his community, and later he entered community politics.

Þór lived with his friend Lárus in a small flat at the time of the interviews. Lárus, aged 23 was paid as an assistant but they shared bills. Both were studying at the University of Iceland, but different subjects. They met first at a summer camp when they were children. Later, they were both boarders in the same high school. Þór said:

I have been so lucky with everything. It was my luck to go to high school, and get to know the guys who helped me. They were wonderful. I was especially lucky to meet Lárus.... Think how fortunate I was, and that it should last...[that] he should come here with me to get educated, it is fantastic. Nobody can have a better friend...

Both Þór and Lárus think Lárus' job as a helper and housemate to Þór is ideal. Lárus described it like this:

“What can be better than to have a job messing about with one of my best friends, drive his car, have fun, and get paid for it?”

and Þór said:

I think this is good for him too, because he is my friend, and he also enjoys himself. It is a comfortable job to be able to be with your friend, drive for him and get paid.

Lárus said that he also found it hard at times to work for his friend. He felt that he was never off the job. Lárus is a competitive tennis player, and said, that he had managed to find time for his tennis most weeks, but there was little
time for other private social activity. Lárus said that he had solved his dilemma of being constantly on the job:

I think that I am at work when I have to do things for Pór I do not like, but I think of it as being with my friend at all other times.

Lárus admitted that he is "sometimes tired from having schoolwork on top of the great strain of the job and the responsibility." He said that he gets particularly tired when he has to wake up several times in the night to help Pór turn over so that he can breath better.

Pór said that he tried not to demand too much of his friends. He mentioned that he had to take some things easily. Lárus said "Pór refuses to let his disability and frequent ill health hold him back". Pór graduated with good grades and went with his classmates on a graduation trip to Hawaii, with help from Lárus. Both the young men said that they had the time of their lives during the trip. It was their first time abroad and Pór tried a lot of new things, even diving and wind surfing.

Both men admitted that they had problems at times but said that they tried to talk about them. Both mentioned other problems they did not talk about. Pór said that he tried not to phone Lárus when he was out unless it was absolutely necessary. Lárus admitted that he probably went out less than he might have done, but added that that was "no sacrifice". He said that he had at times "felt guilty" if he had been too long at school, and afraid that he did not "take good enough care" of his friend. Neither had girlfriends and both said they would have liked to have one. Lárus was protective of his friend. He complained that drunken girls who came up to Pór when they were out, "[they] kiss him out of pity or pat him on the head, and leave."

When I first met the two young men, their lifestyle was at risk. Lárus was about to graduate and move on, but Pór had a couple of years left before finishing his studies. Lárus wanted to move abroad and work in his chosen profession. Pór wanted to continue his studies. They were both deeply worried about this.

When I asked them about the future and their dreams and expectations, their answers were both essentially similar and very different. Pór new that things would not come to him easily. He said he was afraid of the future, but tried to remain optimistic. He dreamt of studying, traveling abroad, being able to drive a car, and one day meeting someone who could see "himself" beyond his disability, marry and have a home, a child and a job in his field.

Lárus too was unsure and worried about his future. He wanted to try to live and work abroad for a while. He wanted to take up tennis seriously and see how far he could get. He said:
He is so wonderful, and we are friends. I would never close my door in his face. But I do realize that we will not be together for all eternity. One can also think about this from another angle. Why are more people not allowed to get to know him and enjoy him as he is? He has so many things to offer... Why not invite [others] to share with Dór, and maybe reduce the pressure a bit, ...I don't know if it is good to have more [helpers], but he needs more service, so that a [new] person is not as tied down...

Lárus too, dreamt of meeting a good woman, marrying her and having children. Even here Dór had his place. He said smiling

If I meet a girl and I cannot move in with her because of Dór, if she moves in with me, to our place and she and I have children, ... Sometimes I think that a girl, if she is ready to do this, then she must be the right one..., but if my wife could not accept this, it would not be love, she would not be the right woman for me.

Alternatively, Lárus could picture himself visiting Dór with his wife and kids, and inviting him to visit in their home. He said [in a low and hesitant voice] that he hoped Dór would meet someone to love.

Dór was less optimistic about finding a future partner. He pointed at his wheelchair (and at his body) and explained that both were a hindrance to fulfilling his dream of a sexual relationship. Once a girl had presented him with a rose, but his shyness hampered him in exploring that single opportunity he had had for sexual intimacy, but still, he remained hopeful.

Summary
The young disabled adults on the highway (group A) had been in inclusive schools for much of their school years, mostly in inclusive classes until high school. All had parents who were prepared to take an initiate on their children's behalf, used professional services creatively, chose inclusive rather than segregated services when possible, and placed their disabled children in the realm of the mainstream of society. This increased the possibility for them to develop rich and varied relationships. The possibilities of forming new relationships and enjoying natural support are, however, not the same as the fulfillment of these possibilities. The down side of social and school inclusion can involve a certain amount of loneliness, especially in the adolescent years, the risk of being mobbed in regular schools and classes, and a negative or fearful image of one's "lived in body", sexuality and sexual desirability.
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In the "special" lane (Group C. tot 15)

Two great girls
Björg and Sólún both aged 19 are classmates from a special school. Both had parents who stood by them, played mostly by the rules of the professional service system, and made sure that their daughters received the special services they were entitled to under the laws and regulations. Both attended special classes in the local high school. Both had mostly been in special settings; in special school, special summer camps, and the special gardening workgroups for disabled youth during their summer holidays. Both spent their leisure time either with family, in organized leisure activities for disabled youth, or with classmates. They were largely dependent on their parents for driving them to and from their destinations. Both women said they liked school, liked each other and the other students, and that they had good teachers. Björg explained it so:

I have learnt a lot there. I did not want to go to the same school as my brother. I know kids in his school, but my friends are here [in the special class], my boy friend, my love, is here and my girlfriends.

Björg's parents confirmed her happiness at school. They said:

She is on 'cloud 9', she is so happy at the special class in the high school. While that is the case we should feel at ease...But everything is unclear...

We want to see her get some kind of a job training...we are worried about her future, what comes next?

Sólún said that she liked her school much better than the adult education program (for people with cognitive or multiple impairments) where she had been two days a week the previous year. She complained that she was still being taught to read, but "I wanted to learn to speak English and they said I had to wait".

Sólún's mother worried that her daughter had not been helped to stretch her abilities at the special school. She said: "one of the teachers told me that Sólún would never learn to read, but then it happened. Now she reads fluently". She said:" Sólún understands what she reads, uses complex words, keeps a diary and leaves elaborate written messages around the house, like the rest of the family is in the habit of doing." Sólún's mother said:

One of the teachers once called it [the special school] jokingly "a sheltered workshop". She meant it in the nicest possible way, but she said it, and she was referring to it as her workplace, not the students.... I have sometimes thought ...I don't know if I may say it...it is as if the [teachers'] work and their [job] security is number one at the school. Some years the school had not yet started properly after the first month and a half of the autumn term, and then
the Christmas holiday was just around the corner. I sometimes thought, "what happened to the school year... what happened to the big work period?".... but Sólrún was very happy at that school. And I said to people that while she is happy we cannot complain...

When I asked Sólrún about becoming an adult she said:

I don't know what is available yet. I finish school next year. I expect to work somewhere. I do not have any dreams yet... I am thinking... when I am really adult I will live in my flat... maybe in a supported flat... [I asked if she would live by herself or with someone]... I have not thought about it yet...

She said she had not thought about having a boyfriend or getting married and having kids. She was not sure she wanted that. She wished that more of her friends from the special class lived near by, so they could attend the "special club" together more often.

Björg seemed to live in the present, with friends and fun. Adulthood was far away, and her mother made sure she used what services were available to pass the time.

These two young women enjoyed life in the special lane. Their friendships, Björg's boyfriend, who came to visit her from time to time, and above all, their caring and supportive families and good teachers composed their world. Their lives resembled that of many Icelandic girls in their early teens. They were certainly in society but hardly a significant part of it. Their world outside the realms of family was the segregated world of disabled people.

Hjalti - fighting for his adulthood

Hjalti has multiple impairments and uses a wheelchair. He was moved, at the age of 11, from a special class for learners with physical impairments to a special school for students with a variety of impairments and labels of moderate to mild cognitive impairment (IQ not bellow 50). His mother said that the special class could not cope with the complex learning and personal needs of her son. She said:

My fight really started at that school. Information did not flow properly between home and school. He got teased... I have always regretted sending him to that school. They were not able to educate a child like Hjalti."
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She wanted more specialized education that coincided with the diagnostic assessment of her child. (The National Assessment Center gives out training programs with their assessment of children with disabilities.) She complained several times to the principal, but that ended in a row. "I felt that they had given up trying to provide [good] service. Hjalti did not want to learn and he got away with it." Consequently she moved him therefore to a special school.

Hjalti said that he was not too happy in the special class:

I was not helped to learn enough because the teacher only wanted to help [that] other boy. She put me into the play corner. I was not happy with this.

Other things frustrated him as well in the special class. He said that he felt he had to spend far too much time waiting for people; to be pushed in his chair, for help to use the WC, to eat, or for the other children to finish whatever they were doing. But there were also good memories. He found a friend there, a boy with physical disability, and he was sometimes allowed to sit in regular classes with non-disabled peers. He described that so:

I found it just great to get into the regular classes. I was happy at being allowed to experience that despite my wheelchair, despite my handicap, I am so grateful for that opportunity. I got most of the help I needed in the regular classes.... The experience from the regular classrooms taught me how I was expected to behave with classmates and teachers. I also think it was good for them to have me there and learn how to be with a handicapped student.

He said that he was pleased about moving to the special school. There he became friends with one of his teachers.

It felt good to have a good teacher. We grew closer, and even now, after I quit school, we phone each other and visit each other. We cultivate our friendship...He is very important to me. If I feel bad I can always talk to him, he never told anybody. I could tell him whatever I wanted.

Yet, he said that he always felt like an outsider in the special school because "I was the only one who was handicapped in my class. ...All the others could walk and talk." Still, he felt that his classmates empathized with him. He said he knew that they had their own problems, but he did not look at them as "handicapped". (I have more evidence of this use of the word "handicapped". Young people who have cognitive impairment and use wheelchairs all used the words handicapped or disabled in this sense).

His mother was also pleased with the special school:
He learnt there, even things he does not want to do now.... He had loads of friends. The mothers helped organize that. ...What I was happiest about at that school was the cooperation with the teachers. The teachers listened [to me]...

Hjalti and his girlfriend dream about getting married one day and having children. He was caught making love to her and suffered humiliation. He tried to rebel, but without success. When his mother decided he should either get sterilized or stop seeing his girlfriend, he said:

I felt really bad both because of what I had done in a public place, and [because] then mother came up with this idea.

He had the operation, much to his own and his fiancée's grief. Then both parent groups watched their children closely for a while to prevent further incidents, despite the fact that they were 19 and 24 years old. Hjalti's mother mentioned this incident to me in the interview and said:

I threatened him. He only had two choices, to decide himself to get sterilized or meet me in court.

Hjalti lived in a group home at the time of the interview and worked at sorting small objects into bags at the local sheltered workshop. He and his fiancée had had to bend to parental authority, but they had gained more privacy for making love. Hjalti still had his dreams of breaking away and having a home and getting married. He dreamt of a better-paid job (his current earnings were 200 Danish crowns a month) on the regular job market, and of receiving adequate support to be accepted as an adult one day.

Summary
The second group of travelers (group C), sixteen in all, was on a slower road and used more special supports than group A. Fewer demands were placed on them. They had in common parents who were more likely to react, or fit in with the service system, rather than use the system and its professionals in a creative way geared to their and their families needs (Bjarnason, 2002). More of the young adults in group C than in group A had cognitive impairment, and the group also included people with physical or sensory impairments. They had all been to special schools or special classes, had learnt to accept their disability in a fatalistic manner, and to fit into the system. Many of these young people were very content with their lives and lead a rich social life inside their particular special 'Gemeinschaft', contrary to most of the young adults in group A (see Gustavsson 1999). Many spent much of their free time at home, either on their own or with family, watching TV or engaging in other pass time activities. For most adulthood seemed far away, even though a few had already moved...
away from home (to group homes) and started to work in sheltered workshops in most cases. All dreamt of normative adulthood sometime in the "far away" future. Some dreamt of having children, but for many of them that was not possible. Eight people in this group had been sterilized, one without her knowledge, the others on advice from parents and experts. Most accepted that explaining that they were not able to take care of children; others regretted it bitterly.

**On the wasteland (Group B tot. 7)**

Jóna aged 18 came closest to this (ideal type) category of all the young adults interviewed. She became physically impaired in her mid-teens as a result of an accident and lost the use of her limbs and her ability to talk. Before that she had done well as a regular student in school and been the president of her class. Jóna had much greater difficulties at the high school. She said that she had taken sedatives to live through the day in the beginning. She had a good helper the first term, but after that her helpers tended to talk above her head and boss her about. She disliked that intensely. She kept to herself as much as she could, tried not to use the WC at school, and did not eat anything because she found it so hard to have to be helped with such things, things she used to be able to do for herself. She wrote:

> Teachers OK, do not [show me] pity, help, give [me] same exams, more time.

She was the first student at the high school with severe impairments and the staff suggested that they should have been better prepared to receive her. The staff, both her present helpers, one of her teachers and the school guidance counselor that I interviewed, complained that they had problems reaching her, and that she was at times uncooperative or blatantly hostile in her interaction with them. A helper said:

> She drives her chair into our legs out of spite. I help her, but she is not a friend. I don't like her...I did try, but I cannot.

There seemed to be little mutual understanding between Jóna and the school staff. The guidance counselor said she did not know how to help this student, and that she did not get enough professional help herself to do this job as well as she would have liked to.

Jóna lost touch with her former friends and had a hard time finding new ones, except on the Internet. Jóna said she was terrified of meeting new people. When I asked her about her future and about adulthood, she said:

> I don't want to become an adult like this. I will just sit and wait for a cure.

**Other Outsiders**

The seven young people in group B all mentioned that they had been the source of grief, hardship or difficulty
for their parents, while not a single person in the other two groups volunteered that kind of information. Daði, who is labeled autistic, said:

I feel in a way...I am to blame for everything 'domestic'. Everything that goes wrong. [a little later] ...I feel as if I am the black sheep in the family. I am the only one who has something wrong with him.

He said that he felt as if he lived in "Outland" with all the other people with impairment, but his family lived with everybody else in "Prideland". He said:

I think we are a different race, the people in 'Prideland' are healthy and so on... I feel as if I have been sentenced to be an outlaw, and I am trying to get back.

Five of the young people in this group had tried to take their own lives, some more than once. Daði was one of them. He said that he had tried to commit suicide first when he was 10 years old. He had hurt his sister and his baby brother. He said:

I felt so bad...I cannot tolerate a baby crying...There are many things that people with autism cannot take, just to look at colors and such. It is like allergy...My little sister was always hurting herself...When she started crying I went amok, I am "that nature". It was horribly difficult for my mum and dad....

Daði had good experiences with the compulsory school where he had been largely included, but managed to get himself into all kinds of mischief in the special class he attended at high school, where, according to his parents, he had inadequate support. He quit high school in his second year there and got a job at a local sheltered workshop. He said:

I pack bags and little and bigger bags into larger plastic bags...[a little later] at first I thought this was bullshit. I found this very childish. It was as if we were in preschool...

He dreamt of a better job, but realized that he was stuck in the workshop for the time being. He did what he could to amuse himself on the job, including putting rude notes in with the things he was packing. He felt his future to be uncertain. When I asked him about friends, romance and the future, he said:

I really only know kids who are 'out of order'. For instance, I feel I cannot have a girlfriend unless she is mentally retarded or something. I feel as if it is an ancient custom. I simply have to marry a girl with mongolism or...[a little later] I had a girlfriend once; we had a kind of a relationship. She was with me in the respite service. She was a sweet girl, but I gave up on her because she was always flirting with other guys too...
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Thinking about the future he said:

In five years time all my peers will be married with children. [Dóra: Do you expect that?] No, I have been "disconnected" (sterilized). [Dóra: How come?] Mother wanted me to do this when I had a girlfriend. I met a girl at a summer camp... They [his parents] felt this was advisable, because we had been together for some time...[Dóra: What do you think about this?] I feel I should be "reconnected". [Dóra: Would you like to be able to have a child in the future?] If I get cured from this (autism) I would be glad to. [Dóra: Was this a difficult decision or did you agree with it?] We talked about it, I and Jonny, the psychiatrist at the mental hospital. We kind of decided this together, but sometimes I feel angry...

Margrét, a striking and graceful young woman who is hard of hearing, provides a different example. She also reported having been a source of difficulties to her parents, but that her father deserved being treated badly sometime because he did not try hard enough to understand her. She added that her father was improving, and that she herself was learning to control her temper better. Margrét, like Daði, had experienced both special and regular classes, and she had attended a Deaf school. Neither had a steady friend, but Margrét had a number of "people who knew her sometimes and sometimes didn't". Margrét had spent some years testing herself and her environment. She said she had tried drugs and alcohol, experimented quite a bit sexually, tried to commit suicide, and had had a number of regular jobs both in Iceland and abroad. But, while Daði seemed to have lost hope of a "cure", Margrét remained optimistic that she would fit into regular society one day. She said:

I accept myself now...even though I will never be perfect...I have matured...I am getting happier and happier. I don't know if I will get married... I want to help people, go abroad as a volunteer [a little later] One has to try and be strong. I try and succeed when I manage to stay calm.

A year later Margrét had made her dream of going abroad a reality. For her, membership in group B may be an interval period.

Summary
Loneliness and confusion about self, others and own prospects and possibilities characterized the young adults in this group. For some it may have been a temporary problem with finding a place, for others the sense of not belonging seemed to have deeper roots. What characterized these young people in the "wasteland" is how they seem to jump from one road to the other without belonging on either. They had no real friends, although some had
"paid friends" or only "hi-friends". They sometimes advocated for themselves, but more often took the fatalistic attitude. Many found it difficult to accept that adulthood could apply to them. Not all wanted to become adults. These young people seemed in search of meaning in their lives or of having lost any kind of meaning. As a young man labeled autistic said: "I don't know if I will be an adult. I just hope I will become something".

**Conclusion**

All the young people in my sample who allowed themselves the luxury of dreaming, shared a similar vision. This vision involved living in one's own home, having a job and meaningful leisure or a hobby. Many hoped for a partner and maybe a child. Neither disability labels nor a disabling society managed to stifle that dream, which they share with most other young people (Oliver, 1990, Shakespeare et al 1996, see also Barnes, Mercer and Shakespeare 1999). For the young disabled people in group A, the status of adulthood was well within reach or already achieved. For others it remained a far-away dream, obtainable sometime in the future. (The only exception to that was that of a woman who lived largely within the Deaf community and identified as Deaf, grouped here with the group C.) Finally, for a few there was much greater uncertainty as to whether they would reach adulthood at all or wanted to. Type of impairment does not seem to co-ordinate with differences in the young disabled people's approaches to adulthood or their perspectives there of. Social factors, on the other hand, coincide better with these, in particular, the type of social networks and relationships that have enmeshed the young disabled adults at home, in school, friendships and, for some, at work.

Communicating adulthood is a joint effort of providing adequate support (by doing what it takes) for removing social and other barriers, and adding symbols of cultural normativity to those who have problems upholding their adult status (Ferguson and Ferguson 1993, 1996, Ferguson in press). For example, people with cognitive impairments are in special need of friends, peers and family members willing to help tell their stories and establish for them and with them the symbols of adulthood recognized and accepted by the culture. This communication takes shape within the family and its immediate social network, within the community, and wider society. "When the status of adulthood is bestowed upon a person with severe disabilities, there is a gradual shift in the balance of family advocacy and responsibility, student self-determination, and professional involvement over time." (Ferguson and Ferguson 1996). In the case of a child with disabilities, the professionals and the special service system move in and contextualize the disability early in the
lives of the disabled person, and give the perspective on childhood, youth, and adulthood specific "disability" content and meaning.

All the young people who expected to survive are likely to run up against social, economic, political and other barriers in their pursuit of reaching the state of adulthood, but in different ways, depending on the nature of their relationships and social networks. Some, particularly some of the young people from group B and group C may never reach that status fully, or reach a limited and fragile version of an adult status, that could be called ‘disabled adulthood’, if professionals and the immediate social network, manage to balance supports adequately, on the tricky continuum between indifference and paternalism (Kirkebæk 2002 in press). By combining the theoretical perspectives of interpretivism and the social model of disability, I have provided a focus for better understanding of the conditions and aspirations of the young disabled people in my sample. Disability studies developments are the most recent articulations of the social model, and I believe, hold the promise of taking the ideas further into policy and practice. Shared themes have a good possibility of being heard, and shared stories, when critically analyzed and interpreted have a way of connecting people together and the potentiality of empowering them. They may forge in people’s lives the connection between private problems and public issues (C Wright Mills 1959). The Fergusons point out that even though interpretivism emphasizes description rather than intervention, "description itself can be reformative if it gives voice to those not usually asked to describe anything". Thus the voice of people, who usually have little power in society, can become powerful through complete description "by legitimating the perspectives of those usually at the bottom of society as well as those at the top" (Ferguson and Ferguson 1995: 106-107). One of my aims in this work is to make the voices of young Icelandic people, who are labeled disabled and thus not normally listened to, heard. If the growing up process is a joint effort, then choices at each stage, and the values they are based on focus the meaning and direction of that effort. The lived space where choices and decisions are made rests on a web of old and new social relationships that are wrapped in cultural and ontological perspectives. Social structure and its institutions, including laws, regular and special schools, high schools and universities, and the world of adulthood, put up barriers against including disabled people. My study shows that these barriers can be weakened at each juncture, securing young disabled people a fragile inclusion in regular society.

The good news from this research is that the decisions some of the parents and their disabled children made, often without much support from schools and professionals, can bring disabled people
on to the main road of society and keep them there. Imagine how much more effective these parents and young adults would be if they had tailor-made supports from regular services, the local community, and from professionals in the special service system.

Endnotes:

1 Three question have emerged from the data that will be dealt with in a full report of the study (forthcoming in 2002):
   1. What does it mean to be an adult with impairments in Iceland? 2. How do young people see themselves reach that milestone when they have severe (multiple) impairments, and how do they negotiate adult status? 3. How is the adulthood achieved by young people with disabilities, related to the parenting they receive, including parents’ actions, choices, social status and approach to social service bureaucracy? Does the role of parents’ influence vary according to the young person’s age, type of disability and need for support? See also my articles. (Bjarnason 2001 and 2002).

Table 1. The young adults with disability’s home, school and work place in 1998

| SCHOOL TYPE                  | HOME           | WORK PLACE         | REGION          |
|------------------------------|----------------|--------------------|-----------------|
| Special school               | 0 Parental home| 22 Regular work    | 4 Reykavik and gr. Rvik area |
| Special class in high school | 12 Own flat/living alone/living with partner | 8 Sheltered workshop | 7 Towns and villages |
| Regular high school/Tertiary ed/ University | 11 Group home | 5 Unemployed but available to work | 1 Farms |
| Adult education for disabled learner | 4 Other | 1 Farms | 1 |
| TOTAL                        | 27*            | TOTAL 36           | TOTAL 13        |

*The 9 remaining adults had either finished school by 1998 or dropped out.
Table 2. The young adults primary disability-labels

| Disability Labels                              | Number |
|------------------------------------------------|--------|
| Cognitive disability                           | 18     |
| Multiple disabilities                          | 2      |
| Sensory disability (3 deaf/hard of hearing, 1 visual impairment) | 7      |
| Emotional disability (autism)                  | 4      |
| Physical illness/accident                      | 2      |
|TOTAL                                           | 36     |

Almost all the young adults were identified as severely disabled according to the Icelandic Disability Pension regulations and all were entitled to disability pension paid by the National Social Security Bureau. Many had been given multiple disability labels. In most instances the primary label was "mental retardation" or "physical impairment", sometimes with an additional condition or a particular syndrome such as cerebral palsy, seizure disorder, or sensory problems or physical illness. The most common label of "cognitive disability" referred to a broad variety of handicapping conditions that were included.

This was done by reading and re-reading the data, comparing different pieces of data, relating them to the themes and patterns already identified. At this stage new insights and concepts were added. For example, as I sorted units of data into earlier codes such as family, and parents actions, mother-father actions, parents feelings, mother-fathers-feelings, patterns formed, and later codes of anomie, action, reaction and passive acceptance, were gradually derived. Three assistants coded parts of the data independently from me and we compared codes and discussed interpretations.

References

Abberley, P. (1987). The Concept of Oppression and the Development of a Social Theory of Disability. *Disability and Society,* 2:5-19.

Allan, J. (2001). Inclusive Education: Exploring the Possibilities and Practice: Disability Arts and the Performance of Ideology. A lecture at a seminar: *Research in Disability, Inclusive Education and Handicap History.* 7th of October 2001 at DPU in Copenhagen.

Arnet, J.J. (1998). Learning to Stand Alone: The Contemporary American transition to Adulthood in Cultural and Historical Context. *Human Development,* 41: 295-315.

Barnes, C. (1996). Theories of Disability and the Origins of the Oppression of Disabled People in Western Society. In: Barton, L. (ed.). *Disability and Society: Emerging Issues and Insights.* London: Routledge and Kegan Paul.

Barnes, C. (1998). The Social Model of Disability: A Sociological Phenomenon ignored by Sociologists. In: Shakespeare T (ed.). *The Disability Reader. Social Science Perspective.* London, Cassell: 65-78.

Barnes, C. and Mercer, G. (1997). *Doing Disability Research.* Leeds, The Disability Press.

Barnes, C., Mercer, G. and Shakespeare, T. (1999). *Exploring Disability: A Sociological Introduction.* Cambridge, Polity Press.

Barton, L. (1999). Struggle, Support and the Politics of Possibility. *Scandinavian Journal of Disability Research,* 1:13–22.

Barton, L. and Armstrong, F. (2001). Disability, Education and Inclusion: Cross-cultural Issues and Dilemmas. In: Albrecht, G.L., Seelman, K.D. and Bury, M. (ed.).
New Voices in Iceland

Ferguson, P.M. and Ferguson, D.L. (1996). Communicating Adulthood. *Topics in Language Disorders*, 16:3:52-67.

Ferguson, P.M., Ferguson, D.L. and Taylor, S.I. (ed.). (1991). *Interpreting Disability: A Qualitative Reader*. New York, Teachers College Press.

Frönes, I. (1995). *Among Peers: On the Meaning of Peers in the Process of Socialization*. Oslo, Scandinavian University Press.

Gabel, S. What is Disability Study? [unpublished paper/handout] Proceedings of the AERA Congress 2001. Seattle, Washington.

Garfinkel, H. (1967). *Studies in Ethnomethodology*. Englewood Cliffs, NJ, Prentice-Hall.

Geertz, C. (1973). *The Interpretation of Cultures*. New York, Basic Books.

Glaser, B.G. and Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York, Aldine Publishing Company.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ, Prentice-Hall.

Grue, L. (1998). *Paa Tersklen* [On the threshold]. Nova. Rapport 6/1998, Oslo.

Grue, L. (1999). *Funksjonshemmet Ungdom og Livskvalitet* [Disabled Youth and the Quality of Life] Oslo, Noyam, Gyldendahl.

Gustavsson, A. (1999). *Inifrån Utanförskapet. Om at vara Annorlunda och Delaktig* [Inside the outsiders' group. On being different and participating]. Stockholm, Johansson and Skyttmo förlag.

Hirch, J. (1999). “A Poor Crippled Woman: Disability Identity in a Southern Mill Village.” *Disability Studies Quarterly*, 19: 113-118.

Högsbro, K., Kirkebæk, B., Blom, S.V. and Danø, E. (1999). *Ungdom, Utvikling og Handicap* [Youth, Development and Disability]. Copenhagen, Samfunds litteratur.

Johannesson, Í. Á. 1993. Principles of legitimation in Educational Discourses. *Journal of Educational Policy*, 8:4: 339-351.

Kirkebæk, B. *Det Onde og de Gode: Om Forholdet mellem Paternalisme og Ligegyldighed. (in press)*. Sætersdal,B and Heggen, K. I den beste hensikt? "Ondskap" i behandlingssamfundet. Akribe forlag, Oslo 2002.

Kvale, S. (1996). *InterView: An Introduction to Qualitative Research Interviewing*. London, SAGE Publications Ltd.

Lög um aðstoð við þroskahefta nr.47/1974 [Law on Support to the Mentally Retarded]

Lög um aðstoð við fatlaða nr. 41/1983 [Law on Support for the Handicapped]

Lög um málefni fatlaðra nr. 59/1992 [Law on the Affairs of the Handicapped]

Lög um grunnskóla nr.63/1974 [Law on Compulsory Schooling]

Lög um grunnskóla nr. 49/1991 [Law on Compulsory Schooling]

Lög um grunnskóla 1995 samþykkkt 25. Febr. á Alþingi [Law on Compulsory Schooling]

Lög um framhaldsskóla nr. 81/1994 (breyting á lögum nr.57/1988 [Law on Upper-Secondary Schools]

Lög um sjálfrædi. (Law nr. 74) (1997) [Law on Self-determination]

Lutfyya, Z.M. 1991. A feeling of being connected: Friendships between People with and without Learning Difficulties. *Disability Handicap and Society*, 6: 233-245

Margreidsdóttir, M. (1976). *Könnun á fjölda vangefinna og skiftingu þeirra eftir landshlutum* [A report on the number of intellectually handicapped and their division between the different parts of Iceland]. A report for the Minister of Health and Social Insurance, Iceland.

Marks (1999). Dimensions of Oppression: Theorising the Embodied subject. *Disability and Society*, 15: 235-256.

Mead, G.H. (1934). *Mind, Self, and Society*. Chicago, University of Chicago Press.

Miles, M. (1992). Concepts of Mental Retardation in Pakistan: Towards Cross-cultural and Historical Perspectives. *Disability, Handicap, and Society, 7*: 235-256.

Miles, M. (2001). Studying Responses to Disability in South-Asian histories: Approaches Personal, Practical and...
Dóra S. Bjarnason

[Report of R. Guðmundsdóttir, the Minister of Social Services, to Alþing, on Politics related to Disabled Icelanders].

Smith, R. (2000). Mystery or Typical Teen? The Social Construction of Academic Engagement and Disability. *Disability and Society*, 15: 909-922.

Taylor, S.J. and Bogdan, R. (1984). *Introduction to Qualitative Research and Methods: The Search for Meaning*. New York, Wiley.

Tomlinson, S. (1995). The Radical Structuralist View of Special Education and Disability: Unpopular Perspectives on their Origins and Development. In: Skitic, T.M. *Disability and Democracy: Reconstructing (special) Education for Postmodernity*. New York, Teachers College.

Traustadóttir, R. (1992). *Disability Reform and the Social Role of Women: Community Inclusion and Caring Work* (unpublished Phd thesis). New York State, Syracuse University.

Traustadóttir, R. (1999). *Women and Multiculturalism in Iceland* (unpublished paper). The NNDR conference, 9th to 11th November, Throndheim.

Weeber, J. (1999). Belonging and Understanding: Disability Identity grounded in Community. *Disability Studies Quarterly*, 19: 107-112.

Wendell, S. (1996). *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York, Routledge and Kegan Paul.

Williams, G. (2001). Theorizing Disability. In: Albrecht, G.L., Seelman, K.D. and Bury, M. (ed.). *Handbook of Disability Studies*. London, Sage Publication.

Wisdom, J. (1965). *Paradox and Discovery*. New York, Philosophical Library.

Wittgenstein, L. (1958). *Philosophical Investigation*. (3rd ed.). New York, Macmillan.

Wolcot, H.F. (1995). *The Art of Fieldwork*. Walnut Creek, Alta Mira Press.

Pragmatic. *Disability and Society*, 16: 143-146.

Mills, C.W. (1959). *The Sociologica Imagination*. New York, Oxford University Press.

Oliver, M. (1990). *The politics of Disablement*. Basingstoke, Macmillan.

Omanssky-Gordon, Rosenblum, B. and Rosenblum, K. (2001). Bringing Disability into the Sociological Frame: A Comparison of Disability with Race, Sex and Sexual Orientation Statutes. *Disability and Society*, 16: 5-19.

Ólafsson, S. (1993). Ìðrún velferðarríkisins [The Development of the Welfare State]. In: Hálfdánarson, G. and Kristjánsson, S. (ed.). Íslensk þjóðfélagsþróun 1880-1990 [Icelandic Social Development 1880-1990]. Reykjavik, Háskólaútgáfan.

Peters, S. (1996). The Politics of Disability Identity. In: L. Barton (ed.). *Disability and Society: Emerging Issues and Insights*. P. 215-234. New York, Longman.

Punch, K.F. (1998). *Introduction to Social Research: Quantitative and Qualitative Approaches*. London, Sage Publications.

Reglugerðir um frámaldsskóla 1996 og 1998. (Statutory regulations on Upper-Secondary schools 1996 and 1998). Reykjavík, Ministry of Education.

Schlegel, A. (1998). The Social Criteria of Adulthood. *Human Development*, 41: 323-325.

Schutz, A. (1972). *The Phenomenology of the Social World*. London, Heinemann Educational.

Shakespeare, T., Gillespie-Sells, K. and Davies, D. (1996). *The Sexual Politics of Disability*. Cassell, London.

Sheldon, A. (1999). Personal and Perplexing: Feminist Disability Politics evaluated. *Disability and Society*, 2: 93-113.

Skyrsla Rannveigur Guðmundsdóttir, félagsmálaráðherra til Alþingis (1994).
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